THE PROCESS OF MEDICAL REFERRAL

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By

LINDA JUNE MUZZIN, M.A.

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AUTHOR: Linda June Muzzin, B.A. (McMaster University)
Hons. Psychology

M.A. (McMaster University)
Psychology

M.A. (McMaster University)
Sociology

SUPERVISOR: Professor Vivienne Walters

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ABSTRACT

The purpose of this research was to develop a model of the complex process of medical referral, in which a physician consults with or refers a patient to a specialist. Fifty cases of referral were investigated by interviewing the referring physician, patient and specialist(s) involved with the case at various points before and after the referral. Referrals were followed first in a southern Ontario city and, for comparison, in northwestern Ontario.

Trust in the competence of specialist advisors was found to be the key component in understanding the process of referral. Referral in settings where there is mutual respect between referring physicians and consultants, particularly where they worked in close physical association, was contrasted with referral in settings where there is isolation of referring doctor from consultant, and a tendency towards breakdown in the process of the referral. Finally, when the activities and beliefs of patients as well as doctors were examined, patients were found to have a much greater influence on the initiation, process and outcome of referral than has been previously recognized.

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CHAPTER ONE

INTRODUCTION

I. WHAT IS MEDICAL REFERRAL?

At some point during diagnosis or treatment of a patient, the physician or the patient may decide to involve another doctor in the process. Technically, the term "consultation" applies to a situation in which the referring doctor retains major responsibility for the patient and merely seeks advice from the consultant, while the term "referral" applies to a situation in which responsibility for the patient is assumed by the specialist for a particular problem. In practice, however, these are points along a continuum, and doctors speak of a "spectrum" of responsibility-sharing, ranging from minimal to maximal specialist involvement.[1]

Referral is analogous to the situation in which the patient decides to consult a primary care physician in the first place and surrenders a certain amount of responsibility for a problem to the physician. In each

case, the seeker of advice must decide to consult and with whom to consult. Advice must be communicated and the seeker of advice must ultimately decide whether to follow it. Since both levels of advice-seeking are part of referral, a complete understanding of the process must be based on examination of what happens at each level.

Referral can proceed from the primary care physician, who may be a general practitioner, a physician who has taken the certification examinations for the specialty of family medicine, or a specialist.[2] In Canada, referral can be made to "primary specialists", whose specialty is broadly based, such as general internists, obstetrician/gynecologists, psychiatrists, pediatrician/geriatricians or general surgeons. There are also subspecialties within these primary specialties. In internal medicine, the subspecialties are cardiology, respirology, dermatology, gastroenterology, neurology, rheumatology, oncology, nephrology/urology, and allergy/virology. In surgery, the subspecialties are otolaryngology (ears, nose and throat or ENT), ophthalmology, orthopedics, neuro- surgery, plastic surgery, anesthesiology, cardiac surgery, cardio-vascular surgery, pediatric surgery and rehabilitation

(Bryans et al., 1981). Subspecialists may make referrals to general specialists, but, aside from directing patients to acquire a family doctor, they do not make referrals to primary care physicians.

II. WHY SHOULD REFERRAL BE STUDIED?

The process of referral is of sociological interest because it is an essential component in the organization of Western medical care. However, there have been few systematic attempts to examine the process and, as a result, how it works is little understood. Historically, the division of labour in medicine has existed since classical times (Galdston, 1958; 1959), but Stevens (1966) traces the practice of referral to the late 19th century in Britain. She claims that the system evolved when members of the British Royal Colleges tried to exclude general practitioners (GPs) from voluntary hospitals and the GPs began calling the specialists informally for a "second opinion" in cases where the primary caregivers maintained responsibility for their patients.

In the U.S. and Canada, where GPs were not historically excluded from the hospitals, a great deal of concern has been expressed about the finding that

GPs on this continent have tended to hold on to rather than refer cases outside their areas of expertise (e.g. Williams et al., 1961; Clute, 1963; Wolfe & Badgley, 1973). If the referral system does not "work", this poses serious questions about the quality of care being provided to patients. Freidson's study of referral (Freidson & Rhea, 1963; Freidson, 1975) suggested that the referral system might operate as a mechanism of professional control if referring doctors "boycotted" consultants whom they judged to be incompetent. However, he concluded that there were limitations on the effectiveness of such a system, and his work on "professional dominance" deals with the problems posed by an autonomous profession that is not able to adequately police itself (Freidson, 1970a; 1970b).

In the literature, there has been a preoccupation with calculation of referral rates, which is probably based on the wish to estimate their economic importance in the system of medical care, and there is now scattered evidence that the rate of referral is higher in nations with universal health insurance. Most of the literature on referral, which appears in the American clinical journals, reports that rates of referral of patients to specialists follow five percent or less of all visits to primary care

providers (Geyman et al., 1976; Metcalfe & Sischy, 1973; Penchansky & Fox, 1970; Riley et al., 1969; Ruane, 1979; Shortell & Vahovich, 1975). However, British and Canadian studies indicate that the rates of referral in these countries are somewhat higher (Brock, 1977; Clarfield, 1980; Cartwright, 1967, p. 38; Hines & Curry, 1978; Royal College of General Practitioners, 1974; Wolfe & Badgley, 1973). Further, there is evidence that rates of referral in countries with national health insurance or near-universal social insurance are rising rapidly (Carson, 1982; Rutten & van der Gaag, 1977).[3]

These observations have particular relevance for Ontario, Canada, where the study of referrals reported in this thesis was conducted. In Ontario, as in Britain, in most specialties and in most locations, patients will only be seen by specialist consultants when referred through another physician, either general practitioner or specialist. The trend away from direct accessibility to specialists in Ontario corresponds roughly with the introduction of national universal health insurance in 1970. The reasons for this cannot be explored here, but the trend is clearly encouraged by the greater remuneration to specialists for seeing physician-referred, as opposed to self-referred

patients.[4] In contrast to the U.S., therefore, where patients may contact specialists directly, and referral rates are lower because of competition for patients, referral has become the important route to tertiary care for the majority of patients in Ontario, as it is in most European nations. Further, unlike many European nations which pay GPs by capitation and specialists by salary,[5] Canada combines an American-style fee-for-service (FFS) payment system with government health insurance. Since FFS payments have been demonstrated to invite more referrals than other methods of paying doctors (Glaser, 1970), Canada provides strong economic incentives to engage in referral. Thus while an investigation of the referral process would be of interest in any part of the world, it has particular significance here.

III. THEORETICAL AND METHODOLOGICAL APPROACH

The research reported in this thesis belongs within the methodological and theoretical tradition of symbolic interactionism. Consistent with this approach, the method of research is that of "grounded theory" as outlined by Glaser and Strauss (1967), which is described in Chapter 4. At the same time, this work has

been guided by the writings of Freidson, who proposed a "sociology of medicine", or the adoption of "the perspective of a critical outside observer" (1970a, p. 42); and it has been further influenced by the theoretical and substantive arguments of the ethnomethodologist Garfinkel (1967), that the generic process of "trust" underlies social order.

Symbolic interactionism attributes a central significance to the assumption that people attach "meanings" to their social interactive experiences and therefore, that cognition/action itself is social (Manis & Meltzer, 1967; Fisher & Strauss, 1978). Thus the adjective, "symbolic" interactionist. The methodological implication of this is that, unlike the psychologist, who is suspicious of individuals' accounts of their own behaviours, the interactionist must "get inside the heads" of the actors in social situations in order to interpret what is going on (Mead 1934/1962). Reflecting their different epistemologies, the preferred method of research in psychology has been "deductive" and laboratory-based while the preferred method in interactionism has been "inductive" and ethnographic/naturalistic. Thus much work in cognitive psychology and symbolic interactionism is not directly comparable. The one exception in the area of medical

referral is the psychological study of Dowie (1983a), since ethnographic methods were used. Only one study that focussed primarily on medical referral in the interactionist/ phenomenological tradition has been undertaken before this thesis (Freidson, 1975). However, there is also useful commentary on the referral process by interactionists studying other topics (e.g. Lorber, 1984; Hall, 1948).

This work has also been informed by the theoretical perspective of the ethnomethodologists Garfinkel (1967) and Cicourel (1964) who, consistent with the assumptions of processual interactionists such as Blumer (1969), Goffman (1967) and Strauss (1959), have argued that while structural sociological terms like "status" and "role" are convenient for the sociological observer "as a kind of intellectual shorthand", they, like grammatical rules, are of limited utility for specifying "how the actor negotiates everyday behaviour" (Cicourel, 1964/1973, p. 11). In Garfinkel's terms, to avoid compressing social interaction into a "fat moment", the unfolding interactive sequence over time must be explored in detail (Heritage, 1984, p. 109). Instead of glossing over what happens in interpersonal exchanges as conformity or nonconformity to norms, processual

interactionists and ethnomethodologists are interested in what the actors do and think in detail. Garfinkel's major contribution to theoretical sociology has been a demonstration that even when deviations from expectations occur in social interaction, people seem almost endlessly to make excuses "in the breach", a rationalizing behaviour he has called, after Mannheim, the "documentary method" (McHugh, 1968). In other words, people attempt to maintain that "nothing unusual is happening" (Emerson, 1970). Interactionists have also been interested in such excuses, called "accounts" (Scott & Lyman, 1981; Hewitt & Stokes, 1981). In examining the process of referral in the research reported in this thesis, this rationalizing process turned up both at the level of patient and referring doctor when any "breach" of trust in the advisor was detected. In general, much of the discrepant evidence collected by the researcher about what was going on in the process of referral was ignored by participants "for all practical purposes" (Garfinkel, 1967).

Ethnomethodologists have criticized interactionists who inadvertently "buy" the "moral persuasion and justifications" offered by their respondents (e.g. Wieder in Bogdan & Taylor, 1975, p. 21). They have further pointed out that since

interactionists use the "documentary method" in interpreting their interviews with social actors, they tend to "fill in" or "gloss" any gaps of information using their own "rules". My antidote for this problem has been, as explained in the section on method, to conscientiously interview all participants to avoid a one-sided view and to confront any discrepancies for their theoretical value.

Thus the thesis retains the primary interactionist emphasis on exploring generic social process in its focus on the relationship between trust and competence and how this is played out in the social situation of referral. At the same time, the critiques of Freidson and the ethnomethodologists have been taken into account in both the method and substantive focus of this work.

IV. OUTLINE OF THE THESIS

This brief introduction to the topic of medical referral and the theoretical orientation of this thesis is followed in Chapter 2 by a more extensive discussion of the significance of this topic. Chapter 3 contains a critical review of the existing literature in this

area, beginning with the clinical work on medical referral that has appeared in the past 30 years. It is argued that failures to integrate most of the clinical data into a theoretical perspective and the heavy reliance on quantification rather than on understanding the process of medical referral, limit its value. In the second part of the chapter, an introduction is given to social psychological studies of referral.

In Chapter 4, the details of the "grounded theory" methodology that guided the interviewing of physicians and patients and the analysis of the data in this thesis, are presented. In addition, some of the issues that were faced in this thesis research are described.

The results of this study of 50 medical referrals are presented in the next six chapters, under the reasons for seeking advice (Chapter 5); the way in which a consultant was chosen (Chapters 6 and 7); the division of responsibility between advice-seeker and advice-giver (Chapter 8); communication in referral (Chapter 9); and compliance with advice and closure (Chapter 10). For each step of the process, an analogy is drawn between what is done by the patient in consulting with the primary physician and what is done by the physician in consulting with another doctor.

Further, the literature relevant to the topic is highlighted, and the significance of each aspect of the process is indicated. Finally, Chapter 11 summarizes the substantive and theoretical contributions of the thesis.

NOTES

1. In keeping with this usage, the terms are used interchangably in this thesis. A discussion about the division of responsibility between doctors in referral can be found in Chapter 8.

2. For brevity, the term "general practitioner" or "GP" is used in this text to denote the primary caregiver, although about half of the primary care physicians in this study were specialists in family medicine with a certificate from the Canadian College of Family Practice. Technically, a GP is a physician with a license to practice who provides routine care to the patient on an outpatient basis. In Canada, most primary care is provided by GPs or specialists in family medicine. In the U.S., unlike Canada, many specialists in internal medicine provide primary care to patients. Secondary and tertiary care in both countries are provided mostly by specialists and subspecialists,, and involves hospitalization or attendance at specialized clinics.

3. The U.S. differs from most Westernized nations in not having universal health insurance of some form. Blue Cross and Shield, the major private insurers, do not cover the majority of the population (Law, 1976) and the 1965 amendment to the social security act providing Medicare for those over 65 barely covers half the health care costs of that group (Davis & Rowland, 1986; Law, 1986; Ginzberg & Ostrow, 1985). Canada, like Britain, has government health insurance financed by taxation, and other European nations, such as the Netherlands, France, Belgium and West Germany have social insurance that covers the majority of the population and which is financed through a payroll tax with both employee and employer contributing (McLachlan & Maynard, 1982). The money flows through an accredited intermediary such as "sickness funds" that are regulated by government but expected to ensure their own fiscal stability (Reinhardt, 1981). Unlike

Canada, these countries, including Britain, have a substantial private health care system alongside the public system that caters to the more economically advantaged segment of the population.

4. Although Canada has a national health insurance plan, health is under the jurisdiction of the provinces constitutionally, and, since 1977, the provinces have taken more fiscal responsibility for running their plans. In Ontario, the Ontario Hospital Insurance Plan (OHIP) remunerates physicians and surgeons for their services. In their published fee schedules, which are negotiated annually, services to physician-referred patients are remunerated at approximately twice the rate of self-referred patients.

5. Under capitation payment, a physician or group of physicians receive a single fee for each patient for a certain period during which the patient is expected to be exclusively treated by him/her (Glaser, 1970, pp. 82-97). In 1948, rather than subsidize a private system with public money, as is done in Canada, the central government in Britain took over all facilities and began paying GPs by capitation and specialists by salary (Walters, 1980; Doyal, 1981). Other European states that have become involved in owning the facilities and paying the physicians are Scandinavia, Portugal, Italy and Spain, which is currently in this transition (Abel-Smith, 1985).

CHAPTER 2

WHY STUDY REFERRALS?

I. INTRODUCTION

This chapter provides an introduction to the major sociological, economic and clinical controversies surrounding the referral process. It is followed by a more complete review of the literature in Chapter 3. Here it is suggested that a systematic study of referrals would contribute to an understanding of a number of substantive and formal sociological questions. Referral is also significant in economic terms, since the cost of referral surpasses the cost of primary care. But the issue perhaps most worthy of consideration is whether referral achieves its clinical goals.

II. SOCIOLOGICAL ISSUES

Although referral for specialized medical care is generally recognized as a basic process in the organization of medical care, it has not received its

fair share of attention from medical sociologists. Physicians participating in this study sometimes spoke of it as an almost mysterious activity that lay beyond the realm of sociological investigation because of its complexity. In Canada, there have been only two non-clinical studies of referral - Wolfe and Badgley (1973) examined it as part of everday medical practice in a Saskatchewan family practice clinic and Modrow (1976), using data originally collected by Freeman and Darsky (1974) in 1963, did a quantitative study of referral in Windsor.

Most American studies of referral are of limited value in their application to the Canadian situation because of substantial differences in the historical development of the institution of referral and in the funding of medical care.[1] However, the work of three American theorists is useful in drawing attention to the issues that should be addressed.

1. How Do Referrals Work? The Traditional Model

Unlike referral in fields such as education (Kerr, 1985), there are no formal prescriptions or laws governing the situations in which medical referral must be made or to whom it must be made.[2] Thus a basic

question that any theory of medical referral must answer is, in the absence of formal guidelines, how do referrals work?

The American theorist Kerr White has described the organization of medicine as a pyramid, with primary care at the base and specialized, or intensive hospital care, at the pinnacle.[3] In his model, the system only makes sense if the pinnacle receives appropriately referred cases from the base. Thus in the first systematic studies of referrals, funded by the Rockefeller Foundation, he called attention to the importance of understanding the relationship between primary care and care by highly-trained specialists (Peterson et al., 1956; Andrews et al., 1959; Williams et al, 1960; Williams et al, 1961; White et al., 1961). Similar work, funded by Rockefeller, was conducted in Ontario and Nova Scotia (Clute, 1973). The original study, which focussed on referrals from GPs in rural North Carolina to a large urban university medical centre there, suggested, contrary to the theory, that GPs were not referring all cases that the researchers felt might benefit from tertiary care. The results of the Canadian Rockefeller study were similar.[4]

2. The Economic and Social Economic Bases of Referral

If the process of medical referral does not match the Rockefeller model, how, then, does it work? The social exchange theorist Stephen Shortell has suggested, approaching the problem from the bottom up, rather than the top down, that we can understand patterns of referral as the aggregate of individual economic decisions made by the doctors involved. Specifically, he argues that the number of patients one doctor refers to another (the "outcome") can be predicted if it is known how "rewarding" or "punishing" the referring doctor calculates the referral to be (Shortell & Anderson, 1971). These decisions are assumed to take into account the status of the consultant in the medical community as measured by his committee positions, number of articles published or presented, and whether he is named by other physicians as influential.[5]

In a study of 127 internists in Chicago, Shortell found that higher status physicians had more cohesive referral networks, while lower-status physicians would refer more often outside their status group, presumably because of the costs of referring to

their low-status group. Friends were named more often as referral partners by low-status referrers and the majority of partners were in the same hospital, although typically not the closest (Shortell, 1973). In using exchange theory to try to explain differences in referral among the Chicago internists (1974), however, Shortell reported disappointment with its predictive power. Specificially, he suggested that the importance of "perceived competence" should receive more attention and that longitudinal studies might be more illuminating than his cross-sectional approach. More recently, he feels he has been successful in explaining referral patterns in a circumscribed rural area from only four family physicians as at least "consistent" with "a practice-building, reward-and-cost model of rural practice" (Moscovice et al., 1979).

However, Shortell appears to have abandoned the attempt to explain large-scale referral patterns quantitatively, in view of the complexity that he has uncovered. The question therefore remains to what extent referrals can be explained by individual economic and social economic decisions.

3. Referral as Medical Dominance

A third sociological model of referral has been outlined by the symbolic interactionist/social phenomenologist Eliot Freidson.[6] He has pointed to the significance of referral in his description of the organization of Western medical care as a system of "professional dominance" in which the social reality of medical patients is constructed by biomedical experts (1970a,b; 1986).[7] Freidson's model has evolved over the years, but is based on the idea that while the patient and his or her relatives are important in referral to the GP, once inside the door of the clinic, medical experts thereafter define the career of the patient and the nature of his or her illness (1970a, p. 326). Referring physician and consultant negotiate the boundaries of their responsibilities within a common "culture" of medicine that defines what "meaning" should be attached to the symptoms that the patient presents (1975).

A number of substantive issues are raised in Freidson's work. The first has to do with how much control the patient vs. his or her physicians have over the process of medical care. Although the North Carolina Rockefeller study suggested that the patient

is a pivotal player, controlling the decision to refer about half the time (Williams et al., 1960), Freidson has characterized the patient as a pawn who must submit to the dominance of the profession (Freidson, 1960).

A second issue has to do with how physicians achieve control over their work in everyday medical practice. The observation that doctors structure their work in order to see what is of interest to them is well documented (e.g. Roth, 1972a,b; Sudnow, 1967). However, prior to Freidson, only Hall (1946; 1948) has attempted to link professional careers to practice patterns.

The third, and most important, substantive issue that emerges from Freidson's work is whether referral operates as a mechanism of professional control or whether, as he contends, referral places incompetent practitioners beyond the control of their peers (Freidson & Rhea, 1963; Freidson, 1975).[8]

4. Trust and Social Order[9]

One recent study of medical referral has questioned why the process of medical referral does not break down completely, in view of the evidence that participants disagree substantially on what is to be

accomplished by it and how (Grace & Armstrong, 1986). A sociological approach that predicates social order on conformity to common norms held by participants faces difficulty in explaining these observations. Freidson's view, consistent with "negotiated order" explanations of social organization (Strauss et al., 1963; Strauss, 1978) is that physicians are able to come to an agreement about how to proceed in referral because they work within a common culture of medicine (1975). However, the worlds of patient and physician are so far apart that they are sometimes characterized by conflict (1961), and more often by the patient passively submitting to the doctor's definition of reality.

How does this submission occur? Does the patient "trust" the doctor? If so, how is this trust established and maintained? If not, how is the interaction sustained? Trust has occasionally been discussed theoretically by exchange theorists (Blau, 1964; Haas & Deseran, 1981) and functionalists (Barber, 1983; Lewis & Weigert, 1985). It has been described by ethnomethodological sociologists as the process that underlies all social interaction (Garfinkel, 1967), but it has seldom been examined, except in the notorious "breaching" experiments and scattered interactionist research (e.g. Henslin, 1968). For example, although

recent work on business transactions suggests that vendors "produce" trust in their clients by presenting themselves as competent and trustworthy (e.g. Prus, 1986; Swan, 1986), the crucial link between "trust" and "competence" has seldom been explored in the medical setting.[10]

In summary, a number of issues concerning the nature of referral await resolution. In addition, a sociological study of referral promises to provide evidence concerning the basic social process of trust.

III. ECONOMIC ISSUES

A rough idea of the economic importance of referral can be gained from a British article that cites Acheson (1985) as estimating that the cost of providing referral under the National Health Service is now £920 million, "a sum only slightly below the total cost of providing general medical services" (Grace & Armstrong, 1986, p. 143). At the level of the clinic, a study at Sunnybrook Medical Centre in Toronto showed that in March 1984, even though the family physicians in the group saw 3723 patients while the specialists only saw 1891 patients, the specialty services accounted for 61 percent of the total direct physician

costs (Norton et al., 1985). As in other countries, there is a large fee differential between specialists and GPs in Canada (Glaser, 1970; Wolfe & Badgley, 1974) which contributes to this cost, as well as the greater reliance on technical investigations.

The problem for traditional economic demand theory in accounting for the referral situation is that it is not clear who is demanding the services - the patient or the referring doctor. This problem is not solved by the finding that referrals rise with the number of specialists available (Shortell & Vahovich, 1975; Rutten & van der Gaag, 1977). Whoever the culprit is, in North America, where the predominant mode of practice is solo-FFS, there is a great deal of concern with the problem of "overdoctoring" including "over-referral" and a large literature on the "efficiency" of alternative practice arrangements. It is well-known that the surgery rate in the U.S. and Canada is twice that of Britain, where there are half as many specialists (Bunker, 1970; Mechanic, 1971; Vayda, 1973). When Medicare was introduced for the over-65 group in the U.S., peer review systems were legislated to restrict anticipated abuses of the funding system.

As Somers (1983) argues, however, there has been "overutilization" under all payment systems as

part of the seeking of more technical care, with perhaps less abuse in European systems where, she believes, GPs serve as "gatekeepers" to specialist services.[11] When the tertiary care system is engaged for a problem that could be treated at the primary care level, there is a substantial "waste" of resources.[12] Is there evidence, then, in Ontario, that unnecessary referrals are being made or that tertiary care specialists are providing services that could be provided by primary care physicians? Is it true, as physicians in this study often charged, that patients increasingly pressure their GPs for a second opinion in Ontario because it is "free"? Or is it true, as other physicians suggested, that general practitioners just try to maximize income in this system by referring on all the difficult cases? In view of the staggering costs involved, an understanding of the process of medical referral should be of considerable interest to economic policymakers.

IV. CLINICAL ISSUES

Clinical studies provide a disturbing critique of the usefulness of referral from the perspective of individual practitioners and raise serious questions about the quality of care in referral. Gillam (1985),

for example, found that 13 referring GPs rated about a quarter of 864 referrals studied as "not worthwhile". Similarly, a Canadian study by Clarfield (1980) reported that staff physicians at a family medicine clinic only "learned something" from 48 percent of the referrals studied. In another British study, M. Brown (1979) classified 80 of his referrals in terms of whether he would make the same referral again, and found that he would not in over half the cases, labelled "not worthwhile".[13] He felt that the number of referrals could be reduced considerably if other practitioners would do this type of "audit".

Another indirect critique of the usefulness of referral can be found in clinical studies that document the less than perfect compliance of referring doctors with the recommendations of hospital internists (e.g. Sears & Charlson, 1983; Klein et al., 1983; Perlman et al., 1975; Mackenzie et al., 1981). However, sociologists, rather than clinicians, have raised the most telling critique of the quality of care provided via the the current organization of medicine of which the referral process is a part.[14] Freidson, in particular, has questioned whether the autonomous organization of medicine allows control over the quality of care, and his work leads him to conclude

that it does not (1970a,b; 1975). This is disputed by others, such as Flood and Scott (1978), who have presented evidence that, within the hospital at least, where surgery can be observed, the collegium or a strong central administration can enforce appropriate procedures and discipline deviant members.

In the outpatient situation, Freidson (1960) has argued, the solo practitioner is never observed by colleagues and thus "must be able to resist all temptations to ethical or technical lapses by virtue of his inner resources alone" (1970b, p. 89). This is also true of specialists who do not make everyday use of the hospital, including some internists, pediatricians, ophthalmologists and gynecologists, as well as GPs. It might be objected that patients provide some form of check on such practitioners, but Freidson argues that "patients' opinions are something few physicians will accept as valid indication of technical performance" (Freidson & Rhea, 1963, p. 123).

In contrast to the "solo practice" situation, in cases where a specialist makes his living from GP referral, there are strong pressures on him to satisfy both patient and GP if he wishes to receive any more referrals, says Freidson. Therefore, these "colleague-dependent" practices, he argues, will be more likely to

conform to professional standards (1970b, p. 93). On the other hand, once the patient has been hospitalized, the "privileges of the attending physician are well-nigh absolute" and there is no longer any countervailing pressure from colleagues to insure standards of practice (1970b, p. 72). Other studies of hospital performance such as those by Sudnow (1967), Duff and Hollingshead (1968), Millman (1977) and Bosk (1979) support the contention that doctors within hospitals have a capacity for "normalizing" errors in the sense that Garfinkel and Freidson speak of it, such that even where errors are detected, they are not dealt with directly.

In the situation of referral, Freidson explains, the process of quality control depends on what Carr-Saunders and Wilson (1933) have called the "boycott", or refusal to refer to a specialist of whom GPs do not approve. In Barber's words, "the disapproval of others will control him or will lead to his exclusion from the brotherhood" (1962, p. 195, cited by Freidson & Rhea, 1963). In a study of a 50-doctor U.S. group practice, however, Freidson and Rhea (1963; 1965; Freidson, 1975) found that each doctor tended to keep his complaints about others to himself, so that only the most outrageous of behaviour would result in total

ostracism. In their words, information about colleagues was available in "such a fragmented, selective basis that it is probably impossible for any individual to have a rounded and informed view of any other" (Freidson & Rhea, 1963, p. 123). Further, fellow GPs or internists might only be able to make evaluations if they have had the opportunity to cover a practice on an emergency or locum basis and see that doctor's patients. The medical record, that might serve as a source of evidence, was only scrutinized after it was suspected that something was wrong. Within the clinic they studied, they found instances where some members had grave doubts about a man that "were not even suspected by anyone else" (1963, p. 125). This led Freidson to speculate that, in large cities at least, each practitioner eventually finds a circle which accepts his standards of practice, and that there is little interaction between these differing networks and thus little inter-network awareness or control. As Freidson summarizes it, this process "operates to place offenders beyond the control of those who disapprove of their performance" (1970b, p. 101).[15]

Another "quality of care" problem inherent in the organization of medical care is the almost total breakdown of referral when services lie outside the

medical division of labour. Freidson observes that while teachers, social workers, ministers, clinical psychologists, optometrists, chiropractors and others routinely refer to doctors, doctors seldom refer to them, nor do they inform the non-medical referrers of their findings (1970b, p. 150). Although these breakdowns presumably limit the "continuity" and "quality" of total medical care the patient receives, this point awaits examination by researchers.

The over- and under-referral problems discussed under the section on costs also carry "quality of care" implications. The original Rockefeller studies, 25 years ago, turned up what the researchers felt was an inappropriate tendency of primary care practitioners, for economic reasons, to "hold onto" cases that should be referred. In such a situation, the patient may undergo surgery with a less competent doctor than could be obtained. Wolfe and Badgley (1973) allege that this is a problem in rural Canada, where GPs are tempted to do unnecessary surgery in the local hospital.[16] However, over-referral, which also presents serious quality of care problems, may be the trend in predominantly urbanized Canada. GPs may not want to waste time on "trivial" or very complex cases and may refer on cases that they are able to handle

themselves, thus disrupting continuity and appropriateness of care (Mechanic, 1971; Hannay, 1975; Cartwright, 1967). Further, over-referral is part of the process of eroding generalist medicine which leads to the fragmentation of care.

In summary, both sociologists and clinicians have identified problems with the quality of care provided under the current system of referral. Perhaps the most serious allegation is Freidson's argument that although the referral situation theoretically provides the opportunity for the profession to monitor and control quality of care, in practice it does not. Other "quality of care" issues not explored systematically by previous research are the effects of the exclusion of non-medical professionals from the referral network and the effects of the perennial problems of under- and over-referral. Clearly there is a great deal to be learned from a systematic study of referral.

V. SUMMARY

Despite the importance of medical referral in the organization of medical care, there has been little sociological investigation of this area. The traditional model describes a pyramid, in which the

"pinnacle" of specialized medicine receives appropriate referrals from the community medicine "base" (White, 1973), but studies have shown that in the real world, referrals do not proceed in such an orderly fashion. Neither can social exchange models, that explain referral as an aggregate of rational economic decisions by individual referrers, account for the complexity of real-world referral.

The most challenging sociological work on medical referral has been published by Freidson. He raises a number of critical substantive issues concerning referral, including how much control the patient vs. the physician has over the process of medical care; how physicians achieve autonomy over their work via the referral process; and whether the referral system operates to place incompetent practitioners beyond the control of their peers.

A systematic study of referral promises to add to an understanding of how trust in an advisor contributes to the maintenance of social order as well as providing clues as to how such order is maintained in the absence of trust. And finally, in view of the cost of specialized medical services and the suspicion that its clinical goals are not always achieved, a

study of referral should be of considerable interest to economic policymakers and clinicians.

NOTES

1. Historically, Canada follows the U.S. in some respects and Britain in others. Specifically, in small rural hospitals in Canada, the American system of having the primary physician care for the patient in the community as well as in the hospital is still in place, while the British system, where the GP provides community care but refers the patient to a consultant in the hospital for specialized care, prevails in urban centres. Another difference is that Canada, in contrast to the U.S., has socialized medical care, which appears to encourage referral (See Ch. 1, pp. 3-5 and fn. 4 in that chapter).

2. There are some very general, non-binding professional guidelines. The AMA, for example, suggests that when two physicians see a case, further action, including informing the patient, should only be taken after discussion of the case with the referring doctor. As Ruane (1979) points out, this procedure is rarely followed. The College of Family Physicians of Canada (the certifying board for the specialty of family medicine) provides similar general guidelines.

3. The interest of Kerr White and his colleagues at the Rockefeller Foundation in how the system of Western medical care "works" is hardly coincidental, since, as historical sociological analyses have documented, Rockefeller funding has been strategic in directing the course of modern Western medicine. Historical accounts reveal that physicians of the last century were constantly lobbying North American legislatures for a monopoly on their trade, despite lack of public confidence in their expertise (Hamowy, 1984; Roland, 1984). Lay practitioners and practitioners of alternate schools, were condemned as charlatans, much as they are today (Ehrenreich & English, 1974). The most influential document of the time was a

report funded by American philanthropists and prepared by Flexner, which deplored the lack of competence of most medical practitioners and called for a reform of medical education (R. Brown, 1980). The influence of these medical reformers, whom Alford (1972) has called the "corporate rationalizers", has been staggering. Through "strategic funding", the Rockefeller Foundation and other private funding agencies have shaped the high-technology, hospital-based system that is in place today, not only in North America, but in many third world countries where "centres of excellence" are particularly inappropriate to meet the needs of the majority peasant population (Donaldson, 1976). In 1961, Kerr White noted that while "vast sums of money" are spent on disease-oriented research in medicine, research on whether health services actually improve the health of those that seek them are rare.

4. More recent American studies of referral, such as the analysis by Creditor and Creditor (1972) of referrals from outside and inside a Chicago hospital, have also shown that a large proportion of patients are either self- or lay referred (in pediatrics, ENT, ophthalmology and obstetrics and gynecology) or generated within the hospital itself (in surgery, urology and neurology). And studies of Rockefeller-type medicine in the third world show a complete hiatus between primary and tertiary levels of medical care (England, 1978; Navarro, 1974; Doyal, 1981), in which primary care is unavailable for the majority of the population of these countries.

5. The basic assumptions of social exchange theory have been presented in Homans (1961) and Blau (1964). Shortell's social exchange theory of referral rests on a body of literature that argues that physicians and surgeons structure their referrals and other work so as to maximize their income, status or other rewards (Glaser, 1979; Roemer, 1962).

6. Friedson's work is probably generalizable to the Canadian situation because it is based on observations of pre-paid practice which more closely approximate the Canadian context than

the observations made in North Carolina by White or in Chicago by Shortell. With economic considerations "out of the way", other social-psychological aspects of the referral process can be more clearly examined.

7. Freidson's dominance theory combines elements of two theoretical approaches in sociology, symbolic interactionism and social phenomenology, that explain social behaviour in terms of the meanings that they hold for the social actors involved (Blumer, 1969) and the "social reality" that the actors construct based on these meanings (Berger & Luckman, 1967). His work brings out the "negotiation" aspect of social interaction that has emerged as a recent emphasis in the interactionist paradigm (1961; 1975).

8. Friedson's theory of referral as social control is presented in the last section of this chapter, since it raises crucial questions concerning the relationship between the quality of care and social settings in which medicine is practiced.

9. Glaser and Strauss' (1967) distingish between substantive (topic-oriented) and formal (generic sociological) theory. The first three topics discussed in this section are "substantive", but this one is "formal".

10. Haas & Shaffir (1974) describe how novice physicians present themselves as competent doctors to their patients. However, they fail to examine the other side of the process, the effect of this presentation on patients. Millman's (1977) discussion of the enactment of trust between cardiac surgeons and patients is one exception to the one-sided approach to issues of competence and trust.

11. Glaser's (1970) review of European payment systems describes the legislative and fiscal controls discouraging over-referral. Health Maintenance Organizations (HMOs) in the U.S. and their counterparts in Canada, called Community Health Centres (CHCs) or Health Service Organizations (HSOs), in which doctors are paid by capitation or salary, have been

shown to reduce hospital use by up to 40 percent, including referral (Luft, 1981). Somers (1984) compares the operation of these organizations to that of the British NHS where GPs are also paid by capitation. (Other reviewers have expressed concern about the potential "underdoctoring" of patients in HMOs that pay primary physicians incentives to avoid referral.) At least one European study has shown a negative correlation between the number of referrals and the number of GPs per 1,000 population (Rutten & van der Gaag, 1977), so it is theoretically feasible that GPs in HMOs (which serve about four percent of the American population) might refer less. Norton et al. (1985), in a Toronto HSO, have argued that the GP can serve as a "gatekeeper" if aware of the costs generated by referral; in their clinic, chiropractors are used extensively, at great savings to the clinic. In contrast, Wolfe and Badgley (1973) reported that the average rate of referral per 100 patients in Saskatchewan was 16 percent in 1965, while in their CHC, it was 22.5 percent (p. 110). Mayer (1982), in a comparison of an HMO and FFS patients in a St. Louis medical centre, found no difference between the two in referral rates. Moore et al. (1983) similarly found no reduction of referral in an IPA (a type of HMO). Gillette (1984) claims that GPs are "ill equipped to deal with the political realties they will face as gatekeepers" (p. 680). Finally, Catlin et al. (1983) sent questionnaires to 104 HMOs to find out if there were lower hospitalization rates in the HMOs with more primary care physicians. Although the majority of these institutions ranked "gatekeeping" very important in their priorities, HMOs with more physicians showed higher hospitalization rates and whether the physicians were salaried or FFS did not seem to make a difference. The authors admit that their measure of gatekeeping is not a good one, but they call for more scrutiny of the assumption that GPs can serve this purpose.

12. Wolfe and Badgley (1973) have argued, based on their experiences with a group practice in Saskatchewan, in which the group survived mainly due to the huge FFS income of its surgeon, that regardless of the rate of

referral, the fee differential for specialty services vs. primary care in Canada is far too great. In the U.S., where Somers quotes this fee differential as 4:1 or 5:1 (1984, p. 305) cost concerns revolve around the fact that GP numbers have been steadily declining over the past 40 years (to 18 percent of U.S. physicians in 1973) although it is estimated that 95 percent of all care provided is primary. Unlike the situation in Britain (or in Canada either, despite Wolfe and Badgley's concern about the "disappearing" family doctor), specialists in internal medicine are delivering a substantial amount of primary care in the U.S. One estimate of this "waste" of expertise comes from a non-university-based Alabama internist (Burnum, 1973) who feels that two-thirds of his patients "could have been managed by someone with far less training" (p. 442). He defends the fact that he sees a majority of his patients as their primary physician, arguing that the internist is better qualified than the new specialty of family medicine to fill in the gap in primary care in the U.S.

13. He concluded that "[t]his leads me to wonder whether I at any rate have been grossly overoptimistic about the likely benefits of referring patients to hospital. It seems that not much harm might result if I backed my own judgement with a little more confidence and referred only half as many patients in the future" (p. 743).

14. Social psychological theory has historically been criticized for its emphasis on microsociological phenomena to the exclusion of larger-scale macrosociological organization (Meltzer et al., 1975; Archibald, 1978; P. Hall, 1986). Much medical social psychology escapes this criticism because patient-doctor and doctor-doctor interactions are placed within the context of the organization of medical care (e.g. Hall, 1948; Coleman, Katz & Menzel, 1966; Freidson, 1960; Friedson & Rhea, 1963; Freidson, 1970a,b; 1975; 1986). In spite of this orientation, theorists have complained that so little is yet known about the effect of variations in the organization of physicians and their work settings on the technical and

social quality of the medical care provided. Goss et al. (1977), for example, cite a few studies that have been done on organization and quality of care, but they assess this work as "a set of building blocks in need of being put together to form a usable dwelling" (p. 3).

15. Wolfe and Badgley (1973), in their account of the history of a Saskatchewan family practice clinic, argued that this process led to the group inviting particular doctors to be formal partners based "upon how his clinical competence was judged by other physicians who had sponsored him" (p. 111). Two doctors, they report, were urged to leave because of incompetence. Like Freidson, they regretted that these doctors were free to set up practice elsewhere and with him, advocated a formal, periodic outside review to detect such physicians. Freidson (1986) maintains that this situation has not changed in the 25 years since he proposed it. However, it is worth noting that, during this time in the U.S., the autonomy of the profession has come into increasing conflict with the "corporate rationalizers", a group of hospital administrators, medical school directors, federal and state officials and corporate leaders (Alford, 1972) who are among the leaders of the movement towards more "efficient" modes of health care delivery described in the previous section.

Some of the business practices reported in the American journal Medical Economics, such as purchasing of specialty clinics and referring hospitals, or "hiring" doctors as a source of referrals, would certainly appear to warrant closer scrutiny. They have provoked an outcry from the profession about the consequences of, for example, not freely being able to choose one's consultant (Schaffer & Holloman, 1985), particularly when referring physicians have sometimes been legally charged with malpractice because they "should have known of the consultant's incompetence" (p. 603). In countries like Canada where such practices do not occur, government is still condemned by the profession as the "rationalizer" that threatens the autonomy of the profession. Governments in

Canada in fact have published a number of reports suggesting sweeping changes in the provision of health care about the time of the institution of national health insurance (e.g. Government of Ontario, 1969). Subsequent legislation in Ontario made hospital accreditation dependent upon a quality appraisal, to which primary care is also subject (Tugwell, 1977). The effects of these moves, however, have not been reported in the public domain. Threats to use the data-base collected as part of the national health insurance system as a comprehensive "surveillance system" to single out abusers of the system (Laframboise & Owen, 1972) do not appear to have materialized, and it can be argued that the fears of the profession that they would lose autonomy with the advent of national health insurance, in general, were unfounded. Further, in Ontario, recently, a major responsibility for peer review has been taken by the Ontario College of Physicians and Surgeons, which traditionally acted as a doctors' guild.

16. More recently, on the American scene, in settings where referral is discouraged by financial incentives, Somers (1984) has asked whether the patient's right to a "free choice" of doctor may be violated and whether subsets of Americans, such as the elderly and the poor, may become "locked into second- or third-rate health care systems without any effective recourse to good medical care" (p. 310). Waitzkin (1984) has argued that this has already happened in California with recent cutbacks in Medi-Cal.

CHAPTER 3

CRITIQUE OF THE LITERATURE

I. OVERVIEW

No review of the diverse clinical, psychological and sociological literature on referral exists, and the first attempt at a critical, comprehensive review is made in this chapter. The clinical literature is large, but is mainly composed of atheoretical calculations of referral rates and quantification of various aspects of the process, rather than explanation of how referral works. The psychological literature focusses in more detail on the process of referral from the perspective of the referring doctor, but, like the clinical literature, ignores the perspective of the patient. The sociological literature takes a broader view of the process, examining the production and maintenance of referral networks. However, like the clinical literature, it concentrates on the American referral experience and avoids examination of actual cases of referral.

II. THE CLINICAL LITERATURE

Over 25 years ago, in their much-cited article entitled "The Ecology of Medical Care",[1] White and colleagues argued that traditional quantitative measures of health are of limited value in explaining the use of health care services. Instead they suggested that the "natural history of the patient's medical care may be a more appropriate concern than the natural history of his disease" (1961, p. 886). However, beyond their early investigations and those of Balint (1957), there have been no studies by practitioners of the "natural history of referral". Instead, clinicians have been preoccupied with calculating rates of referral and speculating whether they are too low or too high. Alternatively, they have complained, on the basis of small-scale quantitative studies, about practical problems such as breakdowns of communication and unsatisfactory outcomes in referral. The largely atheoretical "rate calculation" literature has been unsuccessful in identifying which patient and doctor "variables" are predictive of the rates. Further, the small-scale surveys are typically presented as a prologue to sometimes sweeping proposals for change, without in-depth description of the referral process or

the feasibility of change. And finally, most of the literature is concerned only with the American experience, which is considerably different from the situation in Canada and most of Europe.

1. Preoccupation with Explaining Referral Rates

Morrell, himself the author of a quantitative study of referral in England (1970; 1971) calls the scores of atheoretical studies in the clinical literature that attempt to explain differing referral rates by patient or physician characteristics "unhelpful", since "the factors which determine individual doctor's referral rates are probably much more complex" (in Dowie, 1983a, p. 9). Typically the studies give an overall referral rate from a group of GPs, which may be broken down, for example, by the doctors' age and clinical experience and the patients' age and sex. About the only reliable finding is that since younger doctors have younger clientele, they have more referrals to pediatricians and obstetricians (Brown et al., 1971; Schmidt, 1977). Differences in rates of referral between younger and older doctors, however, are not so easily explained. Morrell's (1971) study of three suburban London GPs showed that the

older physician referred less than two younger ones, but it has been found in other studies that younger doctors refer less than older doctors (e.g. Brock, 1977; Wolfe & Badgley, 1973, p. 110) or that there are no differences (Riley et al., 1969). The occasional study shows no connection at all between the rates and the factors chosen (e.g. McPhee et al., 1984), but more often one or two interesting relationships are turned up and researchers are at a loss to explain them (e.g. Carson, 1982; Clarfield, 1980; Hines & Curry, 1978; Penchansky & Fox, 1970).[2] In general, these studies raise interesting questions and give glimpses of the complexity of the process, but they do not provide any evidence about the source of variation in the referral rates.

Occasionally the "rate" studies make a half-hearted attempt to clarify the dynamics of referral by quantifying the "reasons" that it is sought[3] or its "outcome" in terms of the satisfaction of the referring doctor. Two small American studies[4] address the issue of how GPs and specialists share responsibility for the referred case with the consultant. They argue that the American GP only hands over cases when he is forced to do so when he requires technical assistance because "referral is to some physicians a tacit admission of

the limitations of their own knowledge and resources" (Metcalfe & Sischy, 1973, p. 1692). However, they present no evidence for this hypothesis.

Although Geyman et al. (1976) applaud low referral rates as "cost-effective medicine", historically, White and other spokesmen for the Rockefeller "centres of excellence" model of health care have argued that low referral rates are an indication of poor quality care. Specifically, the finding that rural practitioners are relatively self-sufficient and do not use the referral system as much as their urban colleagues (Peterson et al., 1956; Clute, 1963; Riley et al., 1969; Penchansky & Fox, 1970; Morgan et al., 1979; Ruane, 1979) has been interpreted to mean that rural North American communities "may often be exploited by family doctors who dabble in procedures that they should refer to specialists" (Wolfe & Badgley, 1973, p. 135). About the only sympathetic treatment of lower rural referral rates can be found in a study of referral in a remote region of Australia that documented the extreme disruption to family life and economic costs to referred patients in the rural area, which suggested that about half of them could be seen by a visiting specialist (Smith, 1970; 1971).

The link between low referral rates and poor quality care is not as clear as White and other researchers contend. In the U.S., where most studies have been conducted, the backgrounds of community physicians have changed substantially over the past few decades. Specifically, the proportion of GPs to specialists declined to 1:3 by 1969 (Stevens, 1971) and a significant amount of primary care is done by specialists there (Burnum, 1973; Aiken et al., 1979). In fact, if there is a problem, it is not that primary care physicians in the U.S. are under-qualified, but that they are over-qualified![5] Further, it is doubtful that Canada and other countries share these American problems, since comparable declines in the numbers of family doctors have failed to occur elsewhere, and training in the specialty of family medicine is now an accepted background for young primary care physicians, for example, in Canada.[6]

On the other hand, it is likely that Canada shares with the U.S. the problem that physicians do not coordinate their activities in referral (e.g. American Committee on the Costs of Medical Care, 1962). Changes in the organization of medicine, notably the recommendation for group practice, have been put forward both in the U.S. and Canada as a possible

solution to this problem (Boan, 1966). However, it is as yet unclear what effect these alternative forms of practice have on the process of referral.[7]

2. Clinical Difficulties in Referral

As with "rate" studies, the tendency of clinical researchers has been to quantify problems in referral and then attempt a post hoc explanation, rather than making a systematic attempt to explain the dynamics of the problem. For example, several clinical articles have documented the extent to which referring doctors fail to send information to the consultant about the patient (Williams et al., 1961; Clarfield, 1980). Others document the extent to which consultants fail to communicate with their referring doctors (Cummins et al., 1980; Holmes et al., 1978; Clarfield, 1980) or send their letters too late to be useful to the referrer (Metcalfe & Sischy, 1973; Carson, 1982; Fraser, 1974). However, they fail to examine what is happening and why.

There is a hint at a theoretical orientation in a few of these studies, but it is not pursued. For example, evidence is presented that FFS consultants are better communicators than salaried consultants (e.g.

Hansen et al., 1982), but the researchers do not link this finding to Freidson's observations about "colleague-dependent practice". Similarly, the occasional clinical article on communication breakdown draws attention to the "subtle disdain" of consultants for GPs, hinting at a psychological explanation of these problems in referral (McPhee et al., 1984; Cummins et al., 1980), although, again, no theoretical framework is given for the process and the researchers fail to trace the process in actual cases of referral. The most sophisticated of these studies, by two British researchers (Long & Atkins, 1974) goes beyond psychological and economic explanations to argue that communication breakdown is inherent in the British health care system in the isolation between GP and specialist. However, this hypothesis has not been systematically explored.

Occasionally, clinical researchers express concern about the consequences of communication lapses - for example, Cummins et al. (1980) worry that "the patient's ongoing health care could suffer" (p. 1650), but they, and other researchers, fail to determine whether this is true for the cases in their studies. Neither is the perspective of the patient in communication breakdown explored fully in the clinical

literature, even when data are presented that suggest what the underlying dynamics might be. For example, White and colleagues noted that almost half of the referring doctors in their study were aware that "the patient's own dissatisfaction or desire, for some reason, to go to the medical centre, was the motive for the referral" (Williams et al., 1961, p. 903). They also expressed concern that 40 percent of patients did not return to their GPs after the referral, but did not attempt to explain what was happening.

In a more recent study of referrals in three rural university-affiliated primary care centres in Florida by Curry et al. (1980), there is a similar failure to follow up patient experiences, even though these appear crucial to understanding why, in the authors' words, "poor communication was a major impediment to the successful completion of the referral process" (p. 288). In the study, a "disturbingly low" rate of feedback from consultants to the referring clinics - 28 percent, or the lowest in the literature- is reported. The authors point out that these rural teaching centres suffer "regular turnover of providers, a situation not conducive to interaction between referring physicians and consultants". It would have been interesting to know whether there was any

connection between over half of the patients seeking care elsewhere during the year and the "communication lapses" from consultants. In this situation, perhaps the patient's lack of trust or respect in the referring doctor contributes to the breakdown of feedback from the consultant, who may share the patient's evaluation of the GP. There are only scattered references to this idea in the clinical literature and it has never been examined.[8]

Where "outcomes" of referral are examined by clinicians, "outcome" is taken in the narrow sense of whether the referral was "useful" to the referring doctor. Clarfield (1980), for example, says that 31 percent of the referring doctors in his study "felt that they had learned nothing from the referral" (p. 529). Unfortunately, he has little to say about these findings, except that "it would be useful to study in more detail those referrals in which 'nothing was learned'" (p. 531). In American hospital studies, failures of referring specialists to comply with consultant advice, based on chart review, have assumed, without investigating, that failure to comply reflects some deficiency of the process of advice-giving, rather than a rejection of the advice by the referring doctor (Klein et al., 1983; Mackenzie et al., 1981; Perlman et

al., 1975; Sears & Charlson, 1983). Further, no attempt is made to solicit patient assessments of outcome. With the exception of Williams et al. (1961), no mention is even made of whether the patient returns to the GP after the referral. In the most sophisticated study in this literature, the researchers interviewed the three participants of over 300 referrals and found substantial disagreement among them on the value of the consultation (Grace & Armstrong, 1986). However, a quantitative summary rather than the details of the process is presented and the discrepant perspectives are not linked with unsatisfactory outcomes in actual cases.[9]

3. The "How to" Literature

Prescriptive literature on referral occasionally appears in specialty or family medicine articles, giving advice on what should be done rather than analyzing what is done and why (e.g. de Alarçon et al., 1960; de Alarçon & Hodson, 1964; Savage, 1979; Woods, 1979). Although obviously limited in their theoretical content, these commentaries may be more useful than rate studies, since they focus in more detail on the actual process of referral. For example, an article by Beidleman et al. (1971) is a transcribed

discussion among an American surgeon, psychiatrist, radiologist and internist who argue about when to refer, how to pick a consultant, how to inform the consultant, how to inform the patient, how to determine who's in charge and how to handle fees. Since topics are covered that receive no attention in the other clinical literature, this material could provide a starting-point for a detailed examination of the process of referral.

4. The Psychoanalytic Literature

Finally, there is a small literature that characterizes referral in psychoanalytic terms. The major study was done by a British physician-group that analyzed members' consultations over several years (Balint, 1957). Unlike other clinical investigations of referral, case studies are examined and a theory of the process is presented. Specifically, in Balint's model of patient-doctor interaction, patients, in a series of encounters, "offer or propose various illnesses, and they have to go on offering new illnesses until between doctor and patient an agreement can be reached" (p. 18; italics in original). According to Balint, if the doctor rejects the patient's diagnostic offers, by

trying to reassure him that nothing is wrong, the patient may turn into "a disappointed, suspicious, mistrustful man" (p. 23). While the doctor may be aware of the patient's more general situation, he is forced to record superficial symptoms in the medical record because of the constraints of medical practice. He may also be resisted by a patient if he attempts to take a "psychological approach" (p. 65); thus, while he may achieve a deeper understanding of the case, he may not be able to offer better therapy. When things go wrong between patient and GP, and he is faced with a "crisis of confidence" (p. 69), the GP is forced to refer the patient. However, specialists may also be unable to establish the patient's trust and he may end up being referred to multiple specialists. In such cases, where no one takes responsibility for the patient, there is a "collusion of anonymity", and surgery may be done just because nothing else has worked (pp. 75-6). Although no one is responsible for what happens to the patient in such sequences, the doctors present a common front to the patient, who is thus not able to "play off one against the others" (p. 79). The value of Balint's work, is that, unlike quantitative studies, it explores the details of the process of interaction in order to explain the often unsatisfactory outcome of referral.

Unfortunately, his description of patient-initiated referral, which is widely-read by British practitioners, is seldom cited in the referral literature.

III. THE PSYCHOLOGICAL LITERATURE

The psychological literature on referral is small, but since attention has been paid to the details of the referral process, a more complete picture of what is happening emerges here than in the clinical literature. In focussing on the decision-making of the referrer, however, this work tends to lose sight of the contribution of patient and specialist to the process. One group of investigators led by Elstein, on the basis of chart review, concluded that a major reason for the referral of obese patients to endocrinologists is pressure from patients rather than clinical reasoning (Ravitch et al., 1983; Rothert et al., 1984; Rovner et al., 1985). However, this work was not based on observation or interviewing of patients.

The goal of Ludke (1982), another psychological researcher, was to use mathematical models to predict referral behaviour, but because he was not able to determine which variables to put into his equations by

reviewing the literature, he was forced to informally interview 38 physicians and 23 patients to "gain insight" into "how, where, when and why patients are referred" (p. 784). The factors were then "rank-ordered" by the physicians and used to construct hypothetical cases which included the factors isolated from the ethnographic work. Unfortunately, there is little or no explanation of the list of factors identified as important in the decision to refer, most of which "have not been studied in the referral literature" (p. 792). In general terms, Ludke found that the most important factors in referral decisions are evaluations by the referring doctor of the quality of care that the patient would receive, followed by considerations of convenience and "physician factors" such as income. He noted, without explanation, that the factors found to be the best predictors "were not always consistent with the factors reported by the physicians to be the most important factors" (p. 792). In his concluding remarks, Ludke talked of the importance of personal knowledge of consultants, and the role of the patient in influencing referral decisions, but did not explain how these operate. His study is thus of greater value than much of the work he criticizes, but would have been of more value if the

results of the ethnographic work were presented in more detail.

Dowie's (1983a) work is less constrained by the attempt to be deductive, and is perhaps the best single source of information on the process of referral in the literature. She collected statistical and interview data on referrals to a 400-bed district general hospital (DGH) in England in 1977. The statistical information was on 2400 outpatient clinic visits during a 13 week period, and these data showed some interesting trends. For example, nearly half of the "referrals" were for "follow-up", a population traditionally excluded from referral studies. Her tape-recorded and transcribed interviews with 45 doctors from 24 practices at the DGH were supplemented by records of their use of laboratory services. The combination of these data showed that younger doctors tended to order more tests and do more investigations than their older colleagues, suggesting a model of referral based on the relative lack of self-confidence of the heavy referrers and lab users. This idea is mentioned in the clinical literature (e.g. Morrell, 1971; Everett et al., 1984), but is not developed into a model of referral there. Dowie argued that this effect combined with a greater willingness of

younger and rural doctors to assume more responsibility for a case and thus "work it up" in more detail.[10]

In an examination of her 650 pages of transcripts, Dowie found evidence that high referrers were less confident about their own clinical judgement and more worried about certain rare types of diseases than their probability of occurrence in the population would warrant, a cognitive error that psychologists have called "availability bias" (Slovic et al., 1982). Further, the high referrers were concerned about the risks of trying to perform certain procedures such as endoscopy (putting a tube down the throat into the stomach) and thus preferred to refer such cases. Physician comments on handling specific types of disorders, such as diabetes, suggested that even low referrers would refer in particular areas where they lacked self-confidence.

Dowie also found a defensiveness in referral letters, in that particularly older GPs preferred to leave out their ideas about a case in order to avoid the criticism of consultants (p. 55). When she discussed lapses in referral letters with the doctors involved, they said it was unnecessary to brief consultants fully. When pressed about the fact that few

letters contained their formulation of diagnoses, they said that they feared being found in error by the consultants.

The strength of Dowie's work is in her depiction of the referral process from the perspective of the referring doctor. In deciding to refer a patient to a specialty, Dowie described how the GPs tended towards more conservative medical opinions rather than surgical ones, particularly after bad experiences with surgical referrals. In addition, they preferred to remain with trusted colleagues rather than try out new consultants, exhibiting an intense interest in, but lack of direct information about, the competencies of their consultants. Dowie draws attention to the similarity of these findings with those of Freidson. However, she devotes a chapter to the obstacles to choosing the best consultant. In Britain, delays in seeing the specialist are a serious problem, and GPs are forced to harrass consultants, to choose second-best, or to avoid referral altogether because of lack of availability. New specialists quickly became "swamped" in the jurisdiction she studied. To complicate matters, consultants screened letters for urgency and reported deciding on which cases they would see first by taking into account their evaluation of

the type of case a particular GP had a reputation for sending. GPs were sensitive to the interests of particular specialists and strived to send them cases in their areas of interest, perhaps mainly out of deference.

When Dowie describes aspects of the process in which the patient plays a major role (for example, in referrals that are initiated by the patient or that the patient indicates have not gone well, pp. 90-98), her data are less useful. Although she provides much more information than previous researchers on this important topic, her attempt to discuss it under the "interactional style" of the doctors is somewhat confusing. Similarly, when she attempts to describe the problems faced by the consultants in deciding how much responsibility to take for a referral (pp. 107-116), the discussion becomes unfocussed. There is an attempt to approach the relationship between the two doctors from the perspective of communication breakdown, but none of this material fits into the model she presents of referral as a process dependent upon the confidence of the GP in his own clinical judgement.

Dowie's book is the most detailed source on the process of referral in the literature, and her model of the decision to refer brings together and summarizes

what is known about this part of the process. She is limited, however, in trying to describe a social psychological process in mainly psychological terms, without complete data on the perspectives of the other social actors involved. The data that she has collected is richer than her model, which focusses too microscopically on the cognitive processes of the referring doctor, without exploring the wider context of the referral event. However, her work is a quantum leap ahead of the clinical work that has been described in the first section of this chapter, and demonstrates the value of ethnographic data within a strong theoretical framework.

IV. THE SOCIOLOGICAL LITERATURE

The sociological literature on referral is distinct from either the clinical or the psychological in its attempt to explain large-scale patterns of referral. The social exchange literature, which assumes that the referral decisions of individual doctors are the key to understanding these patterns, provides some hints about the dynamics of the process of referral even if unable to predict those patterns. The interactionist literature, of which Freidson's work is a part, has been the source of much of what is now

known about referral patterns, beginning with Hall's earliest studies of the importance of referral in maintaining networks of physicians within hospitals. The limitations of this work are that it has been done in single locales, mostly American, and that it is now quite old. Another general problem with the sociological literature is that it has virtually ignored the role of the patient in the referral process, which is ironic in view of the voluminous sociological literature on dyadic patient-doctor relationships.

1. Social Exchange Theory and Referral

Simple economic exchange theory can explain some of the more obvious characteristics of referral where paying patients are scarce, as in the U.S. In such a situation, GPs might be expected to be reticent to refer them, and specialists might have a tendency to "steal" them for economic reasons. Exchange theory can also explain why publicly-insured patients are referred more often than privately-insured ones, since it is more economically favorable for the GP to send the publicly-insured patient to the specialist and use the time saved to treat a private patient. Further,

exchange theory predicts the observation that doctors provide more services in states where they have lower fees in order to maintain their income (Rutten & van der Gaag, 1977).

At the same time, referral is an obvious example of the well-known "Person seeking advice from Other" scenario described by Homans (1961), in which advice is exchanged for respect and approval in a social rather than economic interchange. Luke and Thomson (1980) point out that referral "appears to be more of a hybrid of the economic and social exchange concepts" (p. 335) and that the American trend towards prepaid medical groups may shift the emphasis away from economic to to social exchange. In their study of 200 Denver doctors, they found that the physicians involved in a prepaid group (PPG) exhibited a very different referral pattern from the FFS group within the hospital. Specifically, the 37 members of the PPG, which received capitation payment, referred less, relied more heavily than the FFS group on advice from hospital residents and were avoided by the other doctors in referral.

Simple economic explanations can account for these findings (i.e. there is no monetary reward for referral under capitation, advice from residents is

"free" and PPG members are not economically dependent upon referral from others). Luke and Thomson, however, go beyond economics to try and explain these results. They note that the PPG are younger and appear to be considered deviant and of lower "status" than the FFS doctors; thus their avoidance by the others may result in less "integration" in the referral network and less ability to ask for advice. Further, they argue, the PPG physicians have little incentive to build networks and may be content to refer to whomever their insurance plan has contracted with for specialist services. In their terms, "exchange becomes an organizational as well as an interpersonal matter" (p. 326). Finally, their data show three fairly mutually exlusive referral networks in the hospital which they characterize as "negative reference groups".

However, there are some difficulties in applying exchange theory to referral. In the first place, like patient consultations with their doctors, referrals are characteristically non-reciprocal between doctors, or one-way from general practitioners and from specialists to other specialists but not from specialists to GPs. What then, is being exchanged? Piedmont (1968) found little evidence that referring GPs approved of their consultants, who often failed to

reciprocate the referral by providing feedback.[11] A second problem in applying exchange theory to referral is that, as Blau (1964) has cautioned, it cannot be applied in situations where the individuals involved are not free to make rational choices. A strong argument can be made that referral choices are in fact not free, since they are restricted, for example, by licensure, certification and hospital privileges; by the local availability of specialists; and, in the U.S., by agreements with third parties. A third problem that is not examined by exchange theorists such as Shortell (1974) is the influence of the patient on the choice of consultant. Finally, exchange theory offers few details about the process of referral beyond the choice of consultant. Like psychological theories, it tends towards psychological reductionism.

2. Other Sociological Studies of Referral

By way of contrast with the work of exchange theorists, research done by interactionists and others has avoided psychological reductionism by focussing on the details of the process of referral from the perspectives of those involved in it. Like the exchange theorists, they are interested in explaining large-

scale patterns of referral across networks of physicians and in different organizational arrangements, but they do so by examining the concerns of social actors about identity, career, professional dignity and power. As Kerr (1985) has argued, no theory of economic motivation gives enough detail about these important aspects of social life to be able to explain the process of referral.

In the earliest work on referral, the symbolic interactionist Oswald Hall pointed out that,

> [t]here is no set of concepts available to do for the study of the profession what the concept of the cell did for biology, or the concept of the market for the study of economics. The lack of a unified frame of reference makes it difficult to ask significant research questions...
>
> (1946, p. 32)

In that article, he proposed that the study of the informal organization developed by established members of the profession would provide that starting point. In his work and that of others who followed, the spatial distribution of doctors' offices across the city of Chicago by their ethnicity (Hall, 1946; 1948; Lieberson, 1958) provided the clue that ethnicity, not technical ability, was an important organizing factor in medicine there in the 40s and 50s. Both Hall's and Solomon's work showed that there were circumscribed

ethnic hospital-based physician networks in Chicago that restricted access to certain specialists. Established clinicians of the "inner fraternity" would "sponsor" young physicians of their choice by allocating them hospital positions and by sending them paying patients in the form of referrals. Loyalty among members of the network provided stable patterns rather than competition for patients, and the result was a stratification of hospitals by religion and ethnic group.[12]

In another article, Hall (1949a) classified medical careers as of the "colleague type", dependent on members of the "inner fraternity" sending referrals; the "individualistic type", dependent upon pleasing patients; and the "friendly type", dependent upon loyalty to friends, even if this did not further one's career. This categorization emerged again in the early work of Freidson (1960), where he introduced the role of the patient into the analysis by arguing that colleague-dependent practices (based on referral of patients) were less vulnerable or responsive to client pressure, while client-dependent practices were more influenced by the patient. In this early article, Freidson also observed that some patients casually explored diagnoses by passing through an informal

network of consultants, or lay referral system, before reaching the GP. However, the farther into the professional referral system the patient proceeded, the less control he or she was able to exert. Further, he recognized that the patient's GP had some power in this system in that the GP was in a better position than the patient to evaluate consultants, thus laying the groundwork for his later thesis regarding the quality control exerted by the process of referral.[13]

The early work by Hall also provided a focus for a subsequent study of referral by Freeborn and Darsky (1974). In a questionnaire survey of 182 physicians in Windsor, Ontario, they found a similar concentration of power in the local medical society, the local medical and hospital insurance service and hospital offices and committees. As in the Hall study, almost all of the top influentials were found to be Protestant and Anglo-Saxon. However, Freeborn and Darsky found no clear overall relationship between being a member of the medical elite and the number of referrals. Data by specialty was not presented though, and one table showed that almost half of GPs who made high numbers of referrals were in the influential group while only 22 percent of heavy specialist referrers were in this group. It is thus not clear from the

Freeborn and Darsky report how significant were referral networks.

Bentley (1971) has more recently disputed Hall's contention that medical influentials are segregated by within-hospital networks and he argues that physician networks are more related to the technical competence of the doctors involved, as Freidson has suggested. Freidson and Rhea (1963) had theorized that doctors sort themselves into networks relatively isolated from each other in the process of choosing consultants of competence similar to their own and avoiding consultants whom they have reason to believe are incompetent. Such informal "avoidance referral networks" need not correspond to hospital boundaries, however, as Modrow showed in a reanalysis of the Darsky data from Windsor (1976). As he emphasized, it is most convenient for a referring doctor to send patients to specialists within his or her hospital. However, if the referrer believes that more competent specialists are available outside his hospital, s/he will construct referral networks across hospitals. In the study, the 182 physicians were distributed across four hospitals in such a way that certain types of specialists were not available in all hospitals. Further, when respondents named the one or

two doctors whose competence they most respected in each specialty, and these responses were summed and compared, not all hospitals contained highly-ranked specialists in particular disciplines. Modrow's results showed that these highly-ranked specialists were named over half the time as referral partners (p. 56).

Modrow notes that Windsor was about the same size as the largest city in the classic study of physician networks by Coleman, Katz and Menzel (1966) and that neither city was in the shadow of a large medical centre, as in the Rockefeller studies. The Coleman study attempted to explain the pattern of adoption of the new drug tetracycline within a physician network, and, in the process, discovered that adoption of the drug did not follow lines of personal friendship, but instead, spread through professional relationships that did not necessarily involve friendship. Modrow argues that the fact that networks ran freely across hospitals in the adoption of tetracycline and in referral in similarly sized cities may suggest that city size is a key to understanding these organizational and referral patterns.[14] Perhaps the hospital-specific networks described by Hall and Solomon are characteristic of larger cities, while

Freidson's "competence networks" are more visible in smaller cities or rural settings.

Although Freidson has predicted that mutually-exclusive networks will consist of doctors of about the same competence level, Modrow's data instead show that the Windsor network is composed of many low-ranked doctors who report that they refer selectively to the more highly-rated doctors in terms of competence. This point has been the major objection of social exchange theorists such as Hummell et al. (1970) and Shortell (1974), to Freidson's multiple referral avoidance networks. The exchange theorists, equating their concept of "status" with Freidson's "competence", have all found that physician networks contain "low status" or "low competence" referrers who refer to the "high status" or "high competence" individuals.[15]

The concern over whether referral networks are homogeneous or not, however, can be seen as secondary to the agreement among these sociologists about the importance of the assessment of competence in the informal organization of medicine. Within the sociological literature, then, there appears to be a developing consensus that the evaluation of the clinical competence of consultants by referring doctors, inadequate though it may be (Freidson & Rhea,

1965), is of crucial importance in the process of referral, and indeed, in understanding patterns of medical organization. The practical clinical literature is consistent with this viewpoint. All that remains is to demonstrate the operation of this process with actual referrals.

By way of criticism, it should be emphasized that the studies reviewed here, including Freidson's, were based on physician reports of referral partners rather than on examination of actual referrals. Further, the studies are old, and the larger context of referral may have changed since they were done. The studies were undertaken in a limited number of settings, which may restrict the generalizability of the results. Finally, and most important, they have largely ignored the role of the patient in the process. In general, then, while sociological studies exploring referral networks <u>via</u> self-report add spatial and symbolic dimensions to the understanding of referral achieved by psychoanalysts, psychologists and economists, they still tend to stuff the process into a "fat moment" by not exploring what happens in real cases of referral.

V. SUMMARY

Research by clinicians on referral is largely atheoretical and quantitative and thus it throws little light on the process of referral. Typically, referral rates are calculated, correlated with one or two patient or physician "variables" and post hoc explanations of the results are attempted. Sometimes sweeping generalizations are made without evidence, such as the contention that the lower referral rates of rural physicians reflect poor quality care. Further, little attention is paid to the fact that observations made in the U.S. are not directly applicable to other settings, because of substantial differences in the historical development of referral and its funding. Studies that describe difficulties in referral are similarly disappointing, in that they quantify failures to communicate or unsatisfactory outcomes, but fail to explore the dynamics of these problems. Prescriptive articles on "how to refer" are more helpful than "scientific" studies because they focus on referral as a process. The one exemplary study of the process of referral that was based on studies of actual cases is that of Balint (1957). However, this work has been little appreciated by other students of referral.

Research by psychologists has detailed the referral process from the perspective of the referring physician, particularly in the work of Dowie (1983a). In a comprehensive ethnographic study, she found evidence for a model of referral based on GP insecurity about self-competence. While her work is the most detailed in the literature and provides much information on the referral process, the perspective of specialist and patient are unfortunately missing.

Sociological research, which has mainly been concerned with explaining large-scale patterns of referral, is of two types. Exchange theorists have tried to demonstrate that referral patterns can be understood as the aggregate of economic and social exchanges between referral partners and has recently focussed on the assessment of competence as a key factor in explaining these patterns. Other sociologists have described referral patterns as reflections of the sponsorship of powerful members of the profession to keep the networks homogeneous with respect to ethnicity or competence. They add spatial and symbolic dimensions to the study of referral, but, like psychological and clincal studies, fail to fully explore the role of the patient in the process in actual cases of referral.

NOTES

1. In that article they made the calculation that of a population of 1000 American adults, nine will be hospitalized, five referred and one sent to a university medical centre in a given month.

2. The most-cited and comprehensive of these studies was done by Penchansky and Fox (1970) on the referrals of 63 primary care physicians in three prepaid group practices in the U.S., one urban, one suburban and one rural. Their major findings were, breaking down an overall referral rate of 4.7 percent, that internists refer more than GPs; whites are referred more than blacks; and that males are referred more than females, except in the child-bearing years. The researchers can only speculate about the process underlying the numbers - for example, whether blacks may be referred less because they "are less sophisticated about health care and less demanding of the physicians" (p. 382) or because their doctors "do not identify" with them.

   Of the Canadian "rate" studies, Clarfield (1980) calculated an overall referral rate of 7.5 percent in counting 219 referrals from a Toronto family practice unit. As in other studies, the most common referrals were found to be in obstetrics and gynecology, orthopedics and general surgery. Comparing his 7.5 percent rate with rates reported from other studies, however, Clarfield worried that it was "high", and speculated that this might be related to the fact that many of the specialists' offices were in the same building as the family practice or that other studies included fewer referral specialties.

   Another study of Toronto General Hospital family practice units reported a 5.3 percent referral rate, which the authors also

considered high in comparison to American figures (Hines & Curry, 1978). These researchers speculated that in addition to proximity of specialists, there may have been more referral in their study because OHIP requires referral before a specialist can charge a fee and because the patients in teaching units may be more ill than patients in community practices. A third Ontario study also calculated an overall referral rate of 5.4 percent based on the 465 referrals of eight community physicians and 31 staff family doctors and residents in clinics run by the University of Western Ontario, but the author noted that the community physicians showed significantly higher referral rates (Brock, 1977).

Care must be taken in comparing these rates, since some studies calculate rates by taking referrals as a percentage of visits, which yields a much lower rate than calculating the number of patients referred as a percentage of the number of patients seen. In Wolfe and Badgley's Saskatchewan study (1973), for example, the referral rate was 13.4 percent of all patients, but only about four percent of visits. Clarfield's rate of referral of 7.5 percent of all visits, then, is high compared to the Saskatchewan study. It is also higher than the two or three percent rate of all visits typically reported in American studies. However, percentages and types of referrals are obviously related to the practice population being studied - for example, doctors with a young practice might be expected to refer to obstetricians more often than retiring doctors with older practices. This obvious fact is seldom mentioned in the literature.

3. This literature is reviewed in Chapter 5.

4. Geyman et al. (1976) of eight family practices in northern California; and Metcalfe and Sischy (1973) of four in western New York.

5. Since these specialists are trained in tertiary care centres, they tend not to see the type of patient in medical school that they will be

seeing when they begin to practice in the community. Greenfield et al. (1983) have argued that such doctors are not only not trained in delivering primary care, but are not interested in doing so. In his study of "reverse consultations" of patients from subspecialists to generalists, he found that the highly trained men "dumped" older patients with more complex problems, including psychosocial problems, on other doctors as soon as they were able to establish themselves in the subspecialty. Anecdotal evidence from Canada (Shapiro, 1978, ch. 6) suggests that Canadian specialists are encouraged to develop a similar narrow definition of their contribution to patient care, although fewer specialists provide primary care in this country.

How widespread is the provision of primary care by specialists in the U.S.? One early American study of 467 specialists in New York state (Johnson et al., 1965) showed that general internists in the community saw only about a third of their patients on referral, and that half of those referred came from other specialists. Half of these were kept in continuing care, thus serving as a source of competition with the family doctor. A second study of 103 family physicians in New York state, half from Rochester and half with rural practices, argued that the GP was still alive and well in the state, but that since most had graduated before 1955, there would be a decline in general practice in the next decade (Riley et al., 1969). Peterson, who had undertaken the first American study of general practice in 1956, warned in 1972 that young GPs were leaving small rural practices because of "overwork" and "constant demand" (Peterson, 1972). More recently, Mendenhall et al. (1979) surveyed 10,000 American physicians in 24 specialties, collecting information on 400,000 patient encounters in order to find out what doctors actually did. Aiken et al. (1979) has published some of the data from this survey which shows that one in five Americans, an older, chronically ill group, receives primary care from a specialist, which she has called a "hidden network" of specialty physicians (p.

1367). She warns that reliance on specialists is costly and contributes to the problem of geographic maldistribution, since "specialists tend to settle in larger communities in close association with complementary specialists and well-equipped hospitals, whereas family physicians who are less dependent on technology are better distributed" (p. 1370). Elsewhere she has argued that this type of medical system does not meet the needs of the chronically-ill population (Aiken, 1976).

6. American medical educators argue that problems in referral can be solved by appropriate education in how to refer, although such programs have been largely unsuccessful when incorporated in specialist training (Williams et al., 1961; Beidleman et al., 1971; Bomalaski et al., 1983; Moore et al., 1977). In Canada, some success in changing referral behaviour has been demonstrated when referral was taught in family medicine certification programs (Saunders, 1978; Hines & Curry, 1978), but Grant (1982) has recommended that the Canadian specialty colleges should consider resident training for consultation as well, particularly in interdisciplinary groups.

7. See Chapter 2, pp. 24-25 and footnote 11 on HMOs, HSOs and CHCs.

8. An example is Burnum's comment, who speaks as a specialist: "While it cannot be denied that self-referred patients are more easily managed, because they arrive with a strong if tentative confidence in their new doctor and because there is no triangular relationship with the referring physician, consultant internists ...have an indispensable function in the mosaic of medical care and should be imbued while still in residency training with a strong sense of duty to and respect for referring physicians" (1973, p. 440).

9. The clinical literature on breakdowns of communication and outcome in referral is reviewed in more detail in the introduction to Chapters 9 and 10.

10. These arguments are somewhat different than those made by Wolfe and Badgley, who suggested that junior doctors in their clinic referred less than older doctors because, having less confidence in their opinions, they were reticent to expose them to the judgement of professional peers (1973, p. 110). However, the same dynamics are being invoked.

11. Piedmont's study of referrals from 212 clergymen and 131 GPs to psychiatrists in St. Louis showed that feedback from the psychiatrists was seldom obtained and was often assessed as unsatisfactory, although the referrers reported that they would refer more in the future if they received more reports back from psychiatrists. Only 28 percent of the clergy reported satisfaction with feedback, which they said they had to initiate themselves, as compared to 70 percent of GPs. Reciprocity, therefore, seemed to have broken down, although the referral relationship continued. Piedmont noted that GPs appeared less concerned with feedback to a point because they "frequently volunteered that they 'lost track' of patients referred" (p. 34); they were also loathe to criticize colleagues. Those who received no reciprocity referred the fewest patients. However, with increasing reciprocity, they reported more dissatisfaction with reports and then "made a lesser proportion of referrals but received more reports and became increasingly satisfied with them" (p. 36). Piedmont argues that at a certain point, dissatisfaction was so great that the GPs dropped non-reciprocating psychiatrists from the referral network, and were more satisfied with the fewer referrals they then made - in a more realistic kind of matching of patient and specialist. However, he believes that the lack of clear guidelines and formal connections around referral to psychiatrists typically leads to unequal and thus unstable exchanges. In situations where specialists engage in "self-interested reciprocity" in order to garner referrals, they may send feedback on expensive stationery and attempt, in their letters, to display their medical competence. However, he suggests that psychiatrists, who are considered "less physician" than GPs and

whose treatment may be unconvincing to GPs, may not feel the need to engage in this display.

12. Although Hall's study is very old, anecdotal evidence exists that points to similar processes operating in the U.S. today. For example, Schaffer and Holloman (1985) comment: "Referrals are also used by new physicians to develop contacts and enter local practice networks. A targetted and judicious assignment of referrals can assist advancement within the ranks of institutions or professional societies. No estimate of the percentage of referrals that are of marginal necessity, but are politically advantageous, is available. The medical and political use of referrals is widely regarded as an astute business technique" (p. 601).

13. This theory is reviewed in Chapter 2, pp. 27-29.

14. Modrow points out that only three of 104 physicians in the largest city of the Coleman study refused to identify with only one hospital, but 15 of 44 in a smaller city refused to do so and 44 of his 182 in Windsor refused to do so. Respondents in one southern Ontario city in this thesis research explained that affiliations with single hospitals had recently been strongly encouraged, and that this simplified the visiting of patients, who would otherwise be in a number of hospitals all over the city. Although no cases originating in the largest city in Ontario, Toronto, were followed in this study, one Toronto specialist who was interviewed suggested that there were so many competent doctors available in his large urban hospital that he seldom found it necessary to go outside for referral.

15. The Hummell study, for example, which surveyed 332 doctors practising in and around a West German university town, showed that while 59 percent of specialists both received and made referrals, 16 percent received but did not make any referrals. By way of contrast, GPs did not receive referrals but 71 percent made them (with the remaining practitioners not involved in referral). When respondents were asked to

name those they knew best privately and professionally, and responses were summed and ranked, one-fifth of the doctors were never named (and only 19 percent of them received referrals), two-fifths were named only once or twice (and 32 percent received referrals), but two-fifths were named more than twice (and 58 percent received referrals). In support of the arguments made by Coleman et al., Freidson and Modrow, that the important factor in choice is competence rather than friendship, the Hummell study reports that three quarters of those named only for private reasons did not receive any referrals, whereas 61 percent of those named for professional but not private reasons received referrals. Hummell argues that only after competence is recognized does friendship become important, since 35 percent of those named for both competence and friendship received more than 40 referrals per quarter, while only 22 percent of those named only for competence received this volume of referral (and only 10 percent of those named only for friendship). A factor analysis of this data showed that friendship and competence networks were "two relatively independent interaction-systems coexisting within the local medical association and connected with each other by only a few common factors" (p. 601) and that therefore the chances of receiving referrals depends on recognition of one's professional competence by colleagues while the effect of friendship is inconsistent.

CHAPTER 4

METHODOLOGICAL ISSUES, METHODS AND CONCEPTUAL CATEGORIES

I. INTRODUCTION

This chapter describes the methods chosen for this research and provides details of how they were applied. Specifically, a prospective case study design was used, with semi-structured interviewing of referring doctor, patient and specialist for each of 50 cases of referral. Data were collected and analyzed using Glaser and Strauss' (1967) guidelines for inductive research. Dimensions of theoretical interest were sampled - for example, urban vs. rural referral. The concluding section of this chapter presents a brief "natural history" of the study, describing the form that the research took at each stage and the findings and conclusions that were drawn from them.

II. DECISIONS REGARDING HOW TO STUDY MEDICAL REFERRAL

1. The Use of Qualitative Methods

In the preceding two chapters, the argument has been developed that the plethora of atheoretical studies of medical referral fail to contribute to an understanding of the dynamics involved. A number of interesting hypotheses are suggested, but these are not systematically explored. The problem is that the scientific method used by these researchers cuts up the process of referral arbitrarily before achieving an understanding of how it works. In Hall's words, the chopping up into quantifiable sections of any complex "system of action" for mathematical analysis can only be achieved "at the cost of considerable distortion" (1949, p. 9).

Even where lip service is given to the importance of studying referral as a process, as exchange theorists and psychologists do, they often fail to take the process beyond the decision to refer and who to refer to, ignoring its outcome (Ludke, 1982; Shortell, 1974). The research of social exchange theorists may describe a network of physicians in which "choices" of consultants are made, but there is no

examination of the actual decisions being considered by the participants. Choices are assumed to be related to the "status" or "respect" of the chosen consultant (e.g. Shortell, 1974) or his "competence" (Modrow, 1976) but this is not investigated to determine if it applies in actual cases. Instead, a "cross-sectional" approach is taken in which participants rate the members of the network on the dimension, and a statistical analysis is done to see whether there is any relationship between choices and ratings. As Schaffer and Holloman (1985) recognize, the assumptions made in this kind of research "may not reflect actual clinical practice". The problem here is that the researchers have a model of the process into which they "force-fit" the data,[1] instead of "catching the process" and verifying the significance of data in the real world and in the experiences of those being studied, as recommended by Blumer (1969).

Only the qualitative/ethnographic investigations of Balint (1957), Dowie (1983a) and Friedson (1975) have yielded models of the process of referral that both reflect its true complexity and incorporate the perspectives of social actors. Their methods allowed the building of theoretical models that

kept the process intact. Qualitative/ethnographic methods were chosen for this thesis research as well, specifically, the technique of multiple unstructured interviewing of participants.

2. The Case Study Approach

In this study, it was decided to examine actual cases of referral prospectively rather than to interview participants retrospectively as in the Freidson and Dowie studies. This allows the testing of hypotheses about referral on actual cases. There was little initial restriction of cases, with as much interviewing of all parties involved as would be practicable. This approach was taken to avoid limiting the range of data that might be collected.[2]

The case study tradition in the social sciences has a long history (e.g. Thomas & Znaniecki, 1918; Komarovsky, 1940; Lindesmith, 1947). The general idea is to compile as much information as possible that can be cross-referenced so that the theory derived has high internal validity. It is a logical extension of the concept of "triangulation" advocated by Webb et al. (1966), in which more than one source of information on

a phenomenon is sought in order to validate the observations.

Case studies in sociology have often been critiqued for presenting a one-sided view of events from the perspective of only one social actor (e.g. see Douglas, 1976). For example, Davis' (1963) and Roth's (1963) analyses of the experiences of the families of children receiving treatment for polio and of patients undergoing TB treatment, respectively, make little attempt to present an unfolding of these processes from the perspectives of the health professionals involved.

To avoid the problem of one-sidedness, it was decided in this research to interview all parties involved in actual cases of referral, including the patient, who has been left out of almost all other studies of referral. To aid in cross-referencing of data, if more than one referral made by a particular GP-participant could be followed, this was welcomed. Whenever different cases referred to the same specialist could be obtained, this was used to cross-check information. This proved to be very easy in the remote area of Ontario where the second half of this study was conducted. For example, there were so few specialists in this area that most patients were knowledgable enough to offer some information about

them, whereas specialists were typically not known to patients in the city where the first part of the study was conducted. Further cross-referencing of information was possible by looking at patient charts, including records of previous and multiple consults of a patient. Charts were not particularly treated as "objective" information, but any discrepancies they yielded with participant reports were followed up in an attempt to understand them. Multiple interviewing of individuals over time also helped to fill in the fine grain of the referral process.

3. Grounded Theory Methodology

Although there are numerous variations on the method of analytic inductive research, the general guidelines have been repeated many times from Simmel (1950) and Znaniecki (1934/1969) onwards.[3] The underlying epistemology of induction is that "discovery" of data cannot be divorced from its "verification". Validation of data is performed bit by bit as it is collected rather than "by fiat" at the beginning. The basic activity is categorization of cases of the phenomenon of interest until the researcher understands what certain instances of a

category really <u>are</u> (e.g. species, marriage, unemployment, referral, etc.) rather than pre-defining them. Comparison of diverse categories generate hypotheses about why they differ, and these hypotheses about causal relationships can be checked out by observing future instances rather than force-fitting observations to prior hypotheses. The ultimate aim is to produce the "internal consistency" and "generalizability" that are characteristic of properly-validated theories.

In quantitative analysis, the counting of instances of a category is usually considered to be unproblematic,[4] while in qualitative analysis, categorization is the key activity. The method of analytic induction, according to Znaniecki, was used by Aristotle in his detailed analytic study of individual specimens of animals to generate a systematic zoology. Basic to the process is "a deep intellectual curiosity about particular data and an insatiable philosophic tendency to use acquired knowledge for the acquisition of new knowledge" (p. 125). Kuhn (1962/1970) also discusses this process in his accounts of scientists who focus on inherently interesting "anomalies", "puzzles", analogies or metaphors that motivate them to explore the underlying reality. For example, Rutherford

had an image of atoms as "miniature solar systems" (Boyd, 1977). More fruitful are metaphor "themes" composed of a set of "related little metaphors" that allow the researcher to pursue properties of reality and metaphor in what Hoffman has called "complex mapping operations" (Hoffman, 1980, p. 413). In interactionist sociology, for example, the "dramatic" metaphor is exploited to great advantage by Goffman (1969) to explain face-to-face interaction. In each case, deviation from the model or metaphor is the trigger that necessitates theoretical reconceptualization. The crucial activity is comparison of cases with diverse categories.

Glaser and Strauss' (1967) variant of the inductive method, called "grounded theory methodology" (GTM), provides the clearest procedural guidelines and, for that reason, it was used in this research. Following their recommendation that the researcher go into the field having ignored the literature to avoid the "forcing" of data into premeditated categories (pp. 97-98), I avoided reading Dowie's work and the Rockefeller studies. Glaser and Strauss do not mean that the researcher must go into the field with no ideas, which is clearly impossible, although this has been the source of many jokes about ethnographers.

Instead, the researcher should go into the field ready to be "sensitive" (Blumer 1954/1969) to what is there. One set of ideas that I clearly carried into the field came from Freidson, whose important work I had read in the past. At the time I had read it, however, my interest was in his differences with Parsons and his comments about lay referral, rather than his theory of professional referral, so that the idea of "the boycott" did not leap into my mind until I saw evidence for it in the field.[5]

On entering the field, the researcher feels "buzzing confusion", since there are a great number of observations, but no theoretical framework in which to summarize them. In this project, for example, I became concerned with the immediately observable aspects of the process of referral. One of my first discoveries was that the doctors involved in a referral didn't talk to each other about routine cases, nor did they tend to send referral notes. Further, the telephone was only used in emergency cases, and feedback on inpatients to the GP was poor. Therefore, I wondered how the process could stay on track at all. It was obvious why problems developed in complex cases and why there was a tendency for the doctors to "lose track" of cases. Soon after, the "boycott" hypothesis, that GPs avoid referring to

consultants whom they judge to be incompetent, emerged,[6] and the project began to take shape.

Glaser and Strauss suggest that conceptual categories can be identified more easily if comparison groups are chosen that will generate as many properties of the category as possible (p. 49). This approach is called "theoretical sampling" (Strauss, 1970). In contrast to "random sampling", where the researcher is aiming for generalizability in testing a hypothesis, with theoretical sampling, the researcher is interested in zeroing in on the crucial aspects of a process, in order to generate hypotheses to explain it. For example, F. Davis' (1961) theory of "deviance disavowal" is about the visibly handicapped, but one might attempt to understand the process better by comparing what happens with those whose handicaps are not so visible. In this project, the fact that patients did not trust the competence of the first few doctors I studied, who happened to be young family practice residents, cued me to choose the alternate category of older established GPs in an attempt to see how the process differed when patient trust in the GP was present.

According to Glaser and Strauss, comparisons of such contrasting categories will suggest multiple

generalized relationships among the categories, or hypotheses, which can be tested in the field because "the fieldworker literally sees them occur" (p. 40).[7] Thus the core becomes a guide to further data collection and analysis.

The fact that there is an obvious "nested" category of consultation inherent in the referral process - patient consulting doctor and GP consulting specialist - and even a third level of specialist consulting specialist - did not occur to me until well into the project.[8] Until I "saw" the analogy, I did not realize that Hoffman's "complex mapping operations" were possible - that is, that the process of the patient deciding to consult the GP could could be compared with the process of the GP deciding to consult the specialist, and that the two parallel processes could be compared for every step of the sequence of consultation, right down to the final decision of whether to comply with the medical advice given. When this finally occurred to me, I had the wonderful experience that Strauss describes, of having comparisons "run riot" (p. 52). Any concept that had emerged on one level, I looked for on the other - for example, was there any counterpart to the professional "boycott" at the patient level? Did some patients

"shop" like GPs when they couldn't engage the consultant of choice? Did physicians, like patients, fail to comply with the advice of consultants they didn't trust? And so on. Taking advantage of this fortuitous "nested category" situation helped me to considerably strengthen the internal consistency of the work presented here.

In this research, the categories that were being compared eventually became larger and more complex with interconnecting hypotheses. This is obvious in leafing through the summary notes under each category heading that I made when each case was completed. The highest level of comparison began when I moved away from the urban setting and into the rural setting to begin studying referrals there. At this point, I was looking at two broad contrasting categories with many facets, but which could be summarized in the phrase "how the doctors involved in referral divided responsibility for the cases". In discussions with a lab technician who was a patient and later with physicians, the idea emerged that in urban areas, due to career pressures towards finding a "niche", there is more subspecialization than in rural areas. Because specialists "control" urban hospitals, they "squeeze" general practitioners out, so that the

content of general practice shrinks in the urban setting. This becomes a structural feature of medicine, because the superspecialized careers are not reversible, nor are the more general ones of the rural practitioners.

Glaser and Strauss suggest that eventually the researcher should reach a stage of "saturation" at which no new theory is being generated and major modifications become fewer and fewer. Categories can be collapsed to produce a parsimonious and internally consistent theory. My theory of the process of referral was quite detailed at the point of moving to the rural setting, but it remained to compare the situation of the urban "squeeze" with conditions in the North. Almost immediately after entering the field in the North, however, the relationship between my two large "nested" categories of patients consulting GPs and GPs consulting specialists came together. The patients and even some doctors reported their broadly-based mistrust of the competence of local practitioners, both generalist and specialist, and the evidence of their mistrust was reflected in referrals to Toronto and the Mayo Clinic, thousands of miles away. Patient mistrust and "pressuring" for referral clearly fed into the GP's decision to refer in the same way that had been

reported in the rural North Carolina studies. By the time of leaving the field, after 170 interviews, I concluded that the content of general practice in "rural" as well as "urban" medicine was shrinking on a continental scale.

With regards to the process of evaluating competence or its taken-for-grantedness - "trust" - I finally saw that this process underlay not just the choice of consultant, but also the decision to refer- when the GP doubts himself or his patient does; as well as how to divide the responsibility for the case; how and what is communicated; and the outcome in terms of whether the patient or GP takes the advice. At a generic level, then, the central theme of this thesis is that patients as well as GPs judge, on an ongoing basis, or later, on a taken-for-granted basis, the competence of their consultants and that this is the central legitimating process in medical referral. The presence or absence of trust based on these evaluations underlies all the other events in the process.

III. ACCESS TO THE FIELD

My first fieldnotes for this project are dated April 22, 1984, which means that this project took five years to complete. The first year was mainly spent in getting access to the field, the next two years in collecting data and generating the theory, and the final year in literature review and writeup. Prior to designing the topic as a thesis project, it had been briefly discussed as a joint piece of research with an M.D. coinvestigator, who withdrew before the project began. During planning discussions, however, it was debated whether only "typical" referrals should be followed, or whether I should include all types of cases, such as the multiple referrals described by Balint, and I decided on the latter. The decision was also made to ask participating doctors for copies of consultation notes and to draw up consent forms for all three parties to the consults, followed with letters of explanation about the project (See physician and patient consent forms in Appendix A). A research proposal was then submitted to the hospital in which I chose to work and it was approved both by the hospital research committee and by the hospital foundation for a small amount of funding.

After hospital approval, I presented a summary of the project to the local Departments of Medicine and Family Medicine, and I was sent a list of the names, addresses and phone numbers of 85 family physicians, to use in recruitment into the project. Eventually, 13 of these family physicians participated in my study, while another 11 that were approached refused. The requirements of the Glaser and Strauss method, that I plan my next move after evaluating each interview, meant that only two or three cases could be "carried" at this early stage of the project. The first GPs were recruited in a family practice residency clinic[9] and after a few weeks in the Clinic, I moved out into the community to visit GPs in various parts of the city.

Access to the second locale in which referrals were followed was considerably easier than access to the first. For this, I am indebted to the coordinator of the program that places McMaster medical students in practices in this region, whose name I used in letters of recruitment. Ontario medical schools take responsibility for medical education in various parts of the North, and McMaster's area of responsibility corresponded roughly to the area that I chose to visit. All 10 family physicians that I approached there agreed to participate.

IV. IN THE FIELD

Previous sections of this chapter have described the design and methodology of this study and the course of obtaining access to the field. In this section, some of the day-to-day activities of the research are described, including my approach to certain ethical dilemmas and interviewing procedure. An introduction to the participants is included.

1. An Introduction to the Participants

The rationale for choosing a prospective case-study design in this research was basically to produce as internally consistent a data set as possible. None of the decisions regarding design or method were taken as straightjackets, however, and deviations were made whenever useful information about the process of referral could be collected.

Table 4:1 is a roughly chronological summary chart of the cases followed. A case is only "counted" in this list if I interviewed the GP at least once. For almost all cases, the GP, the patient and at least one specialist were all interviewed at least once. This list deviates somewhat from the typical list of

TABLE 4:1 SUMMARY OF CASES AND PARTICIPANTS - To simplify record-keeping, all GP and specialist numbers correspond to case or patient numbers. A "case" includes all the referrals of a particular patient, with the exception of Cases 23 and 24, which consisted of interviews with semi-retired GPs who were not able to volunteer cases for the study. Therefore, for example, GP 25 is the GP for Patient/ Case 25, and not the 25th GP in the study. Where the GP volunteered more than one case, the table shows, in brackets, that, for example, GP 9 is the same person as GP 8. GP 8 volunteered both Cases 8 and 9. In the text, he is called GP 8 when dealing with Case 8, and GP 9 when dealing with Case 9. Eight patients in the study were referred to more than one specialist at the time they were contacted, and these additional referrals were also followed (See Fig. 4:1 for an example.) Altogether, 50 separate referrals from 23 GPs were followed for 39 patients. (For more details, see text, pp. 97, 100).

Case No.	Patient No.	GP No.	Specialist
1	1	1	gastroenterologist # 1
2	2	2	respirologist # 1 & receptionist # 1
3	3	3	otolaryngologist # 1
4	4	4(3)	neurologist # 1 cardiovascular surg. internist # 1 /gastro.#2
5	5	5	pediatric surgeon
6	(refusal)	6(5)	neurologist (no int.)
7	7	7	neurosurgeon #1
8	8	8	cardiologist # 1
9	9	9(8)	cardiologist # 1
10	(no show)	10	dermatologist (no int.)
11	11	11(10)	ophthalmologist # 1
12	12	12	gastroenterologist # 3 internist # 2
13	13	13(12)	rheumatologist # 1
14	14	14	obstetrician # 1
15	15	15(14)	obstetrician # 1
16	16	16	internist # 3
17	17	17(16)	orthopedic surg. # 1
18	18	18(16)	orthopedic surg. # 2 & receptionist # 2

Table 4:1 Continued

Case No.	Patient No.	GP No.	Specialist
19	19	19	gynecologist # 1 rheumatologist # 2 internist # 3
20	20	20(19)	orthopedic surg. # 2 rheumatologist # 2 general surgeon # 1 rheumatologist # 3
21	21	21	dermatologist # 1
22	(refusal)	22(21)	rheumatologist # 3
23		23(ret.)	
24		24(ret.)	
25	25	25	obstetrician # 2
26	26	26(25)	otolaryngologist # 2
27	27	27	rheumatologist # 4
28	28	28(27)	otolaryngologist # 2 neurosurgeon # 2 anesthesiologist
29	29	29	respirologist # 2
30	30	30	general surgeon # 2
31	31	31(30)	dermatologist # 2
32	32	32	general surgeon # 3
33	33	33(32)	ophthalmol. (no int.) & optometrist # 1
34	34	34	obstetrician # 3 pediatrician
35	35	35(34)	cardiologist # 2
36	36	36(34)	gynecologist # 2 general surgeon # 4 & radiologist # 1
37	37	37	ped. ophthalmologist
38	38	38	ophthalmologist # 2 & optometrist # 2
39	39	39(38)	obstetrician # 3 general surgeon # 5
40	40	40	internist # 4
41	41	41(40)	general surgeon # 5

"randomly sampled" cases, in that, as explained above, attempts were made to cross-reference data as much as possible. To simplify record-keeping, all GP and specialist numbers correspond to case or patient numbers. That is, GP 25 is the GP for Patient/Case 25, not the twenty-fifth GP in the study. In addition, two interviews were conducted with retired GPs.

For the first three cases followed, the three GPs were only asked to contribute one case to the study. Beyond that point, each GP was asked for two or three cases. Following multiple referrals of the same GP allowed comparison of patient perceptions of the GP and of variations in the "strategy" of referral used by the same GP for different cases. Altogether, the 23 GPs participating in the study "contributed" 39 patients. (The two retired GPs 23 and 24, shown in the table, contributed no patients.)

It was discovered that eight of the 39 patients in the study were involved in one or two other referrals, and, since "multiple referral" was a theoretically interesting phenomenon, the 11 specialists involved in these referrals were contacted and interviewed. Together with the 39 referrals originally volunteered by the GPs, these 11 made a total of 50 referrals. That is, if the number of

entries in Table 4:1 are counted, the total is 50. Figure 4:1 shows who was involved in the complex multiple referrals of Patients 19 and 20.

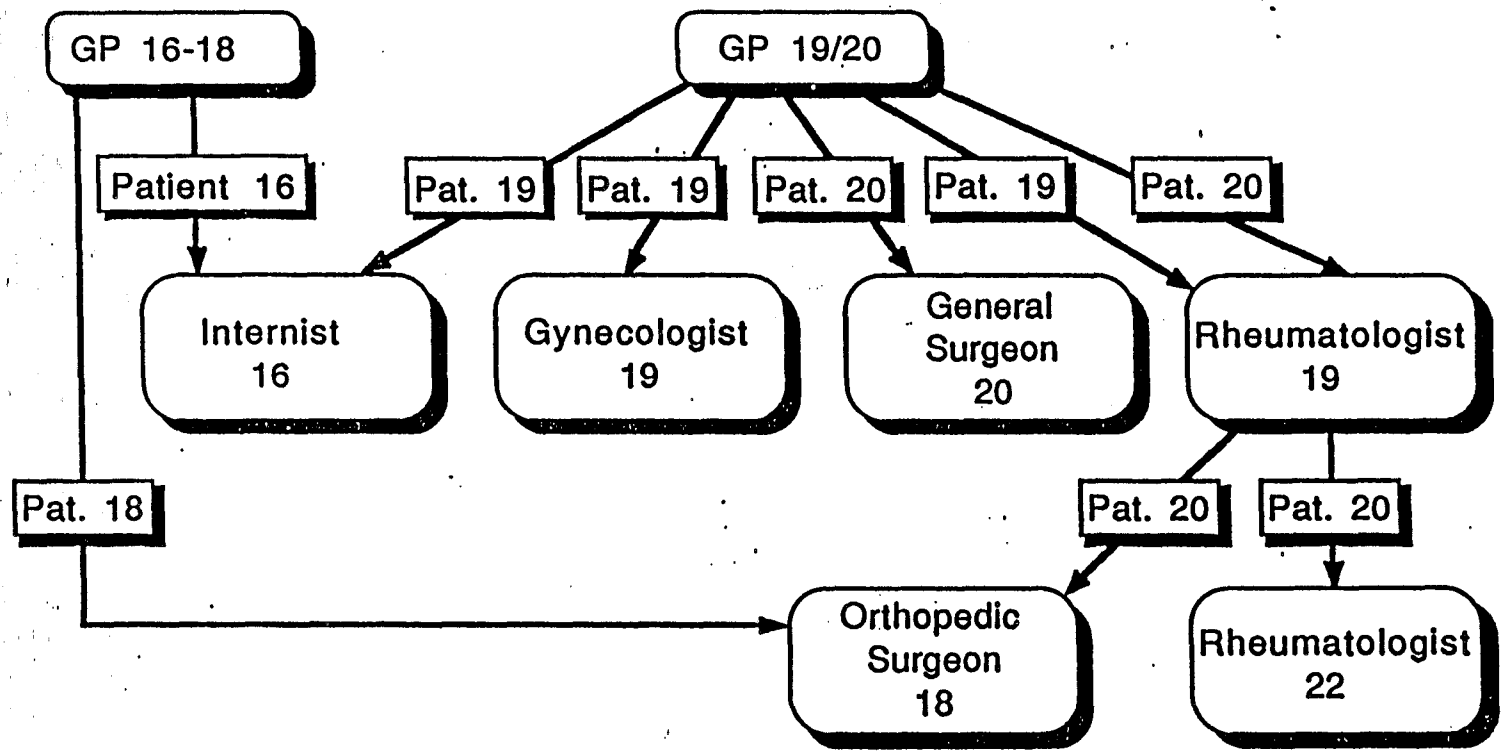
Since a few specialists received more than one of the referrals in the study, 41 specialists were ultimately interviewed.

The first 28 referrals were obtained in southern Ontario and the remainding 22 in northwestern Ontario, although the specialists to whom a few of the northern patients were referred were located and interviewed in southern Ontario or Manitoba.

Although no attempt was made to cover the entire range of specialties, areas of frequent referral, such as obstetrics-gynecology and general surgery are well-represented. "Problem" specialties such as orthopedic surgery in the south and ophthalmology in northern Ontario, are also represented among these cases. Missing in the list of specialties is psychiatry. Although such cases were repeatedly solicited, no GP volunteered a psychiatric referral. This was clearly because of the sensitivity and complexity of this type of referral.

Eleven of 17 patients followed in northwestern Ontario were women and 11 of the 22 patients followed in southern Ontario were women. No attempt was made to

Fig. 4.1 Referral Patterns of Three Patients Depicting the Linkages Among Physicians - Patient 19 was referred to three different specialists: Gynecologist 19, Internist 16 (the same Internist as Patient 16) and Rheumatologist 19 (the same Rheumatologist as Patient 20). The referral sequences for the other patients are also shown. For example, Patient 20 had a "tertiary referral" by Rheumatologist 19 to Orthopedic Surgeon 18.



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make the cases "representative" for gender and there are more women in the northern group because four obstetrical cases were included. In general, this "sample" of patients includes people, some of whom are more and some of whom are less trusting of their GPs; some of whom have had brief encounters with their GPs, and others who have longstanding, personal relationships with them that span decades; some who live in the core of a city, while others live hundreds of miles from even a small city, which makes it difficult for them to seek medical care. Again, although no attempt was made to sample their socio-economic status, they included housewives, labourers, retired workers, health professionals and small business owners. It was difficult to include native Canadians among the participants in northwestern Ontario because most natives live in what they call the "encampments", without telephones; neither could their GPs give me specific instructions as to how to find them in the reservations. As a result, there is only one native Canadian in the study, although data were sought on the referral process for this group of people.

2. Ethical Considerations

a. Informed Consent

Participating physicians and patients were as fully informed as possible as to the goals of the study. When patients were asked to participate by the family physician, three of the 42 refused, two at the point that I sent a letter of introduction to the patient (see Appendix B), and one after a difficult interview in which there were substantial language problems. These cases were not followed beyond the point of refusal.

There were a few irregularities, as in the case of one man with no telephone, whom I located in a local bar, but who did not mind that I did this. In all cases, I did not proceed to interview the patient until I had answered his or her questions about the project, explained why I was using a tape recorder, and after he or she had signed the consent forms. Only one patient and his wife refused to let me use a tape recorder or consult his medical records but consented to participate, and my general impression was that the tape recorder, while making some patients self-conscious initially, generally did not bother them.

Finally, after both GP and patient had been interviewed, and knew what the study was about, which was, in most cases, before the specialist had seen the patient, the specialist was contacted. The signed consent forms of the other parties to the consult were included in my letter to the specialist requesting participation. Addresses of specialists were located in the Canadian Medical Directory. Only two specialists out of 44, both northern ophthalmologists, refused to participate, although I interviewed other persons involved in those consultations, including a receptionist and an optometrist. One other specialist in southern Ontario would not see me during the 1986 doctor's strike, but I was able to interview another specialist involved in the case. Two specialists who participated refused to allow me to use a tape recorder, but agreed that I could take detailed notes. I suspect that the use of the tape recorder may have influenced some doctors to edit their comments, given that they sometimes asked me to turn it off when they were making negative statements about colleagues or making political comments. However, other doctors trusted me enough that they made such statements without asking that the recorder be turned off and,

with the two exceptions mentioned, I did not feel that it had made them uncomfortable.

b. Protection of Participant Identities

Both ethics committees through which my proposals passed expressed concern about the ways in which I planned to protect participant identities, particularly those of physicians. Basically, the names of participants never appeared in my fieldnotes, who were referred to by number or pseudonym. (However, since there were 108 participants in the study altogether, I found that I was unable to keep track of pseudonyms, and reverted almost exclusively to "numbers", which, for me, after having worked with the data so long, quite easily call up the identities of the participants.) Since there are hundreds of doctors in the urban location that I studied, it is unlikely that the 13 GPs I interviewed can be identified. However, it is more likely that the identity of specialists can be guessed, and in northern Ontario, it would be quite easy to reveal the identity of any doctor by merely mentioning his location of practice. After I realized this, I began numbering the towns in

my fieldnotes. I have also changed gender in my writeup where this appeared appropriate.

The real problem with confidentiality of identities in an ethnographic project usually comes not when fieldnotes are being taken but at the point of writing up results. In this thesis, the problem might have been resolved by masking the identity of not only the cities and towns I visited, but also the regions. However, I felt that omission of these general geographical identifiers would undercut the reader's ability to judge the generalizability of my findings. I have omitted a great deal of material that participants asked me not to quote, or that they felt was politically sensitive and which I have determined they would feel was not appropriate for me to discuss. This is an unfortunate "Catch-22" situation that qualitative researchers find themselves in, but I have tried to resolve it in some cases by asking participants directly if I could use certain material, informing them that I was going to use it, or warning them of the possibility that, with some effort, someone could possibly determine their identities. I suspect, however, that with regards to the material I have quoted, my informants would be willing to defend their statements personally.

3. Interviewing Procedure

Almost immediately after entering the field, I abandoned the lists of questions that I had thought might be relevant, to listen to what the participants were volunteering (although I sometimes held the questions on my lap to make the situation look like a traditional interview). Beyond this point, one interview was used to guide the next until "categories" emerged that were used to organize the interviewing. If I had not described and analyzed a previous interview in a case before the next one was scheduled (my interview schedule was sometimes fairly hectic), I made a practice of listening to the tape of the previous interview immediately before visiting patient or doctor and drawing up a plan of the interview that I wanted to conduct. If the participant volunteered any new and interesting information, the time was spent on it, and I returned to my planned questions if there was time.

In southern Ontario, without exception, doctors were interviewed in their offices. In northern Ontario, meetings with physicians were in their offices, homes, hospitals, or, in one case, at a restaurant. Patients were interviewed in their homes most of the time. There were only a few exceptions, such as two who were seen

on one occasion in hospital and two who were interviewed at their GP's clinic.

V. THE "NATURAL HISTORY" OF THIS RESEARCH[10]

1. Special Problems of Inference and Proof

a. Pursuing the "Truth" about Competence

The most challenging problem in this study was how to pursue the "evaluation of competence" and its effect on the referral process. Early into the research, the fundamental importance of choosing a "competent" consultant emerged. In the very first case, an elderly man was referred to a gastroenterologist operating out of a different hospital than the referring doctor. The GP did not reveal (nor did it occur to the researcher to ask) why he had bypassed local gastroenterologists. A similar detour around a local neurologist was made for Patient 4, but the GP explained that the local fellow was a "jerk" - that is, unpleasant to deal with, aside from his competence, upon which she would not comment.

Even in the "practice" interviews that I had done before beginning the project, the importance of

assessments of competence and their link to trust in the consultant and communication difficulties in referral were raised several times. For example, one family doctor told me that GPs are considered "dummies" by specialists; speaking of a specialist with with whom it was sometimes difficult to communicate, he said, "competence comes first and [this specialist] is the best, so it's my responsibility to sort out any problems we have" (Notes, Aug. 31/84, pp. 4-5).

It seemed practically and ethically unwise to pressure GPs into labelling other practitioners as incompetent, and so I used the indirect strategy of asking each GP to whom s/he preferred to refer in each specialty, noting who in the local community was "left out" and asking the GPs why they were left out.[11] This lengthy process eventually elicited comments regarding the incompetence of the specialists in question in attempts to explain why they were avoided in referral. Freidson (1975) reports that he was able to discuss this sensitive material with the physicians that he interviewed. This was also possible in the first city that I studied, but it was very difficult. For example, I found out why no referrals in a particular specialty had been volunteered in the city, not from doctors there, but by a casual remark about the competence of

the specialists in this area that a northern GP had heard about.

To observe the process at closer range, several attempts were made to include specialists who had been labelled incompetent by at least one GP in the study. Since patients also identified incompetence as a reason for leaving their GPs, attempts were also made to have these GPs participate in the study. One specialist and one GP in this category (who, of course, were not told the reason that they had been approached) eventually agreed to participate.

This exercise proved very useful in throwing some light on the point made so forcefully by Freidson and Rhea (1963) that some doctors in the group they studied were not aware of suspicions about particular consultants held by other members of the group. In this study, two referrals to an internist who had been declared incompetent spontaneously by two young female GPs were followed. At the same time, it was noted that two middle-aged male GPs spontaneously made the claim that this internist was supremely competent. The two patients referred to the internist that were followed in this study, one man and one woman, both reported serious difficulties in interacting with the him and suggested deficiencies in his clinical judgement.

However, the third middle-aged male GP declared that he was very satisfied with the specialist's work on this consultation, while the third young female found him unprofessional and behind the times in dealing with her referral.

The "truth" about medical incompetence, then, is relative. GPs and patients alike are unable to separate past judgements based on the ways in which their consultants relate to them from evaluations of current experiences. This is a process which, in addition to the one described by Freidson, where some GPs are in a better position than others to observe consultants, works to make assessments from one GP to the other variable. If subspecialization had not forced the female GPs to refer their patients to this internist, they undoubtedly would have avoided him as Freidson predicts. Further, there will probably never be a convergence of opinion about the competence of this internist. This is a point that, I felt, was well worth learning, despite the roundabout way in which it had been learned.

b. Pursuing the "Truth" of the Patient's Experience

More serious difficulties were encountered in trying to determine the extent to which patients had been informed about their illness by their physicians, and specifically whether conflicting information had been given to the patient by two practitioners, a common problem. In part, the issue is one of "respecting relations between patient and doctor", which I had vowed to do on the consent form, although it goes beyond this. In a number of cases, I was simply unable to elicit convincing evidence about whether the physicians involved had told the patients the details of a bad prognosis. The GP of Patient 7, with an operable brain tumour, stated that he had informed her, but her comments to me suggested a lack of awareness. Neither did I feel compelled to find out "the truth", which will never be known, because the woman died of a blood clot soon afterward. It was subsequently learned that a number of patients had withheld important information from me, e.g. the young unmarried Patient 10 that she was really going to the GP because she was pregnant, not because of a skin rash; the middle-aged Patient 9 that his main concern was not angina, but a

prostate problem; and the headache-ridden Patient 28 that he was experiencing long-standing and serious family difficulties. Thus it is possible that Patient 7 withheld her knowledge of her cancer from the researcher. On the other hand, if the GP's reticience to confront her with the bad news anywhere approached mine, it is also possible that he didn't tell her in a way that she heard.[12]

The rule, elaborated by Wax (1971), that the researcher must never take information volunteered confidentially by one party to an interaction and reveal it to another party, particularly prevented the sorting out of what was happening in certain cases, and who knew what. Often, the situation eventually unfolded so that the outcome of the problematic situation was clear. For example, I was originally unable to assess Patient 20's reaction to the fact that his rheumatologist had notified the Compensation Board (but not him) that his injury was not compensable, because I was unable to tell him I knew this. Later, when he learned through his union that the specialist had failed to support him in his correspondence to the Board, he spontaneously voiced chagrin, and I was able to assess the effect of this event in his case. However, other situations were so complex and

information so contradictory that it was impossible to decide what was going on. Particularly problematic were referrals involving a request for Worker's Compensation. All three such cases in the study elicited protests from the GPs or the specialists or both that the men were not really injured but were "malingering", as well as protests by the men that their physicians were not dealing adequately with the problem. In such cases, the researcher feels torn between believing the physicians at some times and the patients at other times. As Patient 20 remarked, echoing Becker (1970), of whom he certainly knew nothing, the researcher has to decide "which side is she on?" Depending on which side is chosen, these referrals can be seen as the patient forcing the GP to refer unjustifiably or the physicians not showing sympathy for the patient's position. A middle ground, which was all I was left with occasionally, was to say that the definition of the situation was "problematic", both for me and for the participants as well if they had been forced to examine the evidence closely.

2. A Summary of the "Natural History" of this Research

In the section describing method above, an outline of general procedure followed in this research was sketched. The emergence of one category, "evaluation of competence", was described as if this had happened linearly. In fact, it is difficult to reconstruct the exact steps in the emergence of categories. Notes appended to transcribed interviews show that in the first few cases, two major areas of concern were the lack of trust of patients in the young doctors in the clinic whose cases I was following, and the avoidance of a few local consultants by GPs. Because of the design of the project - which required that I approach the GP first - I picked a "contrasting category" at the GP level. The natural contrasting category to study for the untrusting patient was the category of patient who had a long-standing relationship with his or her GP.

However, this "easy", commonsense explanation for why I then chose to approach older, ethnic doctors does not tell the whole story. Because I did not have a typewriter for the first year of the project, I often spent my evenings at the medical centre in order to

transcribe tapes. Fortuitously, I regularly discussed my work with a cleaning woman who was a member of one of the city's ethnic groups and who shared her bad experiences of doctors with me. What this woman told me suggested that there were "other networks" of doctors in the city not as "competent" as the group I was studying. I see in retrospect that what I was contemplating was one of Freidson's networks of doctors considered to be of less competence and at that point, sensed that this was an important discovery.

At this point, I was conscious of soliciting stories about incompetent doctors from everyone, friends and acquaintances, M.D.s and non-M.D.s. My notes show that I was "obsessed" with the dimension of competence. In talking to one M.D. acquaintance, I explained that the reason I wanted to study rural practitioners was that I imagined they were isolated and that they gave patients a different "quality of care" (notes, June 20/85). This man agreed that I was on the right track, but he insisted that competence wasn't just associated with being in the university group. He suggested that, just as I had imagined that rural practitioners were isolated, there were isolated men in the city too, and they probably would be quite willing to see me because they do not perceive

themselves to be deficient. This, then, was the "real" reason for approaching the older doctors, although my previous explanation is correct as well.

In retrospect, my feeling is that it doesn't really matter how the theoretical sampling happened-since the evaluation of competence is such an absolutely basic underlying activity in medical networks, I am convinced that there is no way that one could avoid it no matter in what direction one moved. The fact that other sociological researchers in addition to Freidson (e.g. Modrow, 1976; Bentley, 1971; Hummell et al., 1970) have identified the importance of the evaluation of competence in medical networks reflects the wide generalizability of this finding to other settings.

When I turned to the category of older, ethnic doctors, the most outstanding observation was that patient "trust" was there but that "convenience" was not. Two of the ethnic practices I studied could only be described as "chaotic", resembling the observations that Peterson and colleagues had made 30 years ago about some of the GP offices they had visited (1956). While spending days sitting around these offices, where people constantly came to join the crowds and went, stood in hallways with crying babies, and the doctor

looked like he was ready to have a nervous breakdown, it became clear that some patients had to make "tradeoffs" sacrificing convenience.

This observation led in several directions. In the theory presented here, it stands at the intersection of a number of hypotheses concerning "tradeoffs" that have to be made at various stages in the process of referral. It is paralleled by the observation that GPs also face inconveniences in their choice of specialist and that "tradeoffs" between choosing a trusted advisor and choosing someone accessible often must be made. Eventually, exploration of the source of the constraints at the level of the specialists led to the hypothesis that the social organization or structure of medicine was the source of the problem. Specifically, in the hospital being studied, GPs reported that they faced delays and other difficulties in approaching orthopedic surgeons. When two referrals to orthopedic surgeons were followed, and other participants were interviewed about the problems, it became clear that the "shortages" of orthopedic surgeons were not true shortages but were related to the careers of the orthopedic surgeons.[13]

While interviewing the older, more experienced GPs, it also became clear that they "thought"

differently than the younger doctors and that they would be useful in giving me a historical outlook on referral. Eventually, I spoke with a real "elder statesman" who emphasized that GPs and specialists had had much closer relationships in the past when they were on a more equal footing. He also emphasized the link between the patients' growing mistrust of general practice and increased referral. A second GP in northern Ontario provided a similarly interesting historical perspective on referral there.

One "puzzle" in the data which was repeatedly explored was what preceded the string of patient-initiated referrals that have been occasionally observed (e.g. by Balint, 1957). Did GP lack of self-confidence or patient mistrust trigger these events? After examining a series of "multiple referrals" in which the patient was referred to a string of practitioners and a group of "patient-initiated" referrals, I finally concluded that the two could not be separated but were part of the same process. The more the patients grew in experience through contact with doctors, the more mistrust they felt, the more assertive they became and more responsibility they took for their own care. When they came in contact with someone who was responsive to their opinions and

unwilling or unable to confront them and gain their trust, the inevitable result was a series of open-ended unsatisfactory referrals.

Although I had been contemplating exploration of rural referral from the very beginning of the project, when I was concluding interviewing in southern Ontario, the opportunity arose to follow cases in northwestern Ontario during the summer of 1986. There were good theoretical reasons for choosing this locale, since it contrasted in many ways with southern Ontario, and would provide a basis for testing the generalizability of the theory of referral that I'd developed.[14] Because of geographical, time and financial constraints, I was unable to pursue the leisurely pace of "theoretical sampling", transcribing an interview, thinking about it and proceeding to the next case, as I had in southern Ontario. This was not a serious problem, since, after 100 interviews, I had a fully developed theory of the process of referral, and could use my categorical scheme to "sample" various dimensions in the 10 practices that I approached. In general, the theory of the "process" of referral that had been developed in the southern locale "worked" in the northern locale, with certain aspects of the

process, as will be explained in the subsequent chapters, thrown into "high relief".

VI. SUMMARY

A review of the literature shows that previous studies of referral using quantitative methods do not do justice to referral as a social process. Thus qualitative/ethnographic methods were chosen for this research, specifically, the technique of multiple unstructured interviewing of participants. This approach allows the building of a model of the process that incorporates the perspectives of the social actors involved. In addition, a prospective case study design was employed to produce a theory grounded in actual clinical practice. The guidelines for inductive research suggested by Glaser and Strauss (1967) were followed to generate theoretical categories and interrelated hypotheses. The most important comparison in the thesis was between the process of the patient seeking advice from the GP and the process of the GP seeking advice from the specialist. Hypotheses about the similarity of the patient's and the GP's decision to seek advice, who to seek advice from and whether to

follow the advice were examined and ultimately provided a framework for the theory of referral presented here.

Referral was studied at two locales, one a southern Ontario city and the other, northwestern Ontario, including urban, town and remote settings. Multiple referrals from a particular GP, for a particular patient or to a particular specialist were sought, in order to cross-validate the information collected. Consent was first obtained from referring doctors and then patients. Care was taken to protect the identities of participants by using numbers or pseudonyms in the interview transcripts and fieldnotes and in the presentation of findings.

A "natural history" of the progress of this research is contained in the fieldnotes, which show the form that the research took at each stage and the findings and conclusions that were drawn from them. A brief summary of this history is presented in this chapter, which highlights the strategies developed to examine the operation of the "boycott" system in referral. Another important point in the research process was the identification of "tradeoffs" made in referral decisions, which were traced to the organization of medicine. The rural locale allowed a comparison with the urban locale, which strengthened and generalized the theory of referral presented here.

NOTES

1. The ethnomethodologist Cicourel drew attention to this process of "measurement by fiat" (1964, p. 29), and other ethnomethodologists, such as Mishler (1984), have argued that even in the analysis of transcribed medical conversation, the wider context of the speech must be taken into consideration. The technique of constructing this larger context from the point of view of the researcher (e.g. Waitzkin & Stoeckle, 1984), however, which is an "etic" approach in anthropological terminology, is rejected here. Instead, participants in this thesis research were encouraged, *via* unstructured interviews, to identify the meaning of events for them, in the "emic" approach advocated by Blumer and other interactionists. An "emic" analysis constantly interweaves with an "etic" analysis, as the researcher attempts to understand what is going on from the perspectives of participants. An "etic" analysis ultimately emerges, because the researcher's analysis is based on observations that go beyond the perspective of any single set of actors in a joint activity.

2. The classic prospective case study of medical referral in the literature is the North Carolina Rockefeller project. Following their intention to study "the natural history of the referral process", the research group decided to interview all participants in referrals to a university medical centre. However, certain initial restrictions were made without considering their possible theoretical value (Andrews *et al.*, 1959). Only referrals from the eastern two-thirds of the state were included, and the small percentage of patients referred from the west and elsewhere, which might have provided important clues as to the nature of referral, were excluded. (This was also true in Modrow's study, in which referrals to physicians outside of Windsor were excluded.)

They had some difficulty obtaining an adequate sample, because of what they called the "apparently irregular and unpredictable referral performance by the physicians who refer infrequently" (Williams et al., 1960, p. 1495) and which they eventually attributed to the role claimed by patients. They sought one case from each referring physician (about 20 percent of the 1200 physicians in the area), eventually obtaining 85 cases. As in the Dowie study, the "sample" was restricted by excluding the 19 percent of patients who were hospitalized. Further, the researchers only analyzed via "coding", 50 interviews with patients and physicians, respectively. Through trial and error, a focussed unstructured interviewing technique was chosen, but only physicians interviewed physicians, while an anthropologist and social worker interviewed patients in their homes, so that a direct comparison of responses from each participant in a case could not be made. Despite these limitations, however, this case study approach yielded the important information that patient initiation of referral was a significant factor and that their physicians tended to underestimate this effect.

3. A few of the qualitative methodology texts that have appeared in the last 20 years are McCall and Simmons, 1969; Becker, 1970; Denzin, 1970; Bogdan, 1972; Spradley, 1980; and Shaffir et al., 1980.

4. Occasionally those who "count" instances of a pre-defined category in the clinical literature will admit that they face immense difficulties in attempting to use classification systems. For example, perhaps the most important problem encountered in studies of clinical practice is the one of classifying the types of problems that the practitioner sees. For example, J.W. Brown et al. (1971), studying 12,835 patient visits by 15 GPs, complained that the International Classification of Disease, which began as a coding for cause of death, was inadequate as a classification scheme for reason of visit. Further, they argued, "the physician's office is not a place where

diagnoses are firmly established or fit into neat categories" (p. 305). A similar complaint was made by the American general internist Burnum (1973), in his attempt to classify the types of cases that he saw. He noted that he saw "various inseparable admixtures of 'functional' and 'organic' disorders" (p. 441). Instead of using the ICD classification, he generated categories inductively, based on his own experience, such as "pre-death" and "minor problems", "benign dystopism" (harmless irregularities) and "pones" (asymmetry of body surface).

5. This "eureka" phenomenon concerning "the boycott" in referral happened about six months into the project when I analyzed an interview with Neurologist 4 on June 20, 1985. Here is an excerpt from my fieldnotes: "One reason this interview was so valuable was the description both of how the hospital affiliation might influence referral and how a deviation from the typical pattern might clue one into a personality problem. It never occurred to me to question whether a disjunction occurs between GP and specialist hospital affiliation until [Specialist] 3 described the system. In the case of neurology, the 10 specialists spread themselves among the five hospitals. So the GP might be expected to refer his possibly to-be-hospitalized patients to the specialist who shares his hospital affiliation. <u>If he doesn't</u>, I think I can safely assume that something is going on. For example, say in this case that [GP 4] doesn't refer to the two [local] neurologists...[I]sn't it interesting that given a choice she chooses [a neurologist at a different hospital]? Is she trying to avoid someone [at her hospital]?" In the next few days, I "remembered" Freidson and Rhea's work on "control in a company of equals" and designed a strategy for testing the hypothesis of the boycott (described in this chapter under the section "Pursuing the Truth about Competence").

6. "Emergence" is a key concept in inter-actionist/phenomenological theory (cf. Mead, 1932; Schutz, 1932; McHugh, 1968). Basically it refers to transformation of the meaning of a

situation progressively over time as new information is acquired and related to past information.

7. With respect to the example above, with the two categories, "patients who trust their GP" and "patients who do not", the hypothesis was that people in the latter category would pressure for referrals to a specialist or someone they perceived to be more competent. I "saw" this happen with the untrusting Patient 12, who told me that he did not feel his GP was competent to handle his problem.

Another hypothesis in this study was that there was a tendency in the referral situation for contradictory information to be given to the patient because the GP is more conservative in what s/he says while the specialist is more blunt. Ultimately, I "saw" this happen with Patient 16. Here is an excerpt from my fieldnotes after interviewing his GP, who had made a strong argument for withholding bad news from patients: "[GP 16]'s position on what to tell the patient sets up a potential for contradictory information to be given to the referred patient, because the specialists I've talked to by and large had no qualms about dropping this type of information on a patient. So it's not surprising that he responds to my question about whether this ever happens to him with 'more and more so! I'm very upset about it' (Int. #1, pp. 6-7). What is ironic is that this actually <u>happens</u> in [Patient 16]'s case...[He hasn't really had a heart attack, but] the problem is that he suspects that the GP is a 'nice guy' who would hold back the truth to protect him. And the patient is right - he <u>is</u> that kind of guy, although [there is no bad news in this case]".

8. This insight was from Dr. John Premi, McMaster University, who mentioned it in a rounds presentation in 1985.

9. These are training centres for family physicians studying for their certification that are attached to each hospital in the community. They function generally like giant group practices, except that the "supervisors"

take responsibility and see the cases if a patient visits on a day when the resident is away.

10. This term is used following Becker's usage. In Boys in White, he and his colleagues experimented with giving "a description of the natural history of our conclusions, presenting the evidence as it came to the attention of the observer during the successive stages of his conceptualization of the problem. The term 'natural history' implies not the presentation of every datum, but only the characteristic forms data took at each stage of the research. This involves description of the form that data took...in presenting the various statements of findings and the inferences and conclusions drawn from them. In this way, evidence is assessed as the substantive analysis is presented. The reader would be able, if this method were used, to follow the details of the analysis and to see how and on what basis any conclusion was reached. This would give the reader, as do present modes of statistical presentation, opportunity to make his own judgment as to the adequacy of the proof and the degree of confidence to be assigned the conclusion" (Becker, 1958, pp. 197-8).

11. This is an example of a "shortcut" that Becker (1958) notes that qualitative researchers sometimes discover when faced with researching "abstractly defined variables" that are difficult to observe first-hand. The strategy was suggested to me by a physician-acquaintance who was involved in peer review.

12. As Haas (1977) discovered, he could understand why high ironworkers pretended they were unafraid of heights when he found himself feigning bravado in scaling heights. Similarly, here, I discovered how difficult it must be for a doctor to confront a patient with bad news through my own hesitation in talking about fatal prognoses with patients.

13. See Chapter 7 for the details of this analysis.

14. A survey of Ontario physicians (Bryans et al., 1981) reinforced the idea that I would find the

referral situation in northwestern Ontario radically different than that in southern Ontario. The report showed that the Toronto and Ottawa areas had the lowest proportion of GPs to specialists at less than 40 percent, while northwestern Ontario had the highest at 58 percent. These regions also differed the most in the proportions of community-based vs. hospital specialists; whereas Toronto and area had the highest proportion of hospital-based specialists (25 percent as compared to 35 percent community-based specialists), northwestern Ontario had only 4.5 percent hospital-based specialists and 38 percent community-based specialists (p. 40). Finally, the report showed great differences between the two regions in terms of GP age, with south-central Ontario having the highest proportion of 1950's graduates in the province (33 percent) while northwestern Ontario had the highest proportion of 1970's graduates (26 percent). Since I already knew that GP age was important in trust of the GP and pressure to refer, I wondered if this would be obvious in patterns of referral in the North (a hypothesis that turned out to be true, as described in Chapter 6). The fact that there would be problems between patients and their GPs in the north was already suggested by the concern in the Bryans report that GP turnover was high there because of the lack of job opportunities for spouses (p. 82). The fact that a "visiting specialists" program would be the most rational system for northwestern Ontario referral was also mentioned in the report (p.90).

CHAPTER FIVE

REASONS FOR SEEKING MEDICAL ADVICE: NEGOTIATION WITHOUT WORDS

I. OVERVIEW

In this chapter, an introduction to the referral process is given by discussing why referrals are made. The dynamics of deciding to consult by patient and doctor are compared and contrasted. This is followed by an examination of pressures to refer that originate with the patient and within the specialized community of medicine rather than from the GP. Thus, in contrast to the medical reasons for referral listed in clinical studies, this chapter focusses on how patient agendas and professional restrictions and preferences influence the decision to refer and shape referral rationale.

1. Why are Patients Referred? Issues in the Literature

In the clinical literature, the referring doctor is assumed to be a free agent who decides to ask for advice or assistance in diagnosis or treatment of a patient. These purely medical reasons for referral are estimated in quantitative studies to account for from 55 percent (Carson, 1982) to 80 percent of cases (Grace & Armstrong, 1986), based on the reports of referring physicians.

The wider context of referral, including the motives of participating patients and consultants, are not directly examined in clinical studies, but are implied by the inclusion of minor categories such as "medicolegal reasons", "access to facilities", "lack of time", "physician reassurance" and "patient reassurance" or "patient request". For example, "patient reasons" for referral are estimated to account for from seven percent (Clarfield, 1980) to 25 percent of cases (Brock, 1977). An American study by Ruane (1979) does not even list this category, but claims that almost two-thirds of referrals are made because of the GP's lack of skill and access to facilities, with only one-third made for diagnosis and therapy.

Psychological models of referral, such as that of Dowie (1983a), also exclude patient and consultant motives in their explanation of the referral process. Going beyond the "reasons" stated by the doctors, they link higher referral rates and laboratory usage of younger doctors to their lack of self-confidence in their own abilities (Eisenberg & Nicklin, 1981; Holmes et al., 1982; Eisenberg, 1985; Pinneault, 1974). The trouble with this explanation is that there is contradictory evidence that younger doctors sometimes refer less than more experienced ones. For example, Brock's (1977) study in London, Ontario, showed that community physicians with more than five years experience, who reported that they were more "pressed for time" referred more than clinic staff and family medicine residents. Wolfe and Badgley (1973) also found that younger doctors in the clinic they studied referred less, and speculated that the younger doctors were hesitant to have their professional peers see cases that they have been managing. Clearly, the process of medical referral is more complex than clinicians and psychologists have sketched it.

2. A More Comprehensive View of Referral Motives

In this thesis, in contrast to most previous studies of referral, emphasis is placed on the fact that medical referral and consultation involve at least two levels of interaction and may involve three: the patient seeks out a physician; the general practitioner seeks out a specialist; and the specialist responds in various ways, including sometimes seeking out another specialist. When all levels of interaction are considered, there are found to be other "reasons" for consultation and referral than those discussed by clinicians and psychologists.

a. "Negotiation" Between Patient and Doctor

Specifically, it was found in this research that the patient, in a complex set of interactions with the GP, could initiate a referral without the doctor being completely aware of the extent of the patient's influence on the process. Similarly, the referring doctor could initiate a referral for "reassurance" without the patient being fully aware of the physician's motives. The decision to refer in such cases is an example of "negotiation" without words.

These findings are not completely new, since they have emerged whenever researchers have considered the views of patients in referral research. They are a replication of the only case study of referral, the North Carolina Rockefeller study, in which both patients and physicians were interviewed around specific cases (Williams et al., 1960). In that study, if patient-initiated referrals reported by patients were added together with "reassurance" referrals made for "impending or overt loss of rapport" as reported by physicians, this comprised the largest category, about half. Doctors, however, grossly underestimated the influence of patients on their behaviour and patients were largely unaware of the extent to which physicians had discounted their fears and were referring them for "reassurance". In Britain, Gillam (1985) has more recently found that 40 percent of the referrals to private (vs. public health) consultants were patient-initiated, suggesting to him that patients are "less passive than formerly" (p. 15). Grace and Armstrong (1986), in their study of 316 referrals to 16 British consultants, found that almost no patients realized that they were being referred for "reassurance" as reported by doctors, which is the other side of the coin.

b. "Negotiation" Between Doctors

It was also found in this study that the referring doctor is involved in a complex set of relationships with consultants in such a way that it is impossible to make a completely "free" decision about when and to whom a patient should be referred. The point emphasized in the psychological literature, that a doctor's referral decisions are linked to self-evaluation of competence is important as a basic observation.

However, the doctor also refers cases which he or she may be able to handle when the equipment or techniques are in the jurisdiction of consultants, or when s/he is not permitted to perform these services because of the restrictions of licensing, hospital privileges, commitments to colleagues in group practice or the requirements of agencies such as compensation boards and government departments. In an attempt to "negotiate" some control over the case after referral, it was found that the referring doctor may choose one kind of specialist to get to another, beginning with more conservative colleagues. Where the referring doctor wishes to guard his or her control of the situation, s/he may be threatened by specialists who

"steal" or "dredge" cases, by providing unnecessary or redundant services. Alternatively, referring doctors may abdicate responsibility for cases by "dumping" them on consultants because of a lack of self-confidence or for economic reasons, ignoring the negative statement that this behaviour makes about them.

The idea that referring doctors and specialists "negotiate" without words the boundaries of general practice and specialty medicine has been developed by Freidson in his study of referral (1975, ch. 5). Because these boundaries are continuously negotiated as part of the doctors' identities and careers, Freidson points out that specialization is "elastic" - that is, not dictated by the nature of medical work (pp. 84-85). This point is well-illustrated in this thesis by the fact that the boundaries of general medicine are broader in northwestern Ontario than they are in the urban location studied. However, within a city with different hospitals, generalists and specialists may be more or less in control, and opposite political arrangements may co-exist, thus limiting what can and must be referred.

II. RECOGNIZING THE NEED FOR THE EXPERT

1. The Analogy Between Consulting Patient and Consulting Doctor

Patients often face uncertainty in deciding whether they are ill, whether they should consult a physician, and whether they can accept the physician's conception of their illness.[1] Similarly, uncertainty is an everyday fact of life for practitioners.[2] As psychological explanations of referral have rightly emphasized, in spite of the fact that the doctor has special medical expertise as compared to the patient, he or she sooner or later recognizes limits on this competence, and is faced with decisions about whether a consultant should be sought and whether the advice should be followed.

If the analogy of the consulting patient and consulting doctor is explored, there are similarities as well as discrepancies in the initiation of the process. One similarity is that, as Dowie (1983a) argues, there appears to be a range of "thresholds" for seeking help when faced with uncertainty about diagnosis or treatment. Just as doctors refer at different "rates", patients go to the doctor at

different "rates". For example, one GP in this study placed two of his patients on different ends of the spectrum on this dimension: Patient 8, he claimed, "errs on the side of not coming when he has legitimate reason to come" (Int. #1, p. 1) while Patient 9 "abuse[s] the hell out of the system" (p. 2). Similarly, physicians talked about under-referral and over-referral of patients as failures to recognize one's limitations or abuse of the system, respectively.

Despite this superficial similarity, it will be argued in the next section of this chapter that the initial part of the process of seeking medical advice by patients is distinctively different from that followed by physicians deciding to refer. While the patient goes through a process of trying to determine whether the "definition of the situation" justifies disturbing a doctor, the doctor goes through a process of determining whether the problem falls within the jurisdiction of his or her responsibility.

2. How Doctors and Patients Describe Diagnostic Difficulties

Although it might be argued that referrable problems are more difficult to diagnose than most problems presented to the GP, doctors did not often spontaneously raise the topics of uncertainty in diagnosis or of potential or real errors of diagnosis, except as they related to illegitimate requests made by patients (e.g who are not really ill or who wish to collect compensation). When presented with the fact of an incorrect diagnosis, doctors defended their competence. For example, when faced with the ultimate evidence that Patient 16 did not have a heart attack as he had suspected, the GP argued that there was some objective evidence of a problem in an abnormal electrocardiogram (Int. #2, p. 2). While such abnormalities can be produced by muscle spasm or artefact, the GP emphasized that "it was not just me that was concerned here" - since specialists who saw the patient also suspected heart problems. Another GP, who made a serious misdiagnosis of the pregnant Patient 39's problem as a kidney infection when it was a gangrenous appendix, said, "I felt that I followed what most reasonable GPs would in the situation" (Int. #2,

p. 10) and gave an elaborate defense of his actions by suggesting that the patient "has to take the responsibility" because she had not wanted to stay in hospital. Even the surgeon in this case emphasized that he had made a similar error in the past.

Patients, on the other hand, who are not expected to have any medical expertise, talked freely and with no self-protective concern about the difficulties they faced in deciding whether they were ill. For example, Patient 8 diagnosed himself as having a severe stomach upset rather than a heart attack, because his definition of a heart attack included pain, but he had none. His wife similarly reported her dismissal of a gall bladder attack as arthritis until she was in serious condition (Int. #1, p. 15). Patient 32 ignored the headaches and dizziness that led to her stroke, as a sinus problem (Int. #1, p. 10), and now worries that the "heavy feeling" in her chest is angina and not the "virus" that the local surgeon has diagnosed (p. 13).

Patient 39 laughed about not realizing that she was in labour. "I'd never been in labour before and I didn't know what it was", she said. Patient 19 had difficulty distinguishing her thyroid condition from the stress of her "lifestyle" of having a new baby,

business, living with difficult in-laws, travelling overseas with young children, having an absent husband, etc. "It took me a year to get to the doctor because I'm very stubborn", she said, "and I won't give in. So I kept going" (Int. #1, p. 3). Finally, she linked her feelings of being hot and flushed to the fact that she had lost 40 pounds and realized that she was ill. Patient 36 similarly suffered for "ten or twelve" years with her GI problem until she "was in such pain" that she was forced to decide, "I've got to do something about this" (Int. #1, p. 20).

Patients occasionally reported that they did not perceive that they were in serious trouble until a referral had been made, and that this event suddenly made them realize that they were truly ill. Patient 32, for example, immediately became fearful that she had breast cancer upon her referral to Winnipeg from a small northwestern Ontario town, particularly since "all the arrangements [were made] even before I got out of the office" (Int. #1, p. 11). Patient 33 was similarly complacent until she was referred to Winnipeg and then said that she realized "oh God, an operation...I started getting worried a bit, because going to see a specialist here is a big deal" (Int. #1, p. 5). And Patient 34 failed to be concerned about her

high blood pressure during pregnancy until, she says, "I ended up in the hospital, and that's when I realized how serious it really was" (Int.#1, p. 11).

3. Worries About "Bothering" the Doctor

Although Patient 8 seemed to have a Parsonian conviction that it was his duty to go to the doctor if he is ill (Int. #1, p. 12), like many other patients, he did not want to "bother" the doctor if his judgment was in error. Patient 41 reported a similar reticence which led him to wait a month in pain with a suspected hernia; he reported that he came in to his GP so seldom that his doctor was "almost glad to see [him]" (Int. #1, p. 10). Patient 15 said that she and her husband have to push each other to go to the doctor when there is a question over illness (Int. # 2, p. 14). The dynamics involve the fear of disturbing a doctor when it is not really necessary, balanced against the nagging worry that what <u>you</u> think is trivial may not really be trivial. The wife of Patient 18, who, like Patient 15, is a nurse, explained that the whole family have been altogether "too casual" in deciding to go to the doctor. She herself hesitated to go in with a ruptured appendix, which she left until the last moment

(p. 20). Patient 30, also a health professional, was very defensive about her decision to bother a surgeon to have a breast lump examined, reporting that she was relieved when her GP reassured her that the lump was not just in her imagination (Int. #1, p. 2). Patient 32, also with a breast cyst which had been drained, reported that she "imagined it coming back" but at first dismissed the problem as "just the soreness from the freezing and everything" (Int. #1, p. 32).

Unlike patients, GPs never expressed concern that they might "bother" a consultant with a trivial concern. They were well aware that referral of too many trivial problems might be a signal to the consultant of their incompetence or irresponsibility, however, as one GP pointed out:

> If a person doesn't have the training or experience, he's safer to refer [the patient] to somebody, but the consultant - if you do this again and again and again, if 80 percent of your load isn't sick, will probably form an opinion of you and say, oh well, he's sent me another one.
>
> (GP 21, Int. #1, p. 8)

Thus, unlike patients, whose overriding attitude was one of respect for the doctor's time in seeking advice, doctors themselves, when seeking advice, are more concerned with protection of their own reputation of competence.

4. Jurisdictional Considerations

In contrast to the confusion and procrastination reported by patients during self-diagnosis, physicians instead emphasized that their decisions to consult were based on determining whether they were competent to deal with a particular problem. When they generalized about the specific types of cases they referred, GPs would typically indicate that they sought help when they doubted their own competence to deal with a case. GP 10, for example, explained that he had to refer cardiology cases now because he had "lost his competence" in this area after not handling cardiological problems for a long time.

More often, GPs identified areas in which they would not be able to take full responsibility for a case because they had never acquired competence in the area. Most notable among general practitioners with 10 or less years of practice was reference to a lack of training in obstetrics and gynecology, which was traditionally seen as part of the family doctor's area of responsibility. GP 16 estimated that contemporary students in training may only deliver five babies while he delivered 350! GP 14, for example, explained that her lack of experience in obstetrics and gynecology,

along with her fear that this is a "high risk" area, means that all such cases, which form the bulk of her practice, must be referred ("50 pregnant women a year" - Int. #1, p. 2). For Patient 15, for example, the referral involved a request to explain notations on an ultrasound report, which the GP said was for her own education. She explained that that she did not have hospital privileges for obstetrics because of her lack of training and that, in any case, she was afraid to get involved, in spite of an invitation to do so from the obstetrician. By way of contrast with her lack of experience in obstetrics and gynecology, GP 14 added that she has taken extra training in gastroenterology, and does 90 percent of the workup on the patients that she refers in this area.

In general, physicians argued that less experienced GPs refer more than more experienced GPs, although the emphasis was put on a psychological rather than experiential explanation of this phenomenon. GP 14, for example, thought that she was representative of her age group in making a fairly high number of referrals (Int. #2, p. 11). But she thought that the attitude of GPs in their late 50s was "very, very different" in that they "don't refer" unless it's a very important question - life-threatening, for example

(p. 12). She believes that their "ego" becomes involved to the extent that they don't refer just to learn something. A new graduate in her practice, she suggested, was even less "ego-involved" than her, and was willing to refer anything that might tell her something new: "she's not going to be deflated because of having to refer the patient" (p. 12).

All inexperienced doctors in the study appeared to illustrate this "lack of ego investment" about referring.[3] GP 1, for example, a family medicine resident, said, unlike more experienced practitioners, that he wasn't worried about asking colleagues for advice:

> I think it's important that you collaborate. There's no way we're going to know everything. It's nice to get another opinion on it... Particularly if you feel you've reached an impasse when you've been managing someone for awhile and they haven't gotten any better and you're thinking about referring off to a specialist to get a further opinion. Someone else may be able to tell you, well, I've tried this. You know, why don't you try it?
>
> (Int. #1, p. 14)

Residents are somewhat protected in their referral of patients in that "educational reasons" are legitimate. That is, if a referral is stupid or unnecessary, this doesn't reflect so badly upon the young referrer. GP 25, who had just begun practising in the North, was an

experienced doctor, but was similarly not worried about asking colleagues for advice. GP 34, as well, admitted freely that he referred a patient with a suspected hernia because "I know I'm not great at feeling hernias" (Int. #2, p. 6). GP 3, the youngest physician in the study, commented that having peace of mind about a patient is much more important than protecting one's self-esteem:

> If you're concerned about somebody ...there's ways of making it easier. One way is putting in a call and taking care of it. And you know the patient is in good hands... When people are anxious about a patient...[i]t can make you stay up at night - worried about this and worried about that. If you're smart - everybody knows what they can and can't do - and when you get to the point where you're worried when you go home, what might happen, you're not consulting enough.
>
> (Int. #1, p. 13)

In contrast to this lack of concern about admitting that one is not competent in an area, an experienced GP insisted that he only referred cases that the specialists themselves would find difficult (GP 16, Int. #1, p. 2). But it may also be, as Piedmont (1968) had suggested in his study of referrals, that the reticence of more experienced GPs towards referring is part of a more realistic assessment of what specialists can offer, based on the GP's longstanding experience of their work, rather than just a protection

of ego. GP 14, who had put forward the "ego-investment" theory of referral, agreed that she cannot know consultants first-hand like some of the older GPs who have scrubbed in with them. Perhaps because of this lack of exposure, she is more willing to accept the advice of a specialist, which she said she would not question. The experienced GP 16 suggested that as a GP advances through a career, s/he learns to take more responsibility and to be more confident of his or her abilities and more critical of what a consultant can offer.

Although experienced GPs clearly made fewer referrals in certain areas, even they faced other areas of medicine in which they needed reassurance and assistance. For example GPs 5 and 12, after 30 years in practice, still handle their own obstetrics, and GP 8 handles most of his own cardiology cases. However, GP 12 referred Patient 13 to a rheumatologist for reassurance that he had the right diagnosis and treatment, because, as he pointed out, "arthritic disorders are so elusive".

III. SEEKING OUT THE EXPERT: "LAY" AND "FIRST LINE" REFERRAL

Another way in which initiation of consultation by patients and doctors differs is in the extent to which relatives, peers and paraprofessionals are consulted in "defining the situation" as one requiring medical consultation. Patients were much more likely to consult a variety of others than were doctors, who rarely mentioned consulting even another GP for advice on when to refer. However, they often engaged in a similar type of strategy within the professional network, referring to one specialist who would then help make the decision about who else the patient should see. This process, which has not been reported in the literature to this point, has been called "first line" referral here.

1. The Lay Referral Networks of Patients

Freidson, in a study of subscribers to a prepaid medical plan in the 50s in the Bronx, identified a "lay referral" system through which an ill person passed before contacting the doctor. It consisted of various other lay persons, friends and

relatives, who helped the patient identify the problem and decide on a course of action (1961, pp. 146ff.). He suggested that the lay referral networks of patients from ethnic groups where extended families live in close proximity might be more extensive than those of, for example, health professionals, who would tend to turn to professional help sooner than other patients.

There are many illustrations of the operation of such lay referral networks in this study. For example, Patient 5 reported discussing health problems with members of an extended Italian family: "If we have a problem, we share a problem" (p. 6), she commented. Patient 33, a 16-year-old, was advised by her father to seek out a doctor for an eye injury, although her friends and gym teacher had minimized it as "just a broken blood vessel" (Int. # 1, p. 1). After what the patient considered to be an unsuccessful referral, she was advised by an aunt who "reads medical books" that she "should get a second opinion" (Int. #2, p. 2). Patient 36 originally consulted a specialist for her gastrointestinal problem at the urging of her mother, a nurse (Int. #1, p. 1). In another case, a friend was of help in giving Patient 9 some nitroglycerine which he used to diagnose his angina. GP 38 commented that the pressure to refer a patient in fact often comes from

relatives, particularly relatives who are health professionals, rather than from the patients themselves (Int. # 1, p. 1).

In northwestern Ontario, relatives were particularly likely to be consulted to help decide whether gynecological or obstetrical problems warranted medical advice. Patient 26 had sought advice from a brother-in-law who was a psychologist around her suspected infertility. Patient 32 had asked her daughter-in-law to look at her breast operation to determine whether it was healing properly or whether she should go back to the doctor. Patient 34 emphasized that she always sought out her mother for a "first opinion. And then the doctor for a second opinion" (Int. #1, p. 9).

Neither did patients restrict their consultation to friends and relatives. Pediatrician 34 spoke of a case of a native child where "Mom wouldn't let us do surgery on him because she wanted to speak to the medicine man first" (p. 9). Radiologist 36, who had extensive experience working on native reserves in northern Ontario, explained that native patients often use their medicine men or women as advisors about whether Western medical care should be sought. However, because the native healers do not wish to "embarrass" a

Western doctor such as himself by referring the patient directly, they might send "a relative of the patient to ask me, [asking] would it be alright if I saw the patient" (p. 19).

Optometrists were similarly consulted by patients directly around eye problems in the north, partly as alternative practitioners and partly because of the scarcity of ophthalmologists, but also as experts who could help them decide whether a referral was necessary. As Optometrist 38 remarked, "a lot of times you have to tell [the patient] that it's time to be referred" (p. 17). He had older patients with cataracts who "rely on their children to bring them in" and who, "secure in their own little world", had to be encouraged to have their problems treated.

In contrast to the examples cited, other patients reported little assistance in diagnosis by family and friends. Older women patients who had longstanding relationships with their GPs, such as Patient 7 and and Patient 13, mentioned discussing illnesses with others, but claimed that the information did not influence their perception of their illnesses. Patients who were unsure about whether they had a stigmatizing illness, such as a psychiatric disorder, also reported little help from others. Patient 19, for

example, excused her husband for not detecting her illness, because she had no physical symptoms: "...unless you've got your foot in a plaster cast, it's very difficult to say, I don't feel well, can you help me? (Int. #1, p. 8). She compared her situation to that of a schizophrenic neighbour, whom people expect to "smarten up and get it over with, go out and get a job and stop being ridiculous. Because they cannot see anything wrong" (p. 8). For her, the diagnosis of hyperthyroidism was a "relief": "I didn't feel like I was going crazy anymore" (p. 6), she said.

Neither did Patient 16 discuss his quandary about whether he had had a heart attack or not with his peers. When the illness originally occurred, he was not concerned that the chest pain might have anything to do with his heart. In fact, he called his GP and waited a few hours because he did not think that this illness warranted a visit to the Emergency Room. He was shocked at the diagnosis of heart attack finally given in Emergency and confused by subsequent contradictions. The man now wavers among various diagnoses including hernia and psychological problems. He feels that there is "some similarity" between a "nervous breakdown" that he suffered the previous year and his current episode (p. 11), but imagines that the pain would be "all the

time" if it were psychosomatic rather than real. He is torn between deciding, like Patient 19, whether his problem is physical or psychological. Presumably his hesitation about discussing his condition has to do with the embarrassment of debating, with his friends, the pros and cons of whether he is a legitimate patient or a hypochrondriac. Patient 10, with a similarly stigmatic problem, a fungus, cannot discuss her problem with coworkers from whom she may have caught it, since she believes that she would be fired if anyone knew.

Another important way in which family and friends influenced patients' perception of illness was indirectly by demonstration. Premi (1985) has suggested that a patient may discover in him- or herself evidence of serious illness if a close family member has suffered through such an experience. This happened for Patient 4, whose father had been diagnosed as having Parkinson's disease. The experience of Patient 5 also illustrates this process. This woman had had a breast tumour removed the previous year and was now worried that lumps in her daughter's neck might be cancer (Int. #1, p. 5). The influence of "demonstration" on the patient's perception of illness can also operate positively, as in the case of Patient 34, who was not concerned about her infant's hydrocele because her

brother "had a newborn with one" that has not posed any problem (Int. #1, p. 8). Patient 37 was similarly "not worried" about her son's "lazy eye" because she said that she had "spoken to people and [treatment] is either a patch or an operation", neither of which are matters for concern (Int. #1, p. 4).

2. The Referral Networks of Doctors: First Line Referral

Outside of direct referrals to specialists, GPs almost never mentioned approaching others for advice on diagnosis or treatment. GP 25 admitted that he might confer with another doctor on call about the appropriateness of referral, although not frequently. GP 32 called the local optometrist to look at Patient 33's eye injury, but only because he had superior equipment with which to look at the eye.

Physicians, however, do not always know what is wrong. Dowie (1983a) reported that physicians sometimes were so confused about a disorder that they could not decide which type of specialist would be appropriate for the patient to see. How, then, do they make this decision? Doctors in this study rarely mentioned this type of problem, but instead said that they coped with

difficult situations by referring to a "first line" specialist, fully expecting that this specialist would help "define the situation" so that more appropriate further referral could take place. For example, although Patient 7 ultimately required neurosurgery, her family physician referred her first to a neurologist. Similarly, although Patient 18 ultimately had cardiovascular surgery, he was referred to a cardiologist first. Patient 20 underwent orthopedic surgery, but first was referred to a rheumatologist. Patient 21 required plastic surgery, but was sent to a dermatologist first, who referred her on. In each of these cases of multiple referral, the general practitioner knew that surgery was probably necessary, but s/he decided to refer to a "first-line" subspecialist in internal medicine rather than directly to a surgical subspecialist.

Referring through a first-line specialist might serve a number of purposes: (i) it could operate as a "second level filter" (with the GP serving as the first level filter) to make sure that only absolutely appropriate cases get through to the highly-specialized surgical subspecialists in a way similar to that in which patients "screen" their problems with friends and relatives; and (ii) it could serve the purpose of

directing the referral through a specialist who has a much better idea of who should handle it than the GP, who almost never sees such cases and so cannot make as good a judgement about who to refer it to. Further, (iii) when being referred through a first-line specialist, the patient may not feel that s/he is being kept waiting, and that because s/he is seeing a number of doctors, that a great deal of concern is being shown. And finally, (iv) perhaps the first-line specialist can be used as a way to reach increasingly inaccessible surgical subspecialists, just as many patients in Ontario know that they can only reach a specialist through their GPs.

GPs in this study denied that they tried to reach surgical subspecialists through more accessible medical subspecialists, which would be a perversion of the traditional model of referral (White, 1973). For example, GP 19 claimed that the fact that Patient 20 got a prompt appointment with one of the most prestigious orthopedic surgeons in the city when he was referred through a rheumatologist was something that "just happened". Instead, this GP argued that the responsibility for subsequent referral is passed on to the medical subspecialist when the referral is made.

Speaking of referring to a "first line" cardiologist, she commented:

> If it needs someone else's expertise [beyond the cardiologist], I have no problem with that. I do feel that they should consult me in terms of who to send the patient to...[but] I would not expect the cardiologist to call me to see if I could book a cardiovascular surgeon. Anything to be done on an emergency basis...I'm happy to bow out. (Int. #1, pp. 4,8)

This comment suggests that the GP may be willing to abandon the patient to have his or her problem defined by the experts after making a first-line referral, which would be consistent with Freidson's (1961) argument that once inside the specialty system, the patient loses his or her autonomy.

However, in a number of cases in this study, the first-line referral was clearly a way for GP and patient to maintain control over a case. For example, it might be a strategy for the GP to ensure that a more conservative second opinion is given than might be the case with a surgical referral. This is analogous to the patient seeking out friends or relatives for their presumably more conservative opinions about what should be done before consulting a doctor about an illness. In this way, the GP may be using the first-line specialists to help define the problem but still keep some control over what is done with him or her. GP 12

claimed that this was often why he referred a patient to a rheumatologist rather than a surgeon. In fact, although GP 16 complained about having to refer to a cardiovascular surgeon through a cardiologist, GP 12 emphasized that "I wouldn't want to make that decision on my own anyways" (Int. #2, p. 13). Thus the first-line specialist may be filling a void for the GP who feels less and less competent to deal with referral decisions forced on him or her by a continuously differentiating system. It theoretically allows the GP to keep control as well as giving him or her more information on which to base a decision about what is to be done.

On the other hand, when the GP knows that nothing else has worked, after a number of referrals to subspecialists where s/he has monitored the case, s/he may choose to bypass the first-line specialties and go directly to a surgeon. For example, GP 17 explains that he referred Patient 17 directly to an orthopedic surgeon because he knew that he would not respond to more conservative treatment and would need knee surgery right away (Int. #1, p. 3). This makes him unlike Patient 20 who saw two medical subspecialists between the GP and the orthopod, presumably because the GP wanted to find out if more conservative treatment could

be given before opting for surgery. In fact, the criterion for referral to a surgeon rather than an internist seems to be "showing no improvement". One man for whom this type of referral paid off was Patient 16. He seemed to be showing that his "cardiac problem" could not be managed conservatively with drugs, so that bypass surgery might be an option. However, investigations by an internist suggested that the problem was not cardiac. In cases of this level of uncertainty, the first-line referral system operates as a kind of failsafe device and surgery is treated as a "last resort". As GP 2 summarizes it, "It's a silly system - you pick a specialist who's going to do what you want them to do" (Int. #1).

IV. PATIENT INITIATIVES IN REFERRAL

1. What is "Patient-Initiated" Referral?

In the sense that it is the patient who usually decides to go to the doctor, almost all referrals are patient-initiated. However, the patient's involvement in the referral process does not end at the doctor's doorstep. In the only discussion of patient-initiated referral in the literature, Dowie (1983a, pp. 90-95)

identified four situations in which the patient will pressure to be referred on for greater expertise, special services and techniques. First, both patient and doctor may be aware that the presenting problem is beyond the GP's expertise and that a referral is necessary. A second set of situations involves a patient making a specific request for vasectomy or abortion, with the physician acquiescing reluctantly. With a third type of case, there has been "no noticeable improvement" despite treatment from the GP and "GPs actually welcome the patients' referral initiatives for they provide an opportunity to pass over an exasperating case" (p. 92). Finally, the GP may be faced by a patient demanding referral although there are no clinical reasons, in the doctor's view, for such a demand.

In this research, the common underlying process in all patient-initiated referral was found to be a breakdown of the patient's trust in the GP's expertise, advice or reassurance and a demand to see a higher authority, which was more or less recognized by the physician. All 64 doctors in the study recognized this process. The mistrust may not even be voiced by the patient, but detected as a "need for reassurance" by the GP. For example, GP 24 remarked that although local

GPs are able to technically take care of cases of heart attack, they are sent to the city "just to have the whole thing gone over" because "often it makes them feel better if they see a cardiologist" (Int. #1, p. 1). At the other end of the spectrum, the patient may make the fact that s/he mistrusts the GP quite clear. Since the process is triggered by a breakdown of trust, or confidence that the GP can handle the problem, these types of referrals occurred most often among patients seeing inexperienced doctors, doctors with whom they had not had the opportunity to form a longstanding relationship or doctors whom they had some other reason to mistrust.

Referral for pregnancy or cancer typically involved some patient pressure. For example, GP 14 explained that she referred both Patients 14 and 15 for reassurance about their pregnancies. Patient 14 was distressed about previous pregnancies, so that near the end of this one, which was entirely normal, both physicians were seeing her regularly (Int. #2, p. 2). Patient 15 also needed reassurance around the bleeding that was occurring during her pregnancy (p. 4). Patient 25 sought this type of reassurance when she missed a number of periods, but had had a negative pregnancy test. The GP explained that he referred her to an

obstetrician because of her "cancerphobia", writing to the specialist to tell him of her mother's anxiety and her need for reassurance (Int. #2, p. 2).

2. Physician Awareness of Patient Initiatives

Physicians in this study estimated that as much as one-quarter of all referrals are initiated by patient pressure on the GP and almost all felt that this type of behaviour was on the increase. This estimate was consistent with that made by physicians in the North Carolina Rockefeller study (Williams et al., 1960). Another similarity between the results of the two studies was the underestimation by physicians of the influence of patients in actual cases that were being studied.

Patient pressure to refer was found to be much more intense in the remote area of northwestern Ontario than in the southern Ontario city that was studied, and physicians in that area, like their rural North Carolina counterparts, denied that this was a major aspect of the referral process in the region. There was a myth among physicians that people in remote areas actually trust their GPs more than sophisticated urban patients. Specialist 31, for example, who had practiced

as a GP in Labrador, commented that his "biggest problem" was insisting to patients that a certain problem was outside his field and having them reply, "no, no, I'm sure you can handle this" (p. 11). But by a remarkable coincidence unknown to him, his Patient 31 had actually grown up in Labrador, and she spontaneously remarked, "I believe that all the 'rejects' have been sent to Labrador! I have no faith in the doctors there whatsoever. I really don't" (Int. #1, p. 7). She then proceeded to explain how her mother, after visiting the "doctors at St. Johns [Newfoundland who] didn't really tell her anything" about her respiratory problems, finally ended up halfway across the continent at the Mayo Clinic (pp. 8-9).

A denial that patient-initiated referral was a major aspect of health care in northwestern Ontario was made by every local GP in this study. For example, after I commented that every patient that I had talked to in northwestern Ontario had either been to the Mayo Clinic in Minnesota or had sent a relative, GP 40 insisted that my sample was not "representative" (Int. # 1, p. 4). He thought that only "two or three" out of his practice of 2000 had travelled so far to seek a "second opinion". However, both of the "representative"

patients that this physician asked me to follow reported experience with this type of care-seeking. Patient 40 said that he would wait and see how the local specialist handled the case, and if he felt it was necessary, he would "ask them to send me to a specialist. It don't matter to me if it's Winnipeg or Thunder Bay or where it is." (Int. # 1, p. 11). Patient 41 remarked that travelling to the U.S. is no longer as common as it used to be, although "[b]efore they got doctors in Winnipeg, everybody used to go to Rochester [Minnesota] and Duluth. I remember taking my wife to Duluth" (Int. #1, p. 11).

GP 24, another well-respected northwestern Ontario GP, insisted that patient-initiation of referral was not a problem, because "in an area like this, the people do have faith and confidence and trust in their doctor" (Int. #1, p. 15). However, both Patients 25 and 26, who lived in a nearby town, reported initiating their referrals because of lack of trust in the local inexperienced GP. GP 29 similarly denied that patient-initiated referral was a problem in the region, unaware that his own patient faced a great deal of pressure from relatives and friends to seek care at the Mayo Clinic. Patient 29 indeed expressed trust in the local system in spite of the pressure on

him, but his procrastination about having a lung biopsy suggested that his distrust was so profound that he was attempting to "block" his treatment altogether. GP 34, in another small northwestern Ontario town, also claimed that patients were happier to stay in town than to be referred to Winnipeg (Int. #1, p. 3). The fact that her Patient 36 refused to be referred to Winnipeg for a gastroenterological problem appeared to illustrate this faith in local medical services. But the patient herself reported that her fear of Winnipeg was based on a degrading experience she had had there many years previously while having GI investigations.

Doctors in southern Ontario were similarly unaware of patient initiatives in referral. The Toronto Surgeon 30, who saw the patient twice around a suspected breast lump, was not aware that the original referral was initiated by the patient's mistrust of a local surgeon. He claimed that,

> my referrals are usually doctor-originated...You know, there's the odd patient who I think obviously tells the family doctor, look, I want to see a specialist regardless of what you think. Send me to one. But I think that's a minority.
>
> (Int. #1, p. 3)

Later, however, he admitted that much of his practice involves reassuring women with this problem (p. 9).

Why are doctors so unaware of patient referral initiatives? One basic reason is that patients tend not to discuss these initiatives with their physicians. This type of demand is a direct threat to the "cloak of competence" that physicians attempt to present to the patient and both participants may feel the pressure to maintain respect for the assumption that the doctor is the expert, even when this involves "mutual pretence".

3. Physician Strategies for Dealing with Patient Initiatives

There is a philosophy among physicians that it is the patient's "right" to seek a second opinion, and no attempts were made in cases in this study to block it. However, inexperienced GPs appeared particularly vulnerable to patient pressure, while more experienced GPs had strategies for dealing with such cases.

The semi-retired GP 24, for example, explained,

> [I]f they come in and say, look, doc, I wanna go and see so-and-so about this and that, I just tell them, you're going to have to hold still a moment and tell me about it...And if you don't want that, you'd better go to somebody else.
>
> (Int. #1, p. 15)

For patients who insist on referral for every problem, experienced GPs reported a strategy to keep referral to a minimum by giving them regular appointments (e.g. GP 12, Int. #1, pp. 15-16). This strategy was used by the supervisor of the less experienced GP 3 for Patient 3. However, the resident knew that she had no choice but to refer when faced with the elderly Patient 3 who distrusted her when she refused to remove wax from her ears. The patient made a direct request by suggesting, "[w]hy don't you send me to a specialist so he can figure it out?" (Int. #1, p. 2). The young GP admitted that by referring the woman to an ENT specialist, she was "trying to give her what she wants". What this involved was getting someone more authoritative than herself to say that there was nothing wrong with the patient's ears.

All GPs, however, recognized the inevitability of having to refer a distrusting patient who insists on referral. GP 30, for example, said that in dealing with patients who have "had a local turnoff and that don't think that anyone nearby can handle their problem" (in this case not just a distrust of general practice, but of the competence of local specialists), it is impossible to say, "oh, that's silly! Just take the care here. Because they will come up with an example of

He added that if you "set some standards like that, then they know that doesn't go, and it doesn't become a problem", although "if they insist, it's kind of hard to refuse". (p. 15). Similarly, the experienced GP 19 believes that "most times, just discussing with the patients their concerns...either offering them treatment, guidance or reassurance" will quiet them (Int. #1, p. 9). But she added that once every two or three months, she got patients who were "neurotic or obnoxious or whatever" such that she had to "respect their wishes" (p. 9). GP 7 similarly explained that he gets such patients "occasionally", who come in and ask him to make an appointment with a specialist because they cannot do so directly. He tries to see them first and talk them out of it, unless it's only an "eye appointment" for which he doesn't mind obliging (in what he called "community service"). If a patient whom he feels doesn't need to be referred still insists, he will give in and refer "because otherwise they stay kind of worked up" (Int. #1, p. 9). He explains that referral may help to keep their trust and help them to accept a chronic disease for which they want a more satisfactory treatment. He also recognizes that the specialist may be able to do something new for these patients.

where that went wrong" (Int. #1, p. 1). His Patient 31 reported that he has always dealt positively with her various requests to be referred - to Toronto for a skin problem (Int. #1, p. 2), to a local orthopod to verify whether the surgery suggested by a first orthopod was necessary (p. 19), and finally to the Mayo Clinic for a third orthopedic opinion.

There was only one unusual situation in which a patient's wife reported that a GP had refused to refer her. Caring for a severely brain-damaged child, this woman said that she had learned "that you have to scream and holler and get mad. Otherwise you get nothing" (Patient 12, Int. #1, p. 18). Further, she said, just because a family doctor tries to discourage a referral, this is no reason to respect his opinion. She felt that her referral to an international expert was being discouraged for no good reason - that they were just "dredging up" reasons. This experience appears to have undermined her faith in the referral system. She has defined this refusal as a power-play: "They just did not want me to do it, and so they were doing everything in their power to dissuade me from even going and talking to the doctor" (pp. 18-9). And she added that she hasn't given up trying to see him.

Like GPs, most specialists are also supportive of patients who seek a second opinion. This "philosophy" is best espoused by Specialist 5, who argued that the patient has a right to be seen. After all, he pointed out, they've been warned on TV about cancer, and so physicians have to expect that they will be sought out by patients concerned about such things. In the case of Patient 5, where a child was involved, the specialist didn't want to take any chances either. Even though he did not think that the lumps in the child's neck indicated any serious problem, he decided to see her a second time: "the only time you can really be reassured is to take it out and look at it under a microscope" (p. 4). According to this view, there is no substitute for blood tests, cardiograms, X-rays, pathologists' reports, etc. Specialist 34, also treating a child, admitted that he was "probably not doing anything that the GP couldn't do, but somehow Mom expects you to assess the child and you feel more comfortable reassessing that child" (p. 4). Where adults are concerned, Specialist 17 emphasizes that he is not able to detect the patient who is not ill so easily (pp. 6, 13). In general, he agrees that referral "for reassurance" is legitimate, and he adds the caveat that the GP may really be missing something, just as

he may be missing something when he refers to another specialist.

Perhaps the most positive statement from a specialist about complying with a patient's request for a second opinion was made by Gynecologist 19, who said,

> A lot of [patients] come here because someone they know has breast cancer or cancer of the uterus and they want to...have everything checked...[T]hey want to make sure that they're not getting it...I'm a gynecologist. My job is to look after the well-being of a woman...[I]f I take 10, 15 minutes of my time to ease her anxiety...I think I'm doing my job, I don't think it's a waste of time...I'm not going to tell her, look, you got to go to your family doctor. Family doctors are busy too. Half the time they don't even undress the woman, let alone examining her.
>
> (Int. #1, p. 6)

Specialist 16 emphasized that when a patient tells him that he does not trust his or her GP, he attempts to defend the GP, even if he doubts with them, particularly when they have an inexperienced GP. And he gave the reason for the commonplace observation that doctors tend to support one another: "If you break the faith from one doctor, you break the faith from all doctors" (p. 16).

4. Patient Requests for Referral Identified by Physicians as "Illegitimate"

In contrast to referrals that were recognized by practitioners as "legitimate", including those for reassurance of patients, physicians also described inappropropriate, undesirable or "illegitimate" referrals requests by patients. These included requests for referral from patients for problems that physicians felt were "trivial", requests for special care for routine obstetrical or gynecological problems and often, referrals initiated around claims for compensation of injury.

a. Trivial Requests Encouraged by "Free Care"

While accepting the fact that they should refer when requested to do so by patients, a number of doctors speculated that this trend was on the increase and that it would have dire economic consequences. Three interrelated professional and lay "theories" about the dynamics of "inappropriate" patient-initiated referral were that they were encouraged by the availability of government-financed health care; that they indicated a widespread "failure of faith" in

general practice; and that they were initiated by growing numbers of experienced and questioning patients. Patients generally agreed with these arguments, although they never saw their own contacts as unnecessary. Patient 29, for example, commented that "people run to the hospital if they squash a fingernail with a hammer" (Int. #2, p. 10).

Retired GP 23 argued that there is a rash of patient-initiated referrals because,

> [i]f you give the people something for nothing...they are going to work it to death!...You can come to a doctor now for things you would never <u>think</u> of coming for if you had to pay a bill...Grocery stores aren't free!
>
> (Int. #1, p. 3)

This elderly GP felt that even a token user fee may have headed off the contemporary "free for all" attitude of such patients. He talks of one family which he feels has spectacularly abused the system by costing "OHIP a million dollars over the past several years" because they keep insisting on referrals although "there's nothing wrong with them to begin with" (p. 4). According to this GP, the end result of this kind of behaviour is that "no matter how often you refer, there's always one more specialist to go and see. And this is what's killed the whole organization" (p. 4).

While GP 23 waxes eloquent about the irresponsibility of such patients, he also suggests that there may be reasons other than economic that underlie patient-initiated referral. He believes that older patients are more trusting than younger ones. In the past, he recalled, "[p]eople expected you to handle whatever you were trained for. You were trained to be a doctor...You made the diagnosis" (p. 2). By way of contrast, he thinks that people don't expect much of the GP nowadays: "people used to trust you more than they do now. It doesn't matter what you diagnose now, they say, we'd like a second opinion" (p. 3). Later, he says,

> We've lost nearly all the respect that we had of our patients. Our patients don't have that feeling towards their doctors that they did when I was in practice. They took our word for it, they cooperated in every way, no feeling that you weren't as good as the next person...[T]hey had great confidence in you and it was a big help in treating people too. They had perfect confidence in what you said.
> (Int. #1, p. 15)

Another theory about the "inappropriate" patient-initiated referral was given by GP 8. He linked supersensitivity to health concerns with patient IQ. He suspected that since his Patient 8, whose "elevator [doesn't] go all the way to the top floor" (Int. #2, p. 1) "doesn't have a lot of things bothering him

mentally" (p. 8), he wouldn't have the intelligence to seek out a physician when he needed him. For the other type of patient, who fusses and is "attached to the system", like Patient 9, there is more potential for abuse. However, both he and Specialist 5 seem to discount that the intellectual or questioning patient can use his or her intelligence to understand medical matters. This intelligence, they argue, gets in the way of the simple faith in the doctor that makes a patient "happy" (p. 5). Some physicians tended to talk about this type of patient as a "questioning patient" or an "intellectual patient". The health professional who becomes a patient was not necessarily seen by physicians as a "questioner" - they instead reserved this term for patients who were not knowledgable, but who attempted to control the situation by demanding details or further investigations, thus resulting in a "challenge of authority" (e.g. the business executive demanding an explanation from the doctor, as described by GP 8).

Pediatrician 37 described the "hysterical mother" scenario as an example of a situation in which the "questioning" patient initiates what the physician regards as an unnecessary set of referrals:

> [T]he mother is determined that they're going to find something...[T]he mother

> has a perception that there's a diagnosis and the physician has a perception that there isn't a diagnosis. And yet they've got to do all this travelling to find out. So you've got to go to Physician A, grumble, grumble, grumble. Physician B, grumble, grumble, grumble. Physician C, more negative tests, more negative results, grumble, grumble, grumble...Do you want a diagnosis for those? Twentieth-century disease!
>
> (Int. #2, p. 9)

He added that he much preferred to treat native patients because they "are less neurotic about themselves, so you do fewer referrals for social reasons. You know, you don't have to placate the mother or the patients much" (p. 11).

Specialist 27 combined all three theories of the "inappropriate" patient-initiated referral, but unlike most other physicians, he welcomed what he perceived to be an increase in the numbers of "questioning patients" because he saw them as striving for the best treatment available. According to him, their questioning might have economic consequences, but it is justified in their search for the best care available:

> I don't know how much money that involves, and whether it's increasing exponentially, but I would think that some people have been held back from getting a second opinion because they couldn't afford it in the past.
>
> (Int. #1, p. 4)

Ophthalmologist 38 agreed that this combination of factors underlies current increases in referral when he observed that care was "free and there's more expertise available...If it was going to cost them, it might be a different situation" (p. 14).

b. Problems in Obstetrics and Gynecology

Gynecological and obstetrical referrals were often identified by doctors as being in a special category of referrals where patient initiatives were most important and where requests were often "illegitimate" or at least, undesirable. GP 24 noted that, in the past, when there were "big families and lots of kids", GPs were relied upon to deliver and care for them, but "with the pill, the birth rate dropped a way down and every baby was a federal case" (Int. #1, p. 11). Now, as GP 27 pointed out, describing a mass exodus of women from his small town to the obstetricians in a neighbouring city, women are "voting with their feet" to be delivered by specialists rather than GPs.[4] Obstetrician 25 estimated that while 10 years ago, about two-thirds of babies were delivered by GPs, now, two-thirds are delivered by obstetricians (p. 3).

It was evident in this study, however, that a number of processes were at work alongside this alleged female "paranoia". Obstetricians 14, 25 and 34 and 39, who were all flooded with patients, complained about their schedules, had little time to talk, and all paradoxically confirmed that they see a substantial proportion of their practice not through referral, but "off the street" by self-referral. Although it would make more sense to "close" their practices to "referral only", they admitted that the referral system has broken down in this area, since fewer and fewer GPs are doing obstetrics. As Obstetrician 34 in Winnipeg explained, a few obstetricians are privileged to rely on a cadre of GPs who do most of their own obstetrics and refer only difficult cases. According to this obstetrician, there is fierce competition among obstetricians in recruiting any new GP's obstetrical referrals, but as a beginner, he is forced to "pick up" patients who bypass their family physicians and call the obstetrician directly (pp. 10-13).

Why are more and more new GPs avoiding obstetrics and leaving their patients to contact specialists directly? GP 16 explained that incompetence is easy to detect if you start out with "two healthy people" and they end up ill (Int. #1, p. 9). He also

speculated that the medicolegal fears of GPs in this area have made it easier for specialists to "squeeze" them out (p. 8). He feels that specialists have reacted to GP fear by thinking up all sorts of forms that have to be filled out "where if you don't do it, you are in trouble. If you do do it, you don't know what to do with it" (p. 9). Obstetrician 25 explained that GPs in northern Ontario need more reassurance if they are out in the "boondocks" (p. 7). He understood that this is a particular problem where "you do only a few deliveries a year and you never really gain the confidence" (pp. 2-3). If the GP did enough deliveries to gain confidence, it would be very disruptive to the rest of his or her practice in terms of time. It thus appears that a combination of patient and professional pressures have contributed to the upsurge in obstetrical referrals that was so often noted by participants.

For gynecological problems, as well, a growing preference for female physicians and requests for special services were implicated in increased referral and gaps in the referral system. Experienced male GPs in southern Ontario such as 5, 7 and 12 talked about referring younger women to female GPs or gynecologists for gynecological exams, and the female GP 14 spoke of

having a large female patient population as well as gynecological referrals from male GPs in the same building (Int. #1, p. 3).

The gynecological exam is generally recognized to be the most embarrassing type of medical encounter, and Emerson (1970) has described it as a situation in which patients and physicians are hard-pressed to pretend that "nothing unusual is happening". But the young, male, Obstetrician 34 had a particularly unsympathetic view of women who preferred women doctors to examine them. He emphasized that the patient's primary concern should not be "whether she sees a man or a woman" but "who is competent" (p. 14). In his experience, "normal" patients

> who have a good marital situation and a stable life and good standing in the community tend not to mind who they see. The ones who I consider to be psychologically inept - they're not happy with their life, things are not going exactly right, they tend to want a woman because they think that they may relate better. They're just not as emotionally stable as others.
>
> (Int. #1, p. 15)

Most but not all young women patients in this study reported a preference for seeing a woman for a gynecological exam. Patient 10, although admitting that the only time she feels nervous about going to a doctor is for a "physical" (p. 8), said that her male GP makes

her feel comfortable. Her GP commented that requests for gynecologists tend to come from "some younger girl and someone who might be embarrassed" (Int. #2, p. 4), but he claimed, unlike other GPs, that he doesn't get them very often. His theory was that patients saw him as "gentler" than the local female gynecologists.

While requests for gynecological referrals were not a problem for GP 10, he indicated that requests for abortion were: "It's one of the hardest things I have to deal with" (p. 6). He was relieved that Patient 10, an unmarried teenager, did not pressure him to refer for abortion.[5] This man's view is against abortion and he refuses to refer since he feels that this is tantamount to procuring an abortion. GP 24 agreed that although he'd been "very liberal about it in the past", the line had to be drawn somewhere against allowing women to use abortion as birth control. The male Obstetrician 14 agreed with this, stating flatly, "I don't do it", referring to abortion. GP 32 explained that one of two clinics in his small town would not refer for abortion although he would (Int. #1, p. 2). There thus appears to be a partial breakdown of the referral system around this type of case, such that at least a few patients must pick a complex route through

the system or go through channels other than the regular referral network.

While a few GPs and obstetricians saw abortion as an illegitimate referral request, others disagreed. GP 14 said that when she received requests for referral for abortion from the female patients of local male GPs, she listened to them and referred them on, knowing that the women would only see her this one time. Neither did she contact the original GP or parents (Int. #1, p. 4). Gynecologist 19 was upset that physicians could block this kind of referral and complained that the patient may have to see a newspaper or bus ad, use her lay referral network, or, as one physician told a patient to do, "look it up in the Yellow Pages" (Int. #1, pp. 6-7). It is difficult to estimate how widespread this breakdown is. At the time that the study was being done, there was sensationalistic news coverage of the prosecution of Dr. Morgentaler for procuring abortions in Toronto, which may have influenced what physicians were willing to say. In northwestern Ontario, physicians generally agreed that abortion committees were not functioning as the law had intended. GP 24, for example, remarked that they were "pretty near rubbish" since he didn't have any trouble having abortions done in spite of the few

obstetricians who refused to become involved (Int. #1, p. 3).

The analyses of Badgley et al. (1981) of the experiences of 5000 Canadian women seeking abortions show that physicians discouraged only a very small number. However, the long delays, on the order of months, to see a specialist, may represent a rejection of these kinds of referrals by specialists.[6] Consistent with this hypothesis was the observation that in hospitals in northwestern Ontario with abortion committees, GPs and not specialists tended to perform the abortions (GP 29, Int. #1, p. 3). It should be noted that the legalization of abortion and the disbanding of abortion committees in Canada as of February, 1988, does not address this problem.

c. Referrals for Compensation

Patient requests for orthopedic or other referrals involving Workers' Compensation claims or other kinds of litigation were also often identified as "illegitimate" by physicians. GP 24 recalled that, before OHIP, "a lot of people tended to get compensation who would cut themselves at home and report to the company nurse because it was paid for"

(Int. #1, p. 23). However, even after the advent of "free care", he thought that there was substantial abuse of the system. Two experienced male GPs were particularly outraged by this type of referral. GP 6 discounted the claim of Patient 6 that he had been injured on a construction site and complained about the number of referrals that had been initiated around this case. He was also skeptical of the claims of the husband of Patient 5, pointing out that he had "seen too many" of this type of case, which led to a "vicious cycle of referral" as a kind of "escape" for the patient (pp. 6-7). Occasionally, he added, a patient would consciously try to dupe the physician into agreeing there was a compensable problem (p. 22).

GP 17 felt that the case of Patient 17 was an illustration of this dishonesty. He commented that he no longer even writes down anything that this patient reports in the chart, because, he said, "I don't believe it any more". That is, he no longer believed that the patient was sick, but felt that this man was out to get compensation through him: "Money can make people sick..." and "[o]nce they get the money, everything is fine" (Int. #2, p. 5). There was a strong sense of moral outrage played out by this GP, who accused the patient of "using my friendship". He said,

in disgust, "in my guts, I hate it!" Part of the outrage comes from feeling stupid: "I'm very naive but I'm not stupid", he insisted. However, there is also the tone that a "norm" has been breached in the sense that Garfinkel describes (1955/1967). Although he says he is reluctant to admit it, the GP generalizes that, "[p]eople are willing to do almost anything for financial gain" (p. 6). Since this man thinks of his patients as friends, this kind of breach is particularly distressing to him. He feels that this sort of situation is not "widespread", but not "unusual" either.

How do physicians determine whether a patient can be trusted? As with GPs who have to be trusted by specialists not to "dump" difficult cases on them, a longstanding relationship which allows an assessment of the patient's motives, appears to help. For example, GP 40 said of Patient 40: "[He] never complained about anything in his life, so I'm certain there's a problem" (Int. #2, p. 1). GP 30 said that he trusted Patient 31 was initiating a referral to the Mayo Clinic around her knee injury sustained in a car accident because she gave the impression of being "truly concerned that she doesn't want to be disabled" and wanting to "conserve her image of herself as an active physical person"

(Int. #2. p. 7). "I asked her where she was with the claim [for compensation from the insurance company] and she didn't even know...I don't get the impression that she's trying to fool anyone", he added. However, the patient reported that the first orthopod she had consulted, who did not know her very well, did not trust her. "I guess there are people out there who go in and think they're going to get bucks if they go into therapy", she observed. "And I think he was too quick to judge me" (Int. #1, p. 20).

V. PRESSURES TO REFER FROM THE PROFESSIONAL COMMUNITY

1. Seeking Special Techniques or Equipment

In contrast to the open-ended type of referral discussed above, in which the GP or patient seeks diagnostic or treatment advice or reassurance, there were numerous referrals in this study where a consultant was specifically chosen who could perform certain procedures that the GP wished to have done. GP 17, for example, referred Patient 17 to an orthopedic surgeon who could do an orthoscopy on his knee (Int. #1, pp. 3-4). This GP also referred Patient 18 to a

surgeon for a hip replacement operation and to a "lipid clinic" for monitoring of his diet. Patient 16 was referred by one specialist to another for an angiogram and Patient 7 was referred to a neurologist for a CT scan. Patient 31 was referred to a dermatologist who might have a "jet injector" that would make her cortisone shots less painful. Thus referral in these cases was for technique or equipment rather than advice.

The lack of access to special techniques and equipment in northwestern Ontario was strongly felt by physicians and surgeons there. Perhaps the person who missed this technological backing the most was GP 25, who had been practising medicine in a large city most of his professional life. He complained that there were no catheterization facilities in the nearest city (three hours drive away) so that cardiovascular cases usually had to be referred to Toronto over 1000 miles away. Further, he pointed out, local specialists may often feel that you can handle a case which they can handle with their special equipment, forgetting that, as the GP, you do not have this technological support. The GP vividly recounted his fear in a case where he had to reduce a fracture where a pin had been inserted: in the city, he would have gone to a radiologist first

in order to establish whether he had the confidence to go ahead and do the reduction (Int. #2, p. 9). But the local orthopod was "firm" over the phone about not handling the case, and so he was forced to go ahead. Even in less demanding cases such as that of Patient 26, who was referred to an ENT specialist for investigation of her ear pain, the GP says that he would probably do a lot more investigation before referring on if the facilities were available: "you tend to do almost all the investigations at your disposal, partly as a teaching exercise" because "you've got the equipment" in the city (p. 5).

Another case in which GP 25 reported he would have felt better about the specialist taking the case was a pregnancy where he felt uncomfortable, but which the obstetrician refused to take on. He subsequently spent two nights with the patient in delivery, her baby was born blue and he had a great deal of difficulty saving it. If the specialist had taken the case, the GP explained, he would have had the equipment necessary for picking up fetal distress earlier and would have monitored her (p. 7). This GP prefers to send women with any irregularity of pregnancy to the city, including Patient 25, for whom a Caesarian section was arranged.

While referral for the use of special techniques or equipment is thus seen as a necessity of modern medical practice, many GPs in this study said that they did not always feel in control of this process. In fact, they often complained about feeling "forced" to refer for specific treatments or access to specialized equipment. GP 19, for example, complained that she has to make a referral to get an EMG for the diagnosis of carpal tunnel syndrome. "I don't need a neurologist to diagnose it", she claimed, but if she ordered it on her own, without asking the neurologist for a consultation, "I can wait months...[T]his neurologist gets a consultation fee, an EMG fee, and I don't need him" (Int. #1, p. 5). GP 29 also noted that there was always a better response from a consultant who was asked to go beyond assessment and take over the case, a situation for which he said he had "no patience" (Int. #2, p. 5).

Another example of this process occurred at the beginnings of Cases 8 and 9 where the patients had to be referred for an exercise test. There seems to be a built-in requirement that people on anti-anginal medication have to go for regular exercise tests, which typically involves a referral (GP 8, Int. #1, p. 2). A similar situation occurs in the examination of CT scan

results which Surgeon 39 claims are "so simple to interpret" although "interpretation is being restricted to radiologists" (p. 4). He feels that GPs can do their own radiology, since "ninety-five percent of the X-rays that are taken in this town [in northwestern Ontario] are probably acted upon without the benefit of radiological interpretation" (p. 4).

A third example of a referral to obtain access to special equipment was that of Patient 11, who was sent to an ophthalmologist to have her eyes checked. This was not because she had been referred voluntarily by her GP to the ophthalmologist for eye problems. It was a requirement of her place of work. The GP does not have the equipment to check eyes, so she must be referred. And, as the specialist involved remarked, one area GPs "don't like to fool with" is "the eye" (Ophthalmologist 11, p. 8). Ophthalmologist 38 agreed that,

> [M]ost physicians feel uneasy with eye problems, and, due to the lack of equipment in their office, it's very easy for them to say, OK, I'm going to send you off to the ophthalmologist.
>
> (Int. #1, p. 10)

As in the area of obstetrics and gynecology, these ophthalmologists reported a partial breakdown of the referral system, with substantial parts of their practice being self-referred, since GPs tended not to

It's something for them to do" (p. 2). If there was anything she questioned, it was the fact that tests are so often duplicated by more than one doctor, such as blood tests and blood pressure readings (p. 9).

Not all patients were sympathetic to referrals of this type. Patient 19 believed that her GP might have saved her the trouble involved in an investigation of a heart murmur that had to be referred to a cardiologist because she didn't have the equipment to do an EKG (Int. #2, p. 5). She felt she "would prefer not to have it done. It drove me nuts. She's so cautious" (Int. #3, p. 5). This patient suggests that this is the type of finding that you might try and ignore even if something has been published about it: "I feel my mitral valve prolapse has been blown out of all proportion" (p. 6). In general, she observed that

> [T]here's a lot of time, effort and money wasted with all these appointments, machinery and pumping medications into bodies that don't need it to protect them from something that they never had to worry about in the first place.
>
> (Int. #3, p. 6)

GPs complained that government and other agencies support the trend towards investigation using special techniques and equipment by subspecialists. There were a number of cases in the study in which these agencies expected referral to a specialist even

take any responsibility for this specialized area. The area has in fact become so cut off from general practice that these ophthalmologists reported that referrals from optometrists were a major source of their business. Optometrists, like GPs with restricted hospital privileges, are unable to legally perform certain procedures on the eye, which insures that such cases will be referred (Optometrist 38, Int. #1).

The ophthalmologist for Patient 11, whose eye check-up showed no problems, made a strong case for such routine referrals, placing them in the category of "preventative medicine". The patient herself accepted routine check-ups without questioning their utility: "I thought I'd better take them seriously. It's for your own good", she said (Int. #1, p. 1). Part of her reason for being sympathetic to this type of exercise has to do with her faith in the physician's opinion of her health <u>vs</u>. her own opinion: "How many times you think you are right but you find out you are not" (Int. #2, p. 4). This faith may also have to do with her past experiences with the "tests" surrounding a successful kidney problem diagnosis and operation. She did not see the request of the company nurse for a regular checkup as anything other than "normal": it's "just routine", she explained, "They take their job very seriously...

for assessments that the GPs involved felt they might have handled. For example, Patient 8 had to be referred to a cardiologist to provide evidence to the Ministry of Transport around his application for a license upgrade. A neurologist was required to establish that Patient 7 had cancer before she could undergo radiation treatment. Patient 2 expressed concern that specialists' reports be sent to the Department of Veteran Affairs to support his disability claims. Workers' Compensation claims also involved multiple referrals to specialists for Patients 6, 17 and 20, and although their GPs were quite happy to refer them, GP 25 argued that GPs, particularly in northwestern Ontario, could probably handle these cases without referral. According to him, there is an unspoken assumption that the GP cannot make these types of assessments. Further, redundancy is fostered (GP 8, Int. #1, p. 2). GP 16 put the emphasis on the use of "fancy equipment and tests" in the same category as the "squeeze" in obstetrics.

2. The Tertiary Referral

Subspecialists in surgery and medicine also turn to other specialists for advice or assistance, a

practice called "tertiary referral". An example of a tertiary referral made by a specialist is Case 12, where, although the gastroenterologist had done a thorough investigation of the patient's problems (pp. 10-11), he still could not decide whether the amoeba that this man had in his bowel or his colitis was causing his diarrhea. Internist 12, who saw this case, described the gastroenterologist's request as a simple type of "lower level" tertiary referral as compared to the more complicated work of "the primary consultant who is seeing the patient directly for the family physician" (p. 2). But the "higher level" type of tertiary referral may also involve referrals for general services. For example, Orthopedic Surgeon 18 developed a relationship with a local general internist who gives check-ups to his patients that are about to undergo surgery. Although this appears to "short circuit" the GP, taking away responsibility for primary care from him, the orthopod argues that, not only does the GP not have the time to perform these services, but neither does s/he have the skills of a general internist to perform them.

In northwestern Ontario, subspecialists rather than general internists often provide generalist services, much as do American specialists across the

border, because of the shortage of doctors in the region. Although one British-trained specialist complained about this role, most said that it did not bother them. Neurosurgeon 28, for example, said that he did not mind doing neurology. One specialist added that he even carried a primary care practice (Internist 29). Many northern GPs were unhappy about this state of affairs, however, since it put them into competition with the specialist for the provision of primary care services. They also complained about specialists who referred to other specialists without informing them about the tertiary referral, since this effectively involved "stealing" their cases. Large specialist-dominated group practices were boycotted by GPs who feared having their oupatient cases "stolen". GP 30, for example, commented that he avoided one large and powerful clinic for fear they would,

> internally cycle patients without consulting the referrer. Which whether you're concerned about losing the patient or whether you're concerned about having some input in what happens to that patient once they leave your immediate office, does worry a lot of people.
>
> (Int. #1, p. 3)

In the south, a specialist monopoly over treatment is institutionalized in inpatient care. In the first city hospital studied, the GP cannot even

admit the patient without the specialist taking over the case. Gastroenterologist 12 made clear just how irrelevant the GP has become in this hospital by describing what might happen to a family doctor trying to tend to an inpatient:

> [T]he family doctor would go up there. First of all, he wouldn't know who was taking care of his patient, which intern or which house staff. Half the time he wouldn't find a chart because it was down in the cart in the hallway. And I would think if I was a family doctor I would be totally frustrated. I would go up there and I couldn't find the chart, I couldn't ask the doc what was going on, I would have to walk in and ask the <u>patient</u> what was happening! Which is really - I mean <u>you're</u> not in control when you ask the patient!
>
> (Int. #1, p. 8)

An illustration of this irrelevance was given in Case 7, in which the GP suffered through these indignities to follow his patient, but then was not informed of her death. In some northwestern Ontario hospitals, where GPs still provide most of the services, this type of scenario is unlikely to occur, although specialists there predicted that it was an inevitable development.

3. "Dumping" and "Dredging"

Physicians have been quoted in a previous section as laying the blame for increased referral at

the feet of patients who seek "free care" for trivial problems or who make "illegitimate" requests involving gyneological services or compensation claims. However, patient demand could clearly not account for all situations in this study in which patients were involved in multiple referrals for a single problem and where extensive investigation and treatment were initiated by a single abnormal lab finding in an otherwise asymptomatic patient. In addition to increased patient expectations, study participants suggested that referring physicians who "dump" on specialists patients whose problems they could handle themselves and overzealous specialists who "dredge" cases for problems, also contribute to the escalation.

a. "Dumping"

Specialists generally reported that they were sensitive to the concerns of the GP that he or she was not able to handle cases in a particular area or had a difficult patient making demands for a referral. The young Cardiologist 8, for example, commented that the only way to determine which GP is comfortable handling a certain problem by him/herself <u>vs</u>. sending it to you is by getting to know them:

> [For] some family doctors...you may have to follow their patients more closely...[in] an area that they're unhappy treating, such as arrhythmias. They may just feel extremely uncomforable with arrhythmias, whereas another family doctor may feel that he's had a lot of experience, and he only refers the most difficult cases ...They may have had a bad experience where they thought someone had indigestion and, you know, they died.
>
> (Int. #2, p. 11)

However, if too many such referrals are made, the specialist may suspect GP incompetence. He may lose respect for the referring doctor and may assume that the GP is "dumping" cases for economic reasons or for avoidance.

Just as the patient who wishes a second opinion can be seen to "push" his or her lack of confidence and demand for better service "too far", so can the GP who refers too many patients for his own or patient reassurance be seen as making an illegitimate request. It has been suggested that young doctors, such as GP 3, who was not able to convince Patient 3 that there was nothing wrong with her ears, are more likely to err in this direction than experienced GPs, such as 8 and 12, who have developed strategies for dealing with such patients. On the other hand, as GP 16 pointed out, there is very little to stop the experienced GP who wishes to "make money while keeping his hands clean" by

not doing a gynecological exam, but still charging for a visit and referring to a gynecologist who will charge "four times as much" (Int. #1, p. 11). Further, GP 8 explains that referral without a serious attempt to deal with patients' problems is the best way to maximize the number of patients that can be seen in a day and thus the fees that can be collected.

Specialists who were building their practices did not complain about such "dumping", describing it as a lucrative side-effect of the referral system. As Specialist 1 pointed out,

> [Y]ou have to remember that we all make our living by seeing patients...And so I'm always surprised at colleagues who claim to be upset about patients being referred. An inappropriate referral, I suppose, is a modest irritation, but it's also how we all make our living.
> (Int. #1, p. 8)

However, specialists who felt they had a surfeit of clientele tended to complain about "inappropriate" referrals. Specialist 26, for example, claimed that general requests for reassurance are more prevalent in the North. He argued that there wouldn't be a shortage of ENT specialists in this area "if ENT was to stick to ENT and give less reassurance" (p. 6). While he understood, as most specialists do, that a "guy in the boondocks" might need more reassurance, he feels that the "flood" of reassurance cases leads to a much higher

patient load for specialists in the North as opposed to the more populated South. From his perspective, this leads him to practice a kind of medicine for which he was not trained: "...unfortunately, as a surgeon, you have to practice the medical side of medicine...Today I regard them as patients to be reassured...We have to do everything. So I do general ENT" (p. 5).

b. Specialist Awareness of GP Dumping

Just as it is difficult to discriminate the "dishonest" patient from the patient who is overly sensitive to health concerns, so it is difficult to tell an unconscious lack of commitment to patient care or real or imagined lack of competence that might lead a GP to refer too much from a calculated effort to "dump" cases. Balint (1957), based on analysis of referrals reported by GPs, spoke of what he called a "collusion of anonymity" in referral, in which the GP unconsiously avoided the psychosocial aspects of a patient's illness, referring him or her to a multitude of specialists until someone found something specific that could be done for the patient. The GP of Patient 6, for example, suspected deep-seated psychosocial problems of this patient, but, in his admitted

confusion about the case, referred the man to a number of specialists over the years, including an ENT expert and a neurologist, hoping that they might find a physical basis for the "buzzing" that the man reported that he continually heard in his head.

How do specialists distinguish "legitimate" referral for reassurance or assistance from "dumping"? Orthopedic surgeon 17 identified "dumping" as the referral of patients that are so "hopeless" that they can't be operated on: "The GP just [sends] the guy to me because he [can't] do anything either". He and other specialists spoke of keeping track of which GPs tended to consistently send cases like this. GPs often spoke proudly of the reputation that they had attained among specialists for "playing their role" and "not dumping" (e.g. GPs 24, 27). These reputations, like those of patients who can be trusted, appear to be attained through longstanding and sometimes side-by-side relationships with the specialists.

c. Specialist Strategies for Dealing with Dumping

Specialist 16 made a statement that GPs who dump cases "don't give a damn" (p. 18), or, as he later modified it, are too busy to follow up their patients,

and have no idea, therefore, how deep are their patients' problems. He emphasized that the specialist must follow up such problems, because such GPs fail to take the appropriate responsibility for their patients. According to him, GPs refer more now because they are busier, but this won't become an economic crisis because the specialist gets most of his fee on the first visit, so has no real motivation to retain cases.

Orthopedic Surgeon 18 similarly explained that he went through a process of assessing whether the GP is competent to take a case back, or whether he can be trusted: the orthopedic surgeon "makes a judgment call as to whether I think the family doctor should be looking after it" (p. 6). Another specialist who says that he has learned throughout the years that you cannnot always just return patients to the GP and assume they will be looked after is Gastroenterologist 12. His discussion of this issue (p. 5) makes it clear that he ends up seeing such patients more than once because he distrusts GPs and fears medico-legal consequences. His interpretation of the GP not following up such cases is that they are "playing the odds" that the patient will get better, as they do in 90 percent of cases.

Although doctors tended to speak of "dumping" as a problem of individual responsibility, it can be seen that there is no serious disincentive in the system to halt this process once it occurs. If a GP decides to refer for reasons of greed or because s/he is in financial difficulty, this is not a serious inconvenience to the Canadian patient, for whom such extra advice is "free". Neither will the specialist usually complain, since he benefits as well (GP 8, Int. #1, pp. 12-15).

d. "Dredging"

"Dredging" is the term used by GPs to refer to the provision of unnecessary, redundant or multiple, poor quality services by specialists either for economic gain or for reasons of intellectual curiosity.[7] For example, GPs in northwestern Ontario sometimes complained about "irresponsible" specialists who travelled around the north seeing hundreds of cases in a short period of time, presumably for economic gain (e.g. GP 38, Int. #2; GP 27, Int. #1). In the south, GP 21 had encountered a specialist who arranged multiple return visits that eventually made his patients suspicious:

> [W]hen I found out [my patients] had to come back in four weeks and four weeks and four weeks all the time, every time, all the people you refer...And I have quite a number of European ladies, they are not dumb. They come back and you examine them and find nothing and you ask why. And they tell you why, they went three times to [this gynecologist] and [the gynecologist] said, everything is fine, my dear. But if they keep asking you to come back, you get suspicious and think, maybe they aren't telling me everything. Now I'm not saying anything about the competence of [this specialist] as a physician, but...
>
> (Int. #1, p. 5)

Presumably multiple follow-up was being used here for economic gain.

More commonly, however, there were references to a process that might also be classified as "dredging". In this situation, an abnormal finding on a routine exam leads to extensive intervention. Patients 1 and 19, for example, were found to have a low hemoglobin level on a routine exam, which led to a referral to a gastroenterologist for one and a gynecologist on the other. Patient 1, an elderly man with heart trouble, suffered through a series of very invasive and perhaps life-threatening investigations as a result of his referral, and his specialist admitted that his ulcer might have healed on its own without such detailed probing. Patient 19 complained that such referrals were unnecessary and inconvenient[8] but the

attitude of Patient 1 and his wife was more resigned. They explained that these were free services, so that they did not particularly feel at liberty to complain.

It is important to emphasize that not all "dredging" is economically motivated. As GP 25 pointed out, in large cities such as Toronto and in specialties where there is a good supply of practitioners, or in teaching hospitals, cases may be "dredged" in the sense that non-essential procedures are done for teaching purposes or patients are seen for "interest" rather than for the patient's welfare. Sudnow (1971) documented such practices in an American hospital, particularly with dying patients. Fuchs (1986), and more recently Lomas et al. (1988) claim that a large proportion of all medical care is provided in the last year of life.

This issue was raised in connection with Patient 7, who died in hospital. Although the specialist and GP both thought that radiotherapy for this woman's brain tumour would not help, she had already been booked to be assessed at a cancer clinic. Although it was known that she was dying, multiple technical interventions were planned. The immediate reason for her death was that there was bleeding as a result of her biopsy for a brain tumour, which

prevented administering a drug that would have dissolved the clots that were forming in her legs as a result of immobility. She died before the local resident could insert a "Greenfield filter" to stop the clots, mostly for his own education, and before she got the cancer clinic, where additional interventions undoubtedly would have been undertaken.

In outpatient care, specialists often described the intellectual interest they maintained in atypical cases in their specialty, and as Dowie (1983a) has also observed, specialists make their interests known to referring doctors, who may oblige them by sending them such curiosities, even though no one can do anything for the patient. Specialist 31 placed Patient 31 in this category, with her unusual and untreatable skin disorder (p. 5). This patient had been convinced that the Mayo Clinic could do something for her by the intellectual interest that they showed towards this particular disorder (Int. #2, p. 5). Specialist 27 similarly commented that because of Patient 27's rare rheumatological disorder, they were "locked into a situation where not only am I interesting to her, because I've seen these types of people, but she becomes interesting to me" (pp. 3-4). In the same vein, Specialist 34 noted an increase in referral of patients

with a particular type of disorder after he had given a lecture on it to local GPs (pp. 2-3).[9]

e. GP Responses to Specialist "Dredging"

Many senior GPs in this study were outspoken in their criticism about multiple "unnecessary" visits to the specialist. GP 7, for example, commented,

> [I]t's my feeling sometimes that they call them back too many times before they let them go again. And then they still want to see them annually. But to my mind, it's more in their interest than in the patient's.
>
> (Int. #1, p. 4)

He added these multiple visits are mainly a result of "high tech" investigations:

> [I]t takes time to solve the problems. We have the Holter monitor now, we have echocardiograms. I'm picking on cardiology because it's a good example. So it takes time to get all this arranged. So it's quite natural that in a month or six weeks later, when all this information is in, they'd like to see the patient again to give a final word. But if you go back 10 years, it was a cardiogram and that's it. X-ray was done in the same day. So there wasn't that kind of a justification or need or purpose. It's different now.
>
> (Int. #1, p. 4)

Follow-up visits with specialists to go over technical findings in previous visits were arranged for virtually all cases in the urban setting. But GP 24 complained

that this verged on "stealing" of cases. He spoke of one doctor who,

> used to do something that I thought was wrong. He'd say, I'm going to have this patient return in three months or something for follow-up...It was done in such a way that they thought they didn't have to come and see me, and the next thing I knew, he'd end up in the emergency department with a coronary and I'd lost track of what they were doing.
>
> (Int. #1, pp. 42-43)

GPs felt that there was little that they could do about this situation except to boycott specialists who "stole" their cases, but in areas where specialists were in short supply, this strategy was severely limited.

VI. SUMMARY

Focussing on the wider context in which referral takes place, this study revealed that both the patient and professional community could dictate the rationale for the GP seeking advice. The finding that the patient could "negotiate" a referral without the doctor's full awareness is a replication and extension of previous studies (Freidson, 1961; Williams et al., 1960). The finding that referral is a symbolic negotiation of the boundaries of general and

specialized medicine is also a replication of Freidson's work (Freidson, 1975). When these combined pressures on the referring doctor are considered, it can be clearly seen that the referring doctor is not a free agent in the process.

The simplest referral situation involves both a patient seeking advice from a medical expert as well as a consulting doctor seeking advice from another expert, and a comparison of these nested processes reveals that patient and doctor approach referral in different ways. The doctor must determine the limits of his or her competence to deal with the presenting problem, being ready at all times to justify any steps taken to define it, including referral. The patient, without a reputation of competence to protect, may experience procrastination and confusion, and may consult a lay referral network of relatives, friends and paraprofessionals in an attempt to determine whether the problem is one for which the doctor should be "bothered". When the doctor experiences confusion about diagnosis, he or she may go through a similar process of defining the problem by seeking advice from a number of experts, but this type of behaviour, called "first line referral" here, is restricted almost completely to within the professional referral network.

Referring doctors have some awareness of patient agendas when they detect that a patient needs reassurance from a higher authority about a problem. However, in this study it was found that they grossly underestimated the extent of the distrust that patients expressed about their expertise, particularly in the rural area studied, which replicates the findings of the North Carolina referral study (Williams et al., 1961). In particular, they were unaware of the extent to which patients bypassed them to seek care further afield. It was found that experienced doctors had developed strategies for dealing with difficult patients, but that all doctors recognized the inevitability of having to acquiesce to a distrusting patient who insisted on referral. This was institutionalized in a "philosophy" held by doctors, that it was a patient's sacred right to seek a "second opinion". In spite of this philosophy, many doctors and patients alike blamed patients for taxing the system with unnecessary care-seeking because of the "free care" available in Ontario. This one-sided attachment of blame to patients ignores pressures to refer from within the medical community and also avoids considering the legitimacy of what appears to be a

growing failure of confidence in general practice and increasing numbers of sophisticated and questioning young patients.

Pressure from patients was linked by physicians to breakdowns of the referral system in two areas: obstetrics/gynecology and orthopedics. Women were seen as more demanding around pregnancy, and the preference for women to perform gynecological exams was implicated in increased gynecological referral. However, the growing withdrawal of general practitioners from obstetrics and the imperfect functioning of the abortion referral network can also be seen to underlie problems in this particular area. Patients were also condemned by physicians for seeking compensation illegitimately, but it was clear that not all cases of multiple and unsatisfactory referrals were patient-initiated.

In particular, there were found to be pressures to refer certain types of cases that the GP might be able to handle but which require special techniques or equipment only accessible to the specialist, such as fetal monitoring or eye examination machines. Once inside the jurisdiction of the specialist - the hospital or large specialist-dominated outpatient clinic - a process of multiple "tertiary referral"

from one specialist to another might be initiated and referring doctors sometimes complained about losing track of patients in this way. On the other hand, referring doctors themselves were sometimes seen as over-referring patients or "dumping" in order to maximize their incomes or to get rid of difficult patients. Specialists in need of business did not find this a problem, and were willing to take responsibility for such patients. Referring doctors, for their part, were suspicious that some specialists engaged in profit-maximization themselves in a number of ways, including arranging multiple follow-up visits and "dredging" cases with minor or untreatable problems. While these practices, like the case of the patient making an "illegitimate" request, are difficult to detect, physicians became aware of them through longstanding experience with their colleagues. The important point to note in connection with these tendencies is that, in a system of "free care", there is no internal brake. That is, referral for whatever reason does not financially inconvenience the patient, and it is financially and otherwise is of benefit to the doctors involved.

NOTES

1. In classical models of the physician-patient relationship, it was assumed that the two came together as free agents as result of an obligation on the part of patients to seek professional help to maintain their health (Parsons, 1951) or as a result of the amount of threat that the patients perceive to their health (e.g. Kasl & Cobb, 1966). Such models do not see a problematic area in a patient deciding that s/he is ill nor other difficulties around the decision to see the doctor. However, it is well-known that only a small fraction of ill persons actually seek medical help (White, 1973; Mechanic, 1976, Ch. 9). Mechanic and Volkhart (1960) found that the biological presence of disease was not always a good predictor of a person deciding to see the doctor, for example, for trivial or asymptomatic diseases. His introduction of the concept of "illness behaviour" or "the way in which symptoms are perceived, evaluated and acted upon" (p. 87) was a useful way to begin to understand the disjunction between disease and health care service utilization. Perhaps the most popular set of studies in this tradition, done by Zola (1966; 1978) suggest that patients of different ethnic backgrounds not only perceive their illnesses differently but that the "trigger" for the decision to seek the doctor may vary. Some of these triggers included interference with social relationships, including work; sanctioning by others; and a decision to wait a certain period to see if the symptoms resolved themselves.

   Freidson's (1961) conception of the patient as working out his or her conflicting conceptions of illness with the physician was the forerunner of scores of studies on the "mutual exchange" and "negotiated knowledge" that results from these "clinical dances" (e.g.Kleinman et al., 1978). Although a review

of this literature is beyond the scope of this thesis, a good recent review of this current literature can be found in Like & Zyzanski (1986).

2. A very large literature on clinical reasoning documents how this uncertainty is related to diagnostic error (e.g. Garland, 1959; Scheff, 1978), but much less has been written on how physicians cope with this uncertainty. Sociologists have focussed on how medical students develop an attitude of "detached concern" (or in Parson's terms, "affective neutrality") towards patients in their early training to "cope with uncertainty" (Fox, 1957/1969; Lief & Fox, 1963; Becker et al., 1961). More recently, Haas & Shaffir (1982; 1984) have similarly argued that detachment is an "emotional carapace" for the medical student which is acquired as part of the paraphenalia of the role of doctor. How the experienced practitioner copes with uncertainty, however, is an uncharted area. Bosk (1980) suggests several strategies that are used to manage uncertainty, including requests for consultations, although he does not document this process.

3. The fact that Wolfe and Badgley (1973) found lower rates of referral among younger doctors stands in contrast to most clinical studies of referral, that tend to show higher rates of referral among younger doctors. Wolfe and Badgley make the opposite argument of that made here - that younger doctors have an ego-investment in not referring cases that might reveal to consultants their possible botching of the case. It is difficult to reconcile this discrepancy between their findings and the reports made in this study, unless Wolfe and Badgley's younger doctors were actually being more responsible than the older ones by "working up" cases more thoroughly before passing them on, as younger doctors have been found to do (e.g. Dowie, 1983a).

4. One exception to this trend was found in one section of a northwestern Ontario city, where GPs still do the majority of their obstetrics. GP 30 claimed that patients actually trust

certain GPs more than obstetricians in this area.

5. This study was conducted before the legalization of abortion upon demand in Canada.

6. In Chapter 7, it will be argued that this type of streaming is also evident in the referral of back pain and marital counselling, which are other undesirable types of referrals. Patients with stigmatizing problems are avoided by the experienced and prestigious specialists, who have the best control of the type of referral that they will accept.

7. In the literature of referral, reference is occasionally made to a collusion between referring doctor and consultant in which services are provided for so as to maximize the economic gain of the pair. In one version, called "fee-splitting", the GP gets a kickback from the specialist for sending a patient (e.g. Beidleman et al., 1971, p. 47; Robinson, 1973). A number of patients in this study suspected their doctors of fee-splitting, but there was no evidence of this practice in this study. As Schaffer and Holloman (1985) explain, fee-splitting is important to lawyers and other professionals, but is unnecessary in medical referral, since the two doctors can bill the patients for different services rendered. It is particularly unnecessary in a universal health insurance situation, where each doctor in the transaction can be paid. However, a sophisticated version of fee-splitting that was detected in this study was the case of an orthopodic who invited referring doctors to help at surgery in order to make an assistant's fee, a practice also described by Schaffer & Holloman (1985, p. 47). In addition, there were condemnations of the practice of "turning self-referrals into referrals" which Ophthalmologist 11 admitted doing - by calling up a GP for his "number" to put on the insurance form, even though the patient had been self-referred. In such a case, he would collect approximately double the fee of a self-referred patient. GP 38 labelled this strategy, used by a local orthopedic surgeon, as "wrong" (Int. #1, p. 3).

Such practices are presumably more attractive to specialists who need business.

8. Only one patient (#11, whose sister was a GP) complained about the profits that specialists might make from unnecessary referrals. Most, instead, preferred to see the problem as patient-generated demand. As in the case of the GP who initiates a referral unnecessarily, it is unlikely that a patient will protest an unnecessary visit to a specialist.

9. Pediatrician 34, however, pointed out that the specialist can just as easily discourage as encourage certain types of referrals. Referring to his own experience, he commented, "all of a sudden the incidence of umbiliacal hernias being repaired in small children drops because you've seen it and you say, these spontaneously go away...And that gets around, so that you don't see any umbiliacal hernias again" (p. 3).

CHAPTER 6

CHOOSING A COMPETENT DOCTOR

> [Doctors] are just like mechanics and shovel operators and grader operators- you got some good ones, and you got some pretty good ones and you got some that aren't bad, and you got some that aren't worth nuthin'! -Patient 40, Int. #1, p. 11
> (Retired highway construction supervisor)

I. INTRODUCTION

This chapter traces how patients and doctors evaluate the competence of available medical advisors before and during consultation and the consequences of these evaluations. There is a popular assumption that patients have little knowledge of, and therefore must assume, physician competence. However, it is pointed out here that despite the barriers to assessment of competence they face, both patients and their GPs use similar strategies to determine whether consultants can be trusted. Further, patient assessments of, and preferences for, certain consultants are a crucial aspect of the ongoing negotiation of referral. Where

trust in medical consultants breaks down completely, the various routes by which patients continue to seek care are described here. This examination of the consequences of the operation of the generic social process of "trust" yields a model of medical organization that is a "negotiated order" reflecting patient confidence.

1. How Patients and Doctors Choose Consultants: Arguments in the Literature

There is an old clinical maxim, often quoted by doctors in this study, that the referring physician chooses a consultant according to the three A's: ability, accessibility and affability and that the greatest of these is ability. On this point, clinicians and sociologists agree. Freidson and other sociologists and social psychologists (Modrow, 1976; Coleman, Katz & Menzel, 1966; Hummell, Kaupen-Haas & Kaupen, 1970; Dowie, 1983a) have identified the referring doctor's assessment of the consultant's competence as the key factor in choice of consultant and thus in patterns of referral that emerge in the medical community. In Freidson's account of this process, described in Chapter 2, GPs "boycott"

consultants of whom they disapprove, with the consequence that they become part of a circle that accepts their standards of practice. However, the rejected doctors become part of other circles, since doctors tend to keep complaints about colleagues to themselves, and some doctors are in a better position than others to observe and assess competence.

In contrast to the acknowledgement that physicians are able, however imperfectly, to assess the competence of their advisors, patients are generally assumed to be incapable of judging their doctors' abilities (Ben-Sira, 1976; Korsch, 1968). Freidson (1970b, pp. 189-192), for example, argues that patients, generally trusting of their medical advisors, make the assumption of competence and choose their doctors on the basis of ethnicity, convenience and manner. However, there is evidence that patients are acutely sensitive to any information about the competence of their consultants (e.g. Stimson & Webb, 1975; Skipper & Leonard, 1965). Further, the one study in the literature that actually investigated whether patients could evaluate the competence of their medical advisors revealed that they were quite accurate (Kisch & Reeder, 1969). The possibility that patient

assessments might actually influence referral choices has not been investigated.

Further, sociologists have occasionally discussed the "trust" that patients place in their physicians and the consequences of breaking that trust (e.g. Millman, 1977; Hayes-Bautista, 1976), but the relationship between "trust" and assessments of competence has not received detailed attention. Trust is theoretically understood as a state in which persons "no longer need or want any further evidence or rational reasons for their confidence in the objects of trust" (Lewis & Weigert, 1985, p. 970). In long-standing relationships, Berger and Luckmann (1966/1981) speak of social actors displaying an "attitude of everyday life", or "taken for grantedness", such that they do not question what is going on. Garfinkel has shown that "trusting" social actors will actively discount various bits of negative evidence "for all practical purposes" (1967), but this theoretical work has not been systematically applied to the scenario of the person seeking medical advice.

2. A More Comprehensive View of Consultant Choice

In this thesis, ways in which judgements of competence by both referring doctor and patient affect the process of referral are considered. This is a break from the literature, which concentrates only on doctor-doctor assessments of competence or on patient-doctor interactions, without looking at the wider context and consequences of these assessments.

When the analogy of the consulting patient and consulting doctor was examined for similarities and discrepancies in how consultants were chosen, it was found that both use a combination of direct and indirect evidence to justify the trust that they wish to place or that they have already placed in their medical advisors. Participants sometimes spoke of "liking" the person in whom they had placed their trust or identified him or her as having some desirable personality traits. Alternatively, they spoke of "disliking" consultants whom they did not trust, or of them having negative personality traits. However, in their discussion of trusting the person, they made clear that this was based on the evidence of their past interaction with them or on a favourable or negative assessment by someone whose judgement they respected.

First-hand assessments were preferred, but indirect evidence such as recommendations of others were taken into account. In the face of negative or mixed evidence about the competence of an advisor, the seeker of advice might avoid the consultant altogether or take this into consideration in keeping the interaction going and in initiating another consultation. When there was evidence that a relationship was not proceeding smoothly or a there was a disagreement between referring doctor and patient, participants displayed a hyper-vigilant attitude that may be called "guarded trust". In the ongoing process of evaluating the consultant's competence, a point was sometimes reached by patients or doctors at which vigilance was relaxed, and "trust" or an "attitude of everyday life" about the consultant was attained. At this point, participants became highly resistent to considering any negative evidence about the competence of the trusted person. Both doctors and patients would paradoxically point to information suggesting incompetence in the same breath that they declared that they trusted the competence of their advisors! However, even in longstanding relationships, trust could not be maintained in the face of mounting or unequivocal evidence of incompetence, and participants

sometimes reported the emotional experience that accompanied their breakdown of trust and ensuing termination of the relationship.

When the combined influences on the referring doctor of patients, consultants and medical and non-medical organizations were taken into account, the processual organization of medicine could be seen to rest on the "coalitions" of trust formed among participants. Specifically, in a situation where patients have confidence in their GPs, "under-referral" may result, as among older patients with longstanding relationships with their GPs. Alternatively, in rural areas where patients are distrustful of local services, and where there is a high turnover of GPs, they may pressure for referral.[1] If blocked, they may circumvent the referral system and go directly to specialists whom they feel can be trusted, who reinforce this pattern by accepting patients "off the street". Urban patients can also circumvent the GP, even in a "referral-only" situation as exists in many Ontario cities, by going directly to the emergency department of a hospital. These circumventions of the referral system are of special interest, because they reveal the relationship between "trust", breakdowns of trust, and the

utilization of generalist and specialist medical services.

II. CHOOSING A COMPETENT SPECIALIST: DIRECT METHODS

1. First-hand Assessment

a. Trust, "Guarded" Trust and "Divorce"

Doctors Evaluating Doctors. Experienced GPs volunteered that they referred patients as much as possible to consultants that they knew personally from working side-by-side with them. GP 24, for example, said, "I worked at Clinic X and was there for 15 months, and I've always, from the time I started in northwestern Ontario, referred patients to them" (Int. #1, p. 3). GP 5 explained that he doesn't refer much to the university hospital in town because "I just don't know all the doctors [there] and that's why I don't use them that often...You should refer to people that you see every day" (p. 13). He can't even imagine his nurse, who makes most of the appointments for his referrals, calling up someone she doesn't know (p. 18). Cardiologist 8 also says "you usually refer to people you know rather than don't know (Int. #1, p. 10).

Why the preference for consultants that you know? GP 30 explains that it is based on the importance

of a personal assessment - if a consultant has been seen to perform satisfactorily first-hand, s/he is easier to trust. Commenting on the surgeons to whom he prefers to refer, he says,

> [I]t doesn't worry me that I'm not there to see what the surgeon is doing all the time, and get to eyeball him and know what he's like, because I spent four years doing anesthetics with all those guys. I know them so well.
> (Int. #1, p. 30)

GP 32 has a "profile" of the competence of his local surgeon - he will try "most things" but is not as good in vaginal repairs or orthopedic surgery, which has to be referred out (Int. #1, p. 1). For cases that are "very difficult", the GP refers 800 miles away to the Mayo Clinic.[2] GP 24 has a similar profile of local internists, about whom he says, "I know pretty well what they can do" (Int. #1). Optometrist 33, who probably refers more patients to ophthalmologists than local GPs, also had knowledge of the specific competencies of available specialists; for example, he judged that for "certain things, like cataract surgery...generally a better job is done in Winnipeg than in Thunder Bay" (p. 3). GP 38, on the other hand, thought that the services in Winnipeg in certain areas such as ophthalmology had deteriorated over the years, while those in Thunder Bay had improved (Int. #1, p.

1). The fact that the distribution of competence changes all the time was emphasized by Pediatrician 34, who said that GPs in one town he visits prefer to refer infants for procedures that they will do without hesitation on older children. "And that changes all the time in the community", he added, "[d]epending on who they have" (p. 6).

For consultants that they knew personally and whose competence they trusted, GPs were willing to brush aside the significance of negative observations. For example, agreeing that Ophthalmologist 33 was "abrupt" and "busy", GP 32 was willing to excuse this behaviour because it would be "true of anybody...[i]f you've got too much to do. You just get overworked, particularly at the end of the day" (Int. #2, p. 7). GP 19 similarly said that she still refers to an "excellent back surgeon" who was nasty to her receptionist, in claiming that she, not he, should put a cast on a patient one Friday evening (Int. #1, p. 5). Her excuse for this man was that his nasty outburst was "out of character" and "he'd had a lot that week". GP 12 still refers to Respirologist 2 whose technical skill is worth taking a chance that he might "put off" a patient (Int. #2, p. 12) and to Specialist 16, even though patients have to be <u>warned</u> that he will put them

off (p. 15). And sometimes GPs remain with specialists when there is only rumour of a problem. GP 6, for example, said that "some of my colleagues think that [Specialist 6] is a little cold with these people. That he doesn't have an outgoing personality. I don't know how he acts actually" (p. 13).

However, when referring doctors begin to question the competence of even a longstanding advisor, "divorce" may ultimately result. GP 14, for example, claims that she prefers to switch consultants rather than "raking them over the coals" for what they haven't done. In this study, when she realized that the obstetrician's feedback on Patients 14 and 15 was negligible, and that this obstetrician had failed her in this way a number of times recently, she appeared perturbed and said only that she would have to talk to him if things got worse. She then admitted that she'd had to call him around other cases recently (Int. #2, pp. 9-10) and was starting to worry about referrals to him, despite their longstanding relationship. Like a few patients in this study, she was in a hyper-vigilant state of "guarded trust" with respect to this consultant. The fact that trust is not established "for all time" is also shown by GP 12's statement that he now refers less and less to a man who was once his

"idol", presumably because of reassessment of his ability (Int. 2, p. 15).

Patients Evaluating Doctors. Like their physicians, patients emphasized that they preferred to consult a doctor that they knew personally.[3] As Patient 31 remarked,

> I don't have a lot of faith in a lot of doctors. Unless I know them. And it's too bad that I don't get a chance to know them, because I'm usually out the door, saying, well, I'm going to see someone I know.
>
> (Int. #1, p. 14)

Patient 29, who became ill thousands of miles from home, similarly rejected the suggestion of doctors whom he did not know that a lung biopsy should be done there. The GP in the distant emergency department had assured him that a surgeon who wished to do the procedure was the "best man that I know of in the business" and "you'll get the best care that anybody possibly could get" but the patient's response was, "you're not just going to be throwin' me carcass open like that and trampin' around inside! If I'm able to get back home, that's where I'm going! " (Int. #1, p. 2).

After many years with a GP, the patient, like a GP that has worked alongside a surgeon, has had a

chance to observe the outcome of numerous interventions. Patient 18, for example, who had gone to the same GP for 35 years, had a great deal of respect for the doctor's ability, particularly as a diagnostician. This GP has a "natural instinct" which is 99 per cent correct, according to this patient and his wife. Thus the patient emphasizes, "I wouldn't go anywhere else" (p. 3). The GP detected a heart murmur that led to the finding of artery blockage and a triple-bypass operation that this patient sees as having saved his life (pp. 9, 11). The GP, contradicting other doctors, also correctly diagnosed that the patient's wife might have a ruptured appendix after her hysterectomy (p. 20). The couple trust their GP to refer if he's not sure (p. 4) and to make a special effort if they are really in distress (p. 5). In addition to admiration for their GP's abilities, they also respect his dedication to his work. Finally, since the wife is a nurse, she's come to appreciate how "incredibly stupid" some young physicians are by way of comparison (p. 21).

Patient 18 and his wife, like a number of other patients, have observed specific irregularities over the years, but insist that they still trust their doctors over all. For example, the orthopedic surgeon

who replaced the patient's hip came highly recommended by the GP - he'd "worked with him in the hospital" and "thought he was a good man" (p. 2). And although in the first operation he made one leg one inch longer than the other and the glue eventually came apart in the hip, the patient still believes that the surgeon did a good job on it (pp. 2-3). He admires this surgeon for both skill and manner. The patient describes the surgeon as "thorough" and "pleasant" (p. 3). The wife excuses the difference in leg length as a common problem, and the patient excuses the surgeon for the glue problem (p. 25). They don't even blame the surgeon for leaving a pin in after the operation, because, as the patient says, "you take what you get". The wife admits to being "horrified" but too exhausted to complain. And now that everything has turned out well, they seem willing to forgive and forget. The wife also feels that a surgeon "mucked up her rear end a bit" (p. 22), but she's willing to say that perhaps he's a good surgeon (p. 23). They have evidence of lack of skill, but since things have turned out well, they do not let this enter into their overall positive evaluation of the physicians and surgeons.

On the other hand, a few patients who had observed these irregularities but had not yet reached

the point of "divorce", indicated that they maintained a vigilant attitude towards a practitioner of whom they were suspicious but who had performed well in the past. Patients 9 and 17 both gave their GPs the "benefit of the doubt" in insisting that they trust them over the long run, despite evidence of lapses. Patient 17, for example, described his GP's failure to diagnose an Achilles tendon problem and to contact a rheumatologist around the inappropriateness of medication that had been prescribed. However, the patient failed to criticize the GP for this. Patient 9 was also concerned about his GP's failure to diagnose his wife's tumour and his own heart problems for "five years". Despite these irregularities, he claims he trusts him "until such time as he does something that makes me change my mind" (Int. #1, p. 6). The trust that he has in his physician can be called "guarded", since the patient seems to be constantly wary, double-checking his physician's advice with his friends.

Consistent or unequivocal evidence of failure of treatment, on the other hand, leads to fundamental distrust, as the case of Patient 39 illustrates. Before her GP misdiagnosed her condition, which almost resulted in her death, the patient was already suspicious, since she had noticed that he was a less

popular doctor than his wife. However, although she had observed that he would "sometimes be standing around while she was seeing patients" and that she might "push him down the hall because he was in the way" (Int. #1, p. 10), she still felt at this point that "[t]hey're both good doctors" (p. 11). In her account of events, during her late pregnancy, she continued to feel abdominal pain which he diagnosed as a kidney infection, hospitalized her briefly, and then sent her home "with Tylenol" (Int. #2, p. 1). After being rushed to a neighbouring hospital in an acute crisis, where a Caesarian was done (since the obstetrician thought her placenta was separating), it was found that, in her words, "most of my innards were gangrenous" - she'd had a ruptured appendix for some time. A few days after this crisis, she called the surgeon who intervened a "magician", but said that she did not want to see her GP again, since the whole incident was "his fault" (p. 6). Admitting that this was a very difficult diagnosis, she maintained that she had complained to him "about it for a week, and every time I went in there, it was either a kidney infection or nothing, but never what I told him it was" (p. 7). Summarizing her feelings, she said, "[i]t's hard for me to accept [my GP] anymore. You know? I have to think about it" (p. 7). About a

month later, she had started to document all sorts of irregularities that supported her view that the GP could not be trusted. For example, she reported that when she had visited the surgeon after being discharged from hospital, "he wondered about some of the treatment that [the GP] had prescribed" (Int. #3, p. 1). Both the patient and her relatives checked the GP's advice by calling the surgeon (p. 2). Further, they began to question the GP's treatment of the patient's father-in-law (p. 4), whose wife began to pressure the GP for a referral to Winnipeg, presumably to see a more competent doctor (p. 5). The mother-in-law herself is under treatment with this GP, but the patient reports that she's "lost a lot of faith in him" (p. 5). The patient's final solution to the problem, since there was no other doctor within 50 miles, was to trust him to pronounce on "swollen glands" or other minor problems, but to be prepared to seek help farther away for more serious problems: "I know now that if I ever feel as bad as I do, that I will <u>never</u> go back to [my GP]" (p. 10).

b. The Limits of Direct Assessment

Doctors Evaluating Doctors. As Freidson and Rhea have pointed out (1965), because certain specialists practice in the hospital rather than in their offices (and are thus more visible), and because certain types of practices involve selective referrals to certain types of specialists, some referring doctors are in a better position than others to evaluate the work of a particular specialty. For example, Ophthalmologist 38 explained that the treatment being given to Patient 38 by a local optometrist was in conflict with that which would be prescribed by an ophthalmologist, a fact that was not known to the referring GP. In commenting on this problem, the ophthalmologist remarked that,

> It's a difficult situation for the general practitioner because they have a fairly limited knowledge of eyes. And certainly the optometrists have much better training than a general practitioner in dealing with these situations. So the physician may not really be in a position where they can really distinguish between appropriate and inappropriate therapy.
>
> (Int.#1, p. 7)

Why don't GPs know much about eye treatment? The ophthalmologist speculates that they are seldom involved in eye surgery: "[i]t's a small area you're working in so you don't need someone to hold the

retractor like you do when you're taking out a gall bag" (p. 10). Further, due to the "lack of equipment in their office, it's very easy for them to say, I'm going to send you off to the ophthalmologist", without being in a position to make an informed choice.

In addition to these constraints on direct assessment of competence, it was also found in this study that opportunities for first-hand evaluation were related to the referring doctor's career and geographical location. Specifically, the ability to observe a consultant first-hand were extremely limited in northwestern Ontario, and, because of a shortage of specialists, a total "boycott" was sometimes impractical. In the city, family medicine residents who have just come from a hospital rotation and are working in the same hospital system are in the best position to make first-hand judgements of who is competent, since they have just worked with a range of specialists. GP 3, for example, explained that she referred Patient 3 to a specialist who is a "gentleman" and "very good" (Int. #1, p. 3). She says she learned to like him while working with him "in the hospital on the ward":

> [T]hrough the residency, we're exposed to a lot of consultants in the hospital. And you get to know what they're like. If they piss you off, no matter what it is that they do - if they're jerks, regardless of whether

> they're good or not... you tend not to refer to them. Because if they're so hard to deal with...why volunteer for what might be a bad time when you know you can go to somebody who you feel is as good who's not going to give you a hard time?
>
> (Int. #1, p. 7)

GP 19, who interned seven years previously at the same hospital, explained that she learned to avoid a neurologist there when he took her word without examining a patient, adding, "I don't think he should've done that" (Int. #1, p. 6). She also learned that a second neurologist in this hospital can be "dangerous" because she has observed him "overworked" and overtired. In this case, the way a consultant was observed first-hand to run his practice, affected his desirability as a consultant. These "peer review" aspects of residency programs have often been identified in the literature (e.g. Bomaslaski et al., 1983).

In contrast to a referring doctor who has worked side-by-side with a group of consultants, such as family practice residents and many GPs in northwestern Ontario, a GP who "parachutes" into a new area with no first-hand knowledge of who is available finds it almost impossible to very difficult to refer. This is best illustrated by Ophthalmologist 38, who volunteered for a few days' service on an eye van that

travels to small towns in northwestern Ontario.[4] A resident of southern Ontario, the young ophthalmologist was at a loss to make referrals to Winnipeg, where he had not met nor even heard of the local ophthalmologists. Patient 37 complained that another young ophthalmologist on the eye van had referred her to someone in Toronto, almost 2000 kilometres away, since these were the only ophthalmologists that he knew personally. She finally got a referral from her pediatrician to an ophthalmologist in Winnipeg, which was only two hours' drive away.

GP 25 faced a similar problem in opening a practice in a small northwestern Ontario town. He reported that he ran into a great deal of difficulty picking consultants' names out of his predecessor's charts, which underlines the point that it is preferable to know a consultant before assuming competence and referring patients. After six months' of practice, he was beginning to identify the "good" and "bad" consultants by trial and error. Specialist 25, whom he had never met, he assessed as "very sharp, quick, professional" based on telephone conversations with him (Int. #2, p. 2). Specialist 26 he had met and liked. However, most of his trust was still in the people that he knew in southern Ontario, to whom he

persisted in referring. These southern Ontario specialists had given him the names of specialists in Sault Ste. Marie - closer, but still several hundred kilometres away for his patients.

GP 25's situation of not knowing local specialists was compounded by hundreds of kilometres' distance which made them difficult to observe first hand. One way that northern GPs try to get acquainted with remote specialists is by "going to medical meetings", for example, in Toronto, where they can meet them in person. Other northwestern Ontario practices, such as that of GP 34, have partially solved the problem by having specialists from the city visit regularly and see patients with the GP. But there is a problem of not having first-hand knowledge of consultants even if the GP has practiced in another hospital in the same city. As GP 1 explained,

> I am at a slight disadvantage because [I haven't trained here]. So a lot of the [consultants] I've picked up from finding other people sending to them and initially sending new patients to them. What happens to a lot of people going through, if they're working in the same place that they trained... they're aware of what various specialists do and they get a sense of them...but that doesn't apply when you go out of an area...You [have to] get started all over again.
>
> (Int. #1, p.1)

One specialist who knew that personal evaluation is a good advertisement for a consultant's services says that he has asked new GPs to be his surgical assistants, since this is the best way "for them to see the work I do". This orthopodic surgeon claims that he doesn't do this to attract referrals, although this has been a side-effect (Orthopedic Surgeon 18, pp. 4-5). Cardiac Surgeon 4 thought that the importance of one's "reputation", however, was more important than this personal evaluation for large centres like Toronto and Montreal.

The situation of GPs who were several years away from having observed specialists during internship illustrates why this might be so. For many reasons that will be reviewed in Chapter 8, GPs in the urban setting no longer spend as much time in the hospital as in previous years. This means that they are less likely to have side-by-side contacts with surgeons. Some older GPs still make room for scrubbing in despite the inconvenience (e.g. GPs 8 and 16). But most others, including GP 14, hardly ever see consultants at the hospital any more. What this means is that she cannot know these consultants first-hand like some of the older GPs who have assisted them. All she can do is judge the competence of these people <u>second hand</u> by

seeing that they have a good reputation and no complaints. However, this is a less accurate method of referral; this GP, rarely going to the hospital, will never be in a position to redress it, since she will never see the surgeons first-hand. Neither is she the only one in this position, since many GPs stated that they had never met a particular consultant to whom they referred. GP 10, for example, said that he might be passing Dermatologist 10 in the hallway, but wouldn't know it, because he had never met him.

This is a significant observation in view of Freidson and Rhea's (1965) arguments concerning networks of mutually exclusive referral circles. Referring doctors who are not in a position to assess the competence of their consultants first-hand will not necessarily hear any negative reports about their performance. As the trend towards exclusion of GPs from the hospitals continues, it might be expected that more and more GPs will be unable to assist in the "policing" of the profession, signalling a steady strengthening of the "professional dominance" that Freidson has condemned (1970b). In fact, it may be that another reason why doctors hesitate to criticize other doctors - in addition to Freidson's suggestion that they would like the same immunity for themselves - is that they no

longer have much of a chance to see the specialist performing and so are not as confident in their criticism as are patients and students, who do.

In spite of these limitations, was there any evidence of Freidson and Rhea's "boycott" and mutually exclusive "circles" of competence? As in Freidson's study, there were cases of specialists whom some GPs and their nurses "in the know" expressed qualms about, but which other GPs used freely in referral. GP 14, for example, did not appear to be aware of some negative rumours circulating in the hospital about the obstetrician to whom she referred her patients, possibly because she never visited the hospital. Implying that he had qualms about the competence of a particular specialist, GP 12 said that he only cautiously refers "uncomplicated cases" to the man (Int. #2, p. 12). Orthopod 18, however, had no concerns about him and referred all his general internal medicine cases to him. GP 7 also referred Patient 7 to a neurologist about whom GP 16 had nothing good to say. And GP 12 referred Patient 12 to a gastroenterologist that General Surgeon 20 suggested should be avoided except for simple cases.[5]

Patients Evaluating Doctors. A striking similarity between doctors' assessments of doctors and patients' assessments of doctors is that some patients, like some doctors, are in a better position to evaluate the work of their medical advisors than others. Seven of the patients in this study or their wives were health professionals, and, although this is not generally recognized in the literature, knowledgable health professionals form a substantial proportion of the work force and the patient population. Nurses are in a particularly good position to observe performance, and Beidelman et al. (1971) even suggest that referring doctors should evaluate new consultants by "checking with an experienced nurse for a line on hospital performance" (p. 21). Patient 35, a native woman who was a nurse's aide in a local hospital avoided the hospital in which she had worked since she had "got more satisfaction" in another hospital in town (Int. #1, pp. 6,9). She commented that she liked her cardiologist because "I felt that he knew what he was doing" (Int. #1, p. 3). Patient 30, an X-ray technician supervisor, also avoided the hospital in which she had worked because of her first-hand experience and lack of confidence in the services. She reported that she had read her own mammogram and concluded that she had a

breast lump, although the local surgeon, who had not seen it, assured her that there was no problem. This prompted her to insist on a referral to Toronto, several hundred miles away, since, as she remarked, "I have to go somewhere where I have confidence" (Int. #1, p. 2). Patients' relatives who were health professionals also influenced their assessments of their physicians, as with Patient 36, whose sister, a nurse, advised her to seek a second opinion about her gastrointestinal problem when the gastroenterologist she saw prescribed valium, which the nurse felt was an inappropriate way to approach the problem (Int. #1, p. 1).

It is the converse of this, the inability of patients to assess their doctors, that has been stressed in the literature, while only Freidson has emphasized the similar inability of some doctors to assess certain specialties. Patients are hampered in their direct assessments of doctors in that they do not observe them with other patients. However, they are sometimes in a better position than their GPs to observe consultant performance, since the procedures are performed on them.

2. Assessment by Trial and Error: Indices of Competence

When first-hand assessment of a specialist is not possible and the words of a trusted advisor are not available - and this is even relevant for old-timers where a new specialist or a new kind of treatment comes into practice - the referring doctor sends three or four "test cases" through and forms an opinion based on the results. This is the beginning of the process that may flower into the trusting relationships or "divorces" described above. As Beidleman et al. (1971) describe this process:

> In the beginning, it's like courting. You check out each man's credentials and then it's trial and error. If the relationship goes well and you and your patients are satisfied, you continue to depend on the consultant. If you've dated the wrong consultant, you look the field over again. (p. 22)

Although most patients did not go through the trial-and-error sequence in such a purposeful way as their referring doctors, for doctors with whom they did not have longstanding relationships (typically the specialist to whom they'd been referred), they were alert to evidence about competence.

In view of the limits on direct assessment of consultant skill faced by referring doctors and

patients alike, but the fundamental importance of a positive assessment for the establishment of trust, how then were consultants typically evaluated? When referring doctors and patients reported that they went through a trial-and-error process of determining whether a consultant could be trusted, what indices of competence did they use?

a. Evidence of Technical Skill

In the first place, both doctors and patients assessed performance of any technical procedure that they happened to see first-hand. The fact that most patients in this study did not have medical training did not deter them from making evaluative judgements of their doctors. Any time that patients had the opportunity to observe such procedures, they drew conclusions based on their observations. For example, the specialist who did an angiogram on Patient 16 directly demonstrated his competence to the patient by making a "very little cut" (p. 16). By way of contrast, a former GP demonstrated his incompetence to this man by not being able to lance a boil and by being rude:

> I had a cyst under my arm...and I went down there and he said the best thing

> to do was just to lance it, so...I really don't know what he did, but he lanced it and it was really sore. Like worse than it was. And it didn't clear up. But that bothered me for the longest time. He sort of came across to me like a butcher...I didn't have a good feeling at all...[T]wo years later I had a sty on my eye...So I called him...so he says, well, I'm in the hospital, why don't you come down and see me? So I went down there, and he seemed to be miserable at the time. He came down, he took one look at me and said, you came down here for a bloody sty! So he said, don't bother me again like that! So I said, I won't even bother seeing you again at all. I was furious!
>
> (Int. #1, p. 9)

Sometimes the GP would observe the consultant's performance in hospital by visiting the patient. GP 12, for example, said that he now avoids gastroenterologists at a city hospital because they let one of his patients bleed for a week without doing anything (Int. #1, p. 13).

b. Adequacy of Communication

When a referring doctor is checking out a new consultant with whom s/he has had no direct communication, s/he checks the feedback from the patient and looks at the adequacy of the note that the consultant sends back (GP 16, Int. #2, pp. 9-10). GP 1, for example, was originally given the name of

Specialist 1 by a colleague. Then he sent a patient to him and got a favourable impression. He said there was evidence that the specialist,

> spent a long time explaining the risks to [the patient of ulcerative proctitis] and what he was going to do. And the patient came back very well informed about that. You know, much more informed than a lot of other patients than I've sent to other physicians...[H]e puts people at ease, and I think he explains things to people.
>
> (Int. #1, p. 9)

This GP also described testing a cardiologist this way: "I just sent a couple of people and I found out what his judgement was like" (Int. #2, p. 8). But he described a trial-and-error sequence with a negative outcome like this:

> A certain orthopedic surgeon who shall remain nameless - I had a patient who had an unusual sciatica. We'd gone over her several times and...I thought...she might have a tumour - and without seeing her, he admitted her...and she sat for a week and nothing much was decided. When he finally came to see her, she was kicked out in 24 hours. The pain really didn't change and there was never really much communication. I tried to get in touch with him once or twice and he really wasn't very communicative. And there really wasn't a good "feeling". He seemed pretty disinterested. And his resident wasn't much help either. I was still a resident and he would say, speak to my resident, don't speak to me.
>
> (Int. #2, p. 9)

After talking to his supervisor, the GP agreed that he wouldn't send any more patients to this consultant.

Without direct communication with the consultant and without detailed feedback from the patient, the consultant's letter becomes an important source of information with which to assess competence.[6] GP 12 commented that consultants know that their abilities are being assessed in these letters and that this affects what they will write. For example, the GP did not feel that any of the specialists involved were able to find out what was wrong with his Patients 12 and 13, but they did not say so. Instead, they attempted to "cloak themselves in competence" in verbose letters to him. "I think they're afraid if they say [I don't know] too often I won't refer to them", he added (Int. #2, p. 7). He claims, however, that they are wrong about this because he values them being genuine and honest. In fact, although he has no problems with the <u>particular</u> rheumatologist to whom he referred Patient 13 (with whom he has a longstanding relationship), he has a general problem with rheumatological reports: "I've been very disturbed with them because they've been less helpful lately", he says (Int. #2, p. 4). Some rheumatologists, he believes, will not admit that they don't know and will "snow you

with verbiage", thinking you can't see through it, or may even blame you for sending them the case. And what you are left with, he concludes, is that they haven't helped you except that you are left with the reassurance that even an expert would not have done any more in a particular case.

c. Outcome

Both patients and doctors linked favourable assessments with evidence that the treatment that a consultant prescribed was effective. Patient 13's esteem for her rheumatologist, for example, was based on the fact that he gave her medication that works (Int. #2, p. 1). Patients 2 and 12 also gave their specialists credit for prescribing medicine for them that worked. Patient 36, who favorably assessed Gynecologist 34, noted that the medication he gave her "is working for that problem...So that problem was solved, which I was very pleased about" (Int. #1, p. 10-11). Her surgeon, similarly, had promised to do a gastroscopy without causing her any pain, and she now trusts him because he "didn't let me down" (p. 12). Subsequently, when he decided to operate on her son, she had commented, "he's in your hands and we trust

your judgement" and the successful operation, for her, "turned out to be a very worthwhile experience" (p. 17). Now she feels that "if anyone's going to solve my problems, he's the one to solve them. That's how confident I am in him" (p. 20). Patients 14 and 34 similarly base their favourable assessments of their obstetricians on successful deliveries of healthy babies.

GP 12 said that he has learned to respect the skills of the respirologist he now refers to in the same way. This is a relatively new specialty for the treatment of patients who used to die in great pain and now the GP is comforted by having a consultant who gives them "great care", even being able to treat someone who is asthmatic and has heart problems (Int. #2, p. 12). GP 7, on the other hand, reports avoiding certain cardiologists who, he has determined, prescribe too many drugs for his patients (Int. #1, pp. 4-5). Dispensing medicine "for every little sniffle" also prompted Patients 2 and 18 to leave former GPs whom they thought of as "pill pushers". And Patient 30 left a GP after 20 years because she felt that he was "overdrugging" her mother (Int. #1, p. 2).

Doctors sometimes drew different conclusions than their patients about skill from the same outcome.

For example, in the case of Patient 39, in which the patient had decided that the GP was incompetent because he had misdiagnosed a gangrenous appendix, the obstetrician involved pointed out that "we got a live mother and a live baby out of it" - the ultimate criterion of success. "Where a lot of patients make a mistake", he remarked, "is that [they don't see that the doctor] acted correctly for the diagnosis that he had made" (p. 4). The surgeon also supported the GP, arguing that if appendicitis had been suspected and labour had been stimulated by an operation, the baby might have been endangered. In such a situation, "you appear to look wrong anyways", he said (p. 1). "Competence is a relative thing", he added later in the interview (p. 9).

d. Thoroughness

Where the doctor and/or the patient have not had the chance to observe a procedure first-hand, where they could not assess the skill demonstrated in the procedure, or where outcome was uncertain, both used "time spent by the doctor" and "thoroughness" as proxies for skill. Conversely, the "revolving door" treatment was universally condemned. Patient 19, for

example, was reassured by the knowledge that her GP is "very thorough" and that "if she has any qualms about anything, she'll refer you to a specialist" (Int. #1, p. 6). Here, "thoroughness" is evidence of her competence in caring for the patient. The patient's referral to a gynecologist, for example, was initiated when, as part of routine blood tests for her thyroid condition, a low hemoglobin level was detected. This prompted the GP to call the patient and ask her about heavy bleeding during her menstrual periods and the decision to refer her to a gynecologist for advice about them. The GP was also comprehensive enough in her investigations to be able to diagnose the patient's most serious problem, her thyroid condition (Int. #1, p. 6).

Patients 27 and 28, who have a close, trusting relationship with their "old-style physician" in northwestern Ontario, also spoke with warmth about the time and effort that he will spend with them. He is seen as a family friend who "talks about everything under the sun" when they go to him. Patient 28 and his wife see him as a holdover from a "Golden Age" of practitioners when doctors would stop by just to play with the children. Like Patient 27, they contrast his approach with other doctors in the town and do not know

what they will do when he dies. Patient 27's trust in this man is deepened by having seen other doctors when he is ill: "they don't tend to stay here long", she complains, and so it hardly seems worthwhile to see them. When GP 27 retires, she knows she will be faced with a problem: "[T]hen I will be seeking another doctor. This will be the hard part" she says, "Do I feel that I'm going to have the same trust and closeness? Well, this I don't know" (p. 9). She denies that she has been influenced by what other people have said about the other doctors, emphasizing "I go and see for myself" (p. 9). Her criterion is, "if he's got the time" to peruse the chart, she'll see him. "These ones that leaf through it and talk to me, I have no time for this person. Because he has no time for me" (p. 9).

The complaint about being given too little time, or the "revolving door" treatment, was a prominent reason for inferring the incompetence of the practitioner by referring doctors as well as patients. GP 19, for example, said that she no longer referred patients to a neurologist whose "examinations are very cursory" (Int. #1, p. 6). On the other hand, in explaining why she referred Patient 20 to General Surgeon 20 for investigation of a possible hernia, she commented, "he's a lovely man, doesn't rush the

patient, he's warm, his examination is gentle and that's important. Orthopods are so rough and there's no need for it" (p. 7).

Patient 3 said that she didn't like her family practice resident because she was not thorough enough. For example, she didn't take the wax out of the woman's ear and didn't check for cancer at every regular appointment (Int. #2, p. 9). Patient 33 was similarly critical of a GP whom she acknowledged was the "most popular in town", but who failed to visit her after her first day in hospital (Int. #1, p. 8).

Although Patients 2 and 4 reported leaving GPs who they felt were running "revolving door" practices, this was a more common complaint against specialists who saw the patient for very short office visits. Patient 4 and his wife, for example, used the fact that the neurologist spent a very short time with them as a measure of his abilities. This neurologist in fact claimed that he could see immediately that the man had Parkinson's disease and did not need a long visit, but the patient didn't know this and wondered whether he had done a thorough enough job. The specialist recognized that this was a problem and agreed that a physician sometimes has to spend a little more time with the patient just to make them feel that they "got

their money's worth" (p. 6). Patient 31 similarly assumed that since the dermatologist spent only "two minutes in and two minutes out" with her (Int. #2, p. 1) that he had not done a good job. Her GP pointed out that she "has come to appreciate our approach here [where] our average contact time is triple most office visits", which made the dermatologist look brusque by comparison (Int. #2, p. 8).

Patient 28 felt the same way about both the neurologist and anesthesiologist that he saw. He and his wife complained about getting the "brush-off" after driving over 500 miles to Winnipeg. No tests were done as they had expected, but the patient was briefly examined and asked to come back in six months. Seeing someone for a few minutes after a nine-hour drive with an overnight stay, they felt, was a travesty. As a result, the man and his wife don't feel too anxious about seeking out another specialist, since they have no confidence that anything will come of it.

Similarly, Patient 19, who persisted in seeing her thyroid specialist, distrusted his competence when "you were in and out like a flash" from his office (Int. #1, p. 11). Her feeling about him was that "[h]e skims the surface. Any contact or any feeling was through the girls. And you trusted them more than you

trusted him...[H]e just delegated" (p. 11). In striking contrast to Specialist 16, she found the office of Gynecologist 19 to be personal and "like walking into a kitchen" (Int. #2, p. 1) with "such a warm, friendly feeling". And the physician's manner matched this: she was "really gentle, very caring, very considerate and very slow-moving...she didn't rush anybody...she gave you time. She had a very gentle quality which is lacking in a lot of people these days..." (p. 1). Because of her problems with Specialist 16, Patient 19 explained that she "took everything that he said with a grain of salt" (p. 9). "I trust [my GP] but I did not trust [the specialist]", she said, "He's always so busy...he doesn't have time to breathe. But I go back to [my GP] with whatever he tells me. And we work it out with her. She lays everything out..." (pp. 9, 11).

e. Manner

Most referring doctors were sensitive to how their patients were treated by the specialist and this attention means that patient feedback plays a crucial role in choice of consultant, as will be described below. GP 10, for example, talked of a gynecologist he avoids because of "roughness" with patients (the same

one GP 21 accused of "dredging"). There is an assumption in these accounts that ability to relate to the patient adequately is one aspect of competence.

In general, many patients did not expect much in the way of civility and were pleasantly surprised when they were treated well by the specialist. Patient 15, for example, thought that any doctor who was civil and explained things slowly, such as the emergency room residents who saw her, is better than average (Int. #1, p. 2). She was impressed by the fact that they took the time to talk to her about her bleeding and contractions, despite the fact that they were tired. She had not seen Specialist 15 enough to form an impression of him, but also gave him the benefit of the doubt as a "nice person" who not only remembered her but even made a joke about her getting pregnant again so soon (Int. #2, p. 1). Patient 13 was also favorably impressed with her specialist because he was courteous. Her comment was that "there's not too many doctors that walk in a room and say, Hello, Betty, I'm Dr. So and So, and shake your hand" (Int. #2, p. 3).

By way of contrast, patients appeared to see the too-friendly too-quick specialist as somehow less professional or competent. Patient 16, for example, thought that his heart specialist was too "flaky", too

"easy going" and assumed familiarities in a way that his family physician, whom he respected, would not (p. 6). In other words, he thought of him as unprofessional. Patient 19 agreed with Patient 16 about this particular specialist, although her worst encounter with a doctor was with an orthopod. She explains that,

> he was old school, pin-striped suit. And he was unbelievable. He had me in tears. [My daughter] couldn't believe what he was saying to me. She was upset for me. He was terribly abrupt...This guy took time and he went deep, but he was mean...He was just the type who would abuse you in front of anybody.
>
> (Int. #1, p. 17)

Patient 13, who reported that she was generally trusting of her doctors, similarly encountered an orthopod who was so nasty that she refuses to return to him. Patients and referring doctors alike suggest that while these doctors <u>may</u> be competent, it is not worth trying to find out.

III. CHOOSING A COMPETENT SPECIALIST: INDIRECT METHODS

Although both patients and doctors preferred to consult doctors whom they knew personally and had learned to trust through trial and error, they were

sometimes faced with the situation of being new in a community or of having to consult an unfamiliar medical subspecialty. In such cases, they were forced to rely on the assessments of others or to make assumptions about competence based on the doctor's credentials or experience.

1. Recommendations by Colleagues

Doctors Choosing Doctors. No GP, however experienced, can have been in a position to assess, first-hand, everybody to whom s/he may need to refer a patient. Therefore, GPs reported that they used recommendations from various sources. Perhaps the most open situation for adopting such suggestions was the urban family practice clinic that was studied, which is like a very large group practice in which residents share their experiences of consultants with each other. GP 3, for example, says, speaking of other residents, "[i]t's like any other group of people - you learn about people from other people. And your patients" (Int. #1, p. 10). As Hall (1948) pointed out in his description of the stages of a medical career, young doctors depend heavily on the suggestions of trusted elder colleagues, such as supervisors, and often refer to their teachers.

GP 2, who was going to open up a new practice in a different part of the city, said that she was going to ask advice from colleagues and teachers on who were "good" in that area (Int. #2, p. 10).

Clinic receptionists and receptionists in large group practices are in a better position than some of the junior physicians to know who to refer to and thus they help by making suggestions. Further, Receptionist 2 reported that she had a bad experience as a patient with a local specialist and was in a position to influence his referrals.

GP 12 felt that the influence between students and himself had been reciprocal in his practice. Two former students who became colleagues, he reported, had a significant effect on his referral patterns (Int. #2, p. 14). GPs also found relatives helpful. GP 27's son, a lawyer in town, would give him advice on which consultants were "treading too close to the edge" (Int. #1). This GP felt strongly that he should give his patients "not the best I can give, but the best I can get" and so was willing to try out suggestions about people who were thousands of miles away. GP 5 also found his sons helpful in making suggestions when he wanted to refer to a nearby city, pointing out that: "[m]y kids practice [there] and if I'm not sure of

somebody, I'll just phone them up..." (p. 15) In addition, GPs 3, 5, 21 and 30 all spoke of seeking the advice of local specialists when trying to find a specialist "one level up" - for example, someone who was very highly specialized and who might not be found elsewhere in Canada.

Patients Choosing Doctors. Many patients reported finding their GPs through the recommendations of friends and relatives, although this procedure was not very reliable. Patient 14, for example, found her female GP through the recommendation of a girlfriend at work (Int. #1, p. 5). Patient 37, new to a northwestern Ontario town, asked her friends, "is there anyone good around?" (Int. #1, p. 7), explaining that "[y]ou just figure, how many bad things have I heard about him as opposed to him? And then you decide" (p. 15). After some trial and error, she decided to avoid a woman GP who was assessed by patients to be incompetent and chose a man specifically assessed to be competent in obstetrics (p. 11). Another patient new to a small northwestern Ontario town avoided local doctors for a gall bladder operation because she had heard that, "here, they cut you from stem to stern, and I didn't want to be split wide open...so a doctor did it in

Winnipeg" (Patient 38, Int. #1, p. 10). "Everybody had gone to this other doctor and they said he was great", she added (p. 13). She was cautious about seeking recommendations from others, emphasizing that she "asked more than one person" and "probably would not go on one person's advice" (p. 13). She also considered going to Winnipeg because she had wanted "natural childbirth" and had heard that this is not attempted by the local obstetrician (p. 12). Patient 39, on the other hand, who had experienced more modern medicine when she lived as a student in the U.S., was willing to accept that this obstetrician "has old-fashioned ideas and they all work as good as the new ones do" because the doctor's reputation in neighbouring towns was so good (Int. #1, p. 1). Her first baby was born healthy, so, as she remarked several times, "I have complete confidence in him now" (p. 1) and "when I'm having a child, I want a person I can trust" (p. 2).

Patients occasionally reported that their "lay referral and advice" network had painted a picture of a doctor that did not match their own assessments made first-hand. Patient 29 and his wife, for example, said that they were under considerable pressure from their son, who did not trust local specialists, to travel several hundred miles to the Mayo Clinic for treatment

of a respiratory problem. However, they would not consider this as an option since they had generally found the negative assessments of others of local doctors to be inaccurate. For example, the patient had "no complaints whatsoever" about a local orthopod about whom he had heard "other people say they wouldn't let him work on their dog" (Int. #1). "I get all my work done here", he added. His wife complained that,

> You get people who know very little about things. They'll say, oh, if I were you, I'd get a second opinion. Because how do you know that he's treating you right? Because they themselves have had a bad trip somewhere along the line. And they figure every doctor's as bad. And boy, you get eight or ten people telling you the same thing. And some of them have never been to a doctor. You end up, well, gee whiz, maybe I should.
>
> (Int. #1, p. 2)

2. Based on the Doctor's Experience, Position or Reputation

Doctors Choosing Doctors. In the absence of direct experience or recommendations about a medical consultant, assumptions could sometimes be made as a guide to assessing competence. For example, GP 30 said, "I don't know [Surgeon 30 in Toronto] but I do trust an address, and I've referred to many physicians in that building over the years" (Int. #2, p. 16). GP 27

remarked that he used three criteria in choosing a consultant, all of which assumed competence based on experience and position: the consultant had to be ten years out of school; he had to have had some experience; and he had not to be so financially secure that he "never has to open a book" (Int. #1, p. 2).

The name "Mayo Clinic" was, to some, synomymous with excellence, although referring doctors (except GP 24, who had chosen to visit it for his own health problems) would not have had direct experience with these American doctors. GPs generally respected the wishes of patients who wanted to be referred to this distant multispecialty clinic. They sometimes themselves avoided local referrals in areas that had bad "reputations", although they tended to find a competent alternative who was somewhat closer than the Clinic.

The problem with using "reputation" to assess competence is that negative reputations could be partly generated by competing specialists. As GP 30 explained,

> [W]ith the various rivalries among the clinics, it makes it hard to fathom who's doing a proper job or what. I mean, often you hear a lot of criticism and it's sort of to their advantage- say, when one urologist criticizes another urologist...And I don't like that at all. I think you should look at each case for what it's doing rather than take the general opinion of people

> that I don't even know who have political goals in mind.
> (Int. #1, pp. 8-9)

Another illustration of this process could be found in the comments of Obstetrician 34, who complained about how the GPs at a particular hospital "had gotten into the habit of referring all their patients to a generalist in Winnipeg. They developed a rapport with him and I think that's why they use me less" (p. 5). At the same time, he claimed that this man is not as competent as he is, and would "fail" if he tried to write his specialty examinations for obstetrics and gynecology. He charged that in this particular hospital, the usual assessment and re-assessment of consultants' competence has broken down because "why change things, when you're comfortable with what you got" (p. 6). Later in the interview, however, he admitted that the man's competence was not really in question, and that he had a personal vendetta against him because he had been unpleasant to him during his residency.

Patients Choosing Doctors. Like physicians, when more direct evidence of competence is not available, patients sometimes reported basing their choice of the consultant on the evidence that s/he has attained a

high position or a great deal of experience. Alternatively, the doctor's reputation as discussed by townspeople or a particular specialty clinic's reputation had an influence on the patient's choice. In northwestern Ontario, the Mayo Clinic was an established tradition, even though patients would see numerous and different doctors when there and thus not get personal recommendations about particular consultants. As GP 30 described it:

> [M]any of the patients that I first had in my practice who were senior patients [here]...would routinely go to the Mayo Clinic for their yearly checkups...And they'd only come into the offices [here] if it was something trivial or an emergency...I think the reputation of medical care [here] has leapt immensely in the last eight years...[but] there still is a feeling among a large number of people that they can't get what they want done [here].
>
> (Int. #1, p. 5)

The tradition of going to the Mayo Clinic or across the U.S. or Manitoba borders for care was described by patients as an attempt to seek a long-term medical relationship. As Patient 38 explained of her town,

> [Before this group of GPs] came, there were a lot of doctors who'd be here a year, or whatever, and then they'd leave. So a lot of people went across the way...They never knew who they were going to see or if the doctor was the same. And if you're talking about going through the whole thing of establishing rapport with somebody

> different, you almost say, well, what's the point? We'll go to Winnipeg or whatever, and get a doctor who we can see forever. (Int. #1, pp. 17, 20)

Patient 39, from the same area, agreed that "in the 60s, there wasn't a proper doctor here", adding that in fact "everyone who's about 25 years old around here is an American citizen" (Int. #1. p. 11). Currently, she claimed, "doctors in the States are a little behind in some respects. For example, internal examinations are still done with big metal clamps" (Int #1, p. 12). Therefore, some of her American friends were "coming across...because they felt the care was just more modern" (p. 12).

Toronto, although further to travel for these patients, also enjoyed a good reputation among many patients. Patient 27, for example, had a great deal of respect for the abilities of her Toronto specialist whom she regularly travelled over a thousand kilometres to see; she had caught him "speaking on the CBC...so he knows his stuff", she assumed (p. 5). She felt that the fact that he specialized in rheumatology made him the best person for her to consult. If a rheumatologist moved in closer, she said she would see him, but insisted "I would continue with [the specialist in Toronto] because I feel that he is the one at the top. He should know what's going on, he has

more people to practice on" (p. 10). Because of his position, she argued, he will have the "latest, up to datest" information that can best advise her on her rare disorder. She knew even when her disease came on that "it was no use seeing [the GP] because he was only a family practitioner" (p. 2). She saw a rheumatologist in a nearby city whose abilities she respected partly because of his many diplomas on the wall (p. 9), but now that she has gone to Toronto, she wants to stick with "the best".

A similar phenomenon on a smaller scale occurred when patients from small towns where there was a general lack of confidence in local doctors sought a GP in a city. GP 30 explained, "I have a population of patients that come from hinterland towns, sometimes two or three hundred kilometres out, to me because they have confidence in me more than the fellows in their own community" (Int. #2, p. 2). Patient 33 claimed that this was a problem in her community where "[a] lot of people talk about doctors a lot...[and] there's a lot of bad doctors. The only doctor I've every heard anything good about is [my GP]." In part this was due to a turnover of doctors in the town which did not allow patients to establish relationships with them, but she also claimed that "the older doctors have bad

reputations too" (Int. #1, p. 12). Her GP acknowledged the failure of confidence in local medicine when he commented that 10 to 20 years previously, doubting of competence was not a problem, but patients now express concerns more and more (Int. #1, p. 3). Patient 27, in another small town in northwestern Ontario, recalled that the local surgeon, who has now left town for Africa,

> would tend to believe that he could cure all and do all. And a lot of people very nearly died under his care. He did amputations...with complications. Because he refused to refer them...he would try and handle it himself.
>
> (Int. #1, p. 8)

She argues that these bad experiences with the surgeon underlie the fact that townspeople don't trust local doctors "to do certain things". "...A lot of people, anything wrong with you seriously, whisk you off to [the city]!" (p. 8) This caution in trusting both primary and specialty medical care is quite widespread in small towns in northwestern Ontario and appears to be based on numerous instances of what patients regarded as demonstrations of incompetence.[7]

Sometimes only a particular specialty would have a bad reputation locally, and GPs would be forced to take this into account in their referral of patients. GP 30 explained, for example, that

> The cancer unit up here...has not been good in its PR...[Aside from one permanent physician], the other physicians that help in the clinic have been rotating or part-time, or there a short time and gone. And a few patients will develop confidence in their therapy - and they expect to have the same faces around when they go back. But they haven't been able to hold people and I suspect that part of it is that they're underfunded ...[and] that influence in cancer has spread to everything to do with cancer in town.
>
> (Int. #1, p. 22)

(This assessment was not shared by GP 40 from another town, however, who believed that this town had a "super set-up for radiotherapy" - Int. #1, p. 9).

When the specialty was outside the referral system, such as dentistry, patients made their own decisions to avoid practitioners with bad reputations. As Patient 38 explained, she had "heard awful stories" about the dentist in her town, and was quite happy to travel 60 miles to an American dentist recommended by her husband's place of employment (Int. #1, p. 21).

By way of contrast, urban patients did not talk about travelling out of the city to seek out reputable doctors. Like their rural counterparts, however, they often expressed concern about having a young and inexperienced doctor with whom they did not have the opportunity to form a longstanding relationship. In the family medicine clinic that was

studied, the young GPs didn't inspire confidence in the patients, and because the residents were regularly finishing their training and leaving, there was little time to establish a trusting relationship. Patients 1 and 3 agreed that they didn't like being shifted around from resident to resident and that sometimes it was even difficult to tell who the "real doctor" was. Patient 1's wife claimed that going to the clinic is "not like going to a real doctor" and Patient 3 described a "real doctor" as someone you get comfortable with, who's been in practice for awhile, and who doesn't look as young and pretty as her resident. Patient 4 was able to tell who the "real doctors" were at the clinic and didn't like being seen by the others. This patient considered the supervisor to be his doctor, and even the specialists in this case thought the referring doctor was the supervisor, because she had signed the referral notes. Patients in other clinics also made these comparisons among their doctors. Patient 36, for example, noticed that there were "four or five other doctors" that work in the clinic alongside her doctor "and they're very qualified but they [don't] look [it]...I'd like to see a doctor" (Int. #2, p. 4). Patient 31 similarly

complained about how young and inexperienced her dermotologist looked.

Another urban patient who had had previous experience with specialists in Estonia and a clinic in Sweden expressed a similar lack of confidence in fleeting relationships with young doctors. "You think he must be a doctor, so he must know more than I know, so anyways [you] go", she said; however, sometimes "you don't even know the doctor you were talking to" (Pat. 7, Int. #1, p. 7). A permanent family physician with whom she has had a 30-year relationship, on the other hand, has inspired her complete confidence. "When you have confidence in your doctor, then you don't get nervous" (p. 4), she emphasizes, adding that there is "no use to go to the doctor if you don't trust him" (p. 6). GP 1, along with other clinic doctors, were aware of this problem, and agreed that clinic patients "don't have enough time to cement those sort of relationships" (Int. #2, p. 13).

In both urban and rural locations, longstanding residence with a busy practice was an obvious clue to competence. As Patient 37 expressed it, "you know they're a good doctor, because their practices are closed. You can't get in" (Int. #1, p. 15).

For obstetrical and gynecological problems, many patients preferred a woman with children, because they felt that her childbearing experiences gave her special insight and competence in the handling of these areas. Patient 34, for example, commented,

> I think I felt really comfortable with [my doctor] with the baby because she's had two of her own...[S]he's got a nine or ten-month old, so she knows what it's like when you're lying there having the baby...[I]f you're in there and you've got someone in there who's never had a baby, male or otherwise, they don't know what you're actually going through.
>
> (Int. #1, pp. 2-3)

Patient 39, by way of contrast, related the unhappy experience of having an inexperienced male doctor face her when she was in labour:

> Well, it was a doctor but maybe he was a doctor of psychiatry. He hadn't a clue about what to do and [the obstetrician] came flying...up to where I was, three floors, and delivered my baby just in time...[The inexperienced doctor] was practically green! He hadn't a clue, the nurses were ready to deliver the baby...and I came very close to saying, you know, let the nurses do it.
>
> (Int. #1, p. 4)

GP 19 was aware that she was chosen by Patient 19 because she is a woman, and that many of her other patients have this preference (Int. #1, p. 9). Patient 15, who was surprised that her female GP referred her to a male obstetrician, implies that a woman is

preferred because she has a gentler approach with patients. Patient 13 believes that her daughters have turned towards a female doctor in her GP's practice because "they seem to feel that they can talk to her better than they can a man doctor" (Int. #2, p. 8). Patient 19, however, suggests that a woman has special competence: "She understands more about what you're talking about...She's really tuned in to the woman's physical body. When you're pregnant, you don't want somebody who doesn't know the hell what you're talking about. And she has children..." (Int. #1, p. 5).

IV. NEGOTIATION WITH THE PATIENT ABOUT CHOICE OF CONSULTANT

In view of the limits of direct assessment of consultant competence and the inadequacy of indirect methods of assessment discussed above, patients and doctors might do well to pool their knowledge about consultants in order to arrive at the best choice for the patient. However, despite the richness of information about specialists that patients sometimes possessed, they were very selective about what was shared with the referring doctor. The referring doctor was similarly selective about what was shared with

patients. Instead of open discussion, a kind of silent "negotiation" took place when GPs occasionally tried out patient suggestions for possible consultants, tried to "match" patients and consultants, steered them towards or away from specialists they preferred and finally, forced a referral to someone they trusted in order to demonstrate to the patient that the specialist could be trusted. Typically, the issue of competence was not raised in any of these strategies, but the aim was to find a consultant whom both patient and referring doctor could trust.

1. "Negotiating" the Patient's Choice of Consultant

In his account of how he negotiates the choice of consultant with a patient, GP 29 outlines a traditional scenario:

> [M]y approach to specialist referrals in most cases is to sit down and say, now, look, here's who I want you to see and the reasons why. Sometimes I'll say, now lookit, we've got three choices here, and I'm happy with them all...and I'll do little reviews of each of the specialists and give my opinion...And by and large they'll go to who I want.
>
> (Int. #2, p. 8)

His patient recalled that this doctor had laid out the alternatives in referring him to an orthopedic surgeon and had convinced him that the man he chose was "as good as the rest" (Pat. 29, Int. #2, p. 8). However, patients typically did not recall being faced with such rational choices. In their accounts, specific consultants were sometimes chosen by patients themselves, particularly in northwestern Ontario where the reputations of these specialists are well-known to patients as well as doctors.

Even in the cities studied, a patient may have knowledge of a consultant or, occasionally, may obtain a consultant's name by chance. GP 5, for example, described a situation in which one of his patients was spotted in a crowd one day by someone who recognized her scoliosis and gave her the names of "two guys in Toronto" who treat it. The GP responded by making an appointment with them, and "they operated on her and modified her scoliosis and she's a helluva lot better off. So I found them by accident"(p. 15). When his patients move out of his neighbourhood, he sometimes learns about specialists in other parts of the city from them: "[a] couple of times", he says, "patients have given me the names of gynecologists in [another part of the city] - I don't know any of those doctors

out there" (p. 23). This also occurs in northwestern Ontario, as GP 24 pointed out: "[Y]ou get a patient come in [who says], well, I used to go to Dr. J. in Toronto for allergies and he's really good...so you reserve [him] for your difficult problems" (Int. #1).

Several specialists claimed that a great deal of their business was generated by patients. Specialist 3, for example, commmented, "I have a reasonably good reputation. And I think there are patients who will say to the family doctor, look, if you're going to send me to an ear, nose and throat man, my father and cousin have seen [Specialist 3], can I see him?" (p. 17) He added that he has had,

> mothers come in with small children and they will say, you know, you took my tonsils out 25 years ago. Or [since I was a GP up north] I'm having them come and say, you delivered me 25 or 30 years ago, and now I have my child down here.
>
> (Int. #1, p. 18)

GP 24 said that patients who had heard good things about a local psychiatrist would ask to see him (Int. #1).

Should the referring doctor give the patient his or her choice of specialist? In a discussion about the handling of referrals, an American internist advises that the referring doctor should never give the patient such choices, since he, not the patient, is in

a position to know who is best qualified, and would be hard pressed to explain why he disliked a patient's choice (Biedleman et al., 1971). However, GP 29 has no problem with this in certain areas - since "ladies often feel pretty strongly about what gynecologist they want to see" (Int. #2. p. 3), he will usually oblige.

Hummell et al. (1970) further argue, without having studied the process, that patients in Germany are unlikely to influence choice of a particular specialist because the GP has "better knowledge of the competence and specialties of his colleagues", while the patient plays a "typically passive role" (p. 597; italics in original). However, Carson (1982) claims that in 22 percent of 5648 Australian referrals he studied, patients chose their own specialists. In that study, the referring doctor or his staff only made the actual referral arrangment in only 42 percent of cases, with the patient or relative making them for the other cases. In the Canadian study by Brock (1977), in only 10 percent of cases were specialists reported to be chosen by patients, and Brock notes that this was particularly the case where there had been loss of rapport or trust with the GP. GP 5 suggests that the practice of asking for specific specialists in Ontario is increasing and that these kinds of specific requests

can often be a problem for the referring doctor. For example, he recalls that his patients would never ask for a cardiologist by name ten to fifteen years ago, but now "they all know there's a cardiologist around. So they all want to go to the cardiologist" (p. 9). And he claims he gives in almost every time: "I sometimes refer too much. I'm too soft on them" (p. 9).

Sometimes, GP 5 adds, the patient wants to go to the wrong doctor: "Like one patient wanted to see [a certain specialist] but I explained, look, this guy's a surgeon and you need a gynecologist. You need this kind of doctor" (p. 17). Another example of this was a patient who asked for "an ear, nose and throat man - she thought she needed a CT scan!" (p. 27). ENT Specialist 3, in fact, confirms that he is sometimes confronted by people who think that an ENT person should know something about eyes:

> I've had patients come in and say, well, you're an eye doctor too. I've had some problems with my eyes. And I have to say, no, I'm sorry, I know there are only two eyes and some are brown and some are blue and I don't know anything else about them. You know, it makes them laugh a bit, and at least they're not angry so much at themselves and at the family doctor...And so it makes one wonder if patients were making their own decisions about things, if there wouldn't be a lot of inappropriate visits.
>
> (Int. #1, p. 18)

In the situation where the GP is convinced that he should not send the patient to a specialist they name, GP 5 comments: "I'll complain and holler about that and if I don't win, I'll tell them why I don't think it's a good idea. But if he or she still insists, I'll send 'em" (p. 16). He gave an example of a man who had been advised by a doctor in Europe to go to a specialist regarding his deep vein thrombosis. But he was admitted twice to the hospital and the GP felt,

> [The specialist]'s not doing a damn bit of good. So I told him - I talked to him and said, you're wasting your time. He can't help you. And he finally accepted it. Sometimes they're stubborn and I have to be strong and tell them, you're fulla beans! It won't do any good. (Int. #1, p. 16)

Another example given by this GP that also illustrated concerns about competence involved sending a patient for procedures with which the GP had no first hand experience:

> [Y]ou got small veins and instead of cutting them out, they'll inject them for sclerosis. And this lady wanted to see [a certain specialist]...I didn't know, so I asked some of the fellows ...and they said, yeah [he] does it. But none of the surgeons wanted to do that...Either they don't know how to do it or it's no bloody good. But [this specialist] does it. And I told her I think you're better off having it operated on. But this girl wanted it done...So I let her go...I don't blame them for not wanting to have their legs chopped up, because they get massive

> scars...[But if anyone else] wanted an injection...if I didn't think it was worthwhile, I'd try and talk them out of it. If they insist, I'll say, OK, I'll send you. (Int. #1, p. 17)

Occasionally patients who ask for specific specialists are very well informed, for example, if they are physicians. GP 3 explains that she insists on specific referrals for herself:

> [W]ithin the medical community, people have good reputations and bad reputations. Good reputations, I suppose: competence, personability, availability, social skills...and you get to know who's good and overall, who you would trust, who you would go to for specific problems. My doctor has never had any objections. She says, oh, well, I don't usually refer to that person, but...
>
> (Int. #1, p. 8)

In general, this young GP feels that,

> [I]f a patient comes to you and you have [it] within your power to send them to somebody who they think - and you never know - because they may be able to suggest a new prosthesis, or surgery, or whatever - then it's their privilege to have access to those people...I'm the only one who can make the appointment - should I wield my power and say, No! There's nothing we can do!
>
> (Int. #1, p. 10)

2. "Matching" Patients and Specialists

When patients do not express a preference for a particular consultant, which is typically the case in

the urban location studied, GPs sometimes used their own estimations of how the specialist might treat the patient based on their own interaction with the specialists. For example, GP 19 said that she refers to one neurologist who "doesn't make me feel like a ninny" (Int. #1, p. 6). Another specialist whom she prefers she describes as trying to answer and anticipate patients' questions and as well as writing back good consultation notes (p. 12). By way of contrast, GP 3 emphasizes that the referring doctor should try to avoid the "nasty consultant":

> [T]here's some obnoxious consultants, I feel. And I wouldn't send [my patient] to one of those. Because emotionally it wouldn't be worth it. Like, no matter what they did to her physically, it would go the wrong way and it would be a trauma for her...And you want to make things as easy as you can.
> (Int. #1, p. 3)

GPs explain that they sometimes try to "match" patient and specialist personalities to increase the chances of success. GP 2, for example, chose a specialist whom she felt would not be judgemental about her patient's alcoholism, based on her interaction with the specialist around other cases (Int. #1, p. 4). She admitted that just because the specialist is polite to the referring doctor, "it doesn't necessarily mean that

they're going to be polite" to the patient, although this is a promising sign.

One specialty in which referring doctors try to be particularly careful about matching patient and specialist is gynecology. The preference of many patients for women GPs and gynecologists is appreciated, as is the need for someone who is gentle and considerate in physical examination. GP 19 refers most of her patients to a gynecologist who is "warm" and "gentle with them on exam" (p. 2). She always asks the patient if they have a preference for a male or female gynecologist, which, of course, is not done in other specialty referrals (p. 1). If the patient asks for a woman, as did Patient 19, the GP refers to Gynecologist 19, whom she knows by reputation to be "always pleasant with the patient" (p. 2). GP 5 also indicates that he'll refer to a female gynecologist if the patient asks, although he only knows two. He feels that patients ask for female gynecologists if "they're embarrassed" (p. 16). But GP 7 sees it as a "personality" issue. He says that he refers to a wide range of gynecologists since this is an "emotional" kind of referral where the patient has to be "matched" with the consultant (Int. #1, p. 2). Despite "matching", GP 7 expects to hear criticism, since this

specialty, more than any other, depends on patient approval for continuing referral.

3. Taking Patient Feedback Into Account

In addition to being responsive to patient suggestions about possible consultants, referring doctors reported being sensitive to feedback from patients on consultants that they have chosen. In view of the limits faced by GPs in direct assessment, evidence presented by patients, however fragmentary, is useful. GP 19, for example, explained that she no longer referred to a certain neurologist because, "patients I have sent to him have been very unhappy" (Int. 1, p. 6). GP 3, also a young female doctor, agreed that it was important to be receptive to patient preferences:

> [I]f they've seen [a certain specialist] before and they like him, then, I'd say well, do you want to see the same person or do you want to try somebody else? Often they say, OK, I'll see the same person. Obviously, then, it wasn't an unpleasant experience. Sometimes they'll say, we didn't get along. Or I didn't agree with what he said and I'd prefer to go to somebody else. And I say fine. They're being investigated for something that's a physical problem. Why put on top of that an interpersonal problem? If they anticipate that it's going to be a problem, I don't have to put them

> through an exercise of trying to give somebody a second chance.
> (Int. #1, p. 7)

One specialty in which referring doctors have become alert to patient feedback in making referral choices is orthopedic surgery. As another female, GP 14, explained,

> [W]e've had patients come back [from orthopedic surgeons] and at least two of them would not go back again. The personality suffers a bit with a couple of them. And I can only think of orthop[edic surgeons] being like that. I mean, they walk in, and the patient's totally upset with what's happened. There's a couple we would only send to, personality-wise, if it was absolutely the last resort.
> (Int. #1, p. 15)

In northern Ontario as well, GP 30 pointed out that it was common to have a patient have "some surgery by one of [two orthopedic surgeons] and then the next time, say no, I'm going to the other one" (Int. #2, p. 8). In his opinion, the two were similar in technical ability, but because of their brusque manner with patients, they offended people. "I would prefer someone to find competence with the first person they go to because I don't see much difference in the approach of these two" (p. 8), he complained. If a patient has been put off by such a person, GP 19 explains, it is important to reassure the patient that you have tried "to send them to good people", to apologize and then offer them

another specialist of their choice (Int. #1, p. 13). GP 24 agrees that if the patient says, "there's no way that I'm going to that guy", you "send them to another [specialist]" (Int. #1).

4. Getting the Patient to Accept the Doctor's Choice

What happens when a GP insists on sending a patient to a specialist whom a patient distrusts? One case in this study illustrated how an accommodation was worked out. The obstetrician to whom Patient 14 had been referred had been her obstetrician for two other pregnancies that she felt had not gone well. The pregnancies both ended in the babies being kept in intensive care, and the patient and her husband felt that they were under a great deal of pressure from family and friends to change specialists this time. The couple, however, had mixed feelings. The wife felt that she could probably have insisted that her GP send her to someone else, although the GP managed to talk her out of this (Int. #1, p. 8). Before seeing the specialist, the wife seemed to accept the GP's reassurances that there was nothing wrong with the competence of this obstetrician and that she had just been a little "unlucky".

The GP preferred the obstetrician because she was locked into a "shared care" arrangement and was inclined not to refer to a hospital from which the patient named another specialist. When the patient's friends challenged her about going back, she responded that the problems were not due to the obstetrician's lack of care (Int. #2, p. 8). She felt that these friends had to find somebody to blame for these problems. Since they hadn't had the problems, the patient thought that it was a reflex reaction with them to assume that you have picked a bad doctor. She defended him by saying that he had a good reputation, a high patient load and that she personally was confident with him.

There was a progression of attitude change in this case. Before seeing the specialist, the husband and wife, with husband more skeptical than wife, indicated that they were really only giving the specialist another chance because the GP insisted on it (Int. #1, p. 10). Their way of dealing with the problem was to "trust" the specialist but to keep a close eye on him, for example, by having the husband come on the first visit and ask him about the things that were worrying them (p. 13). They focussed on one item of disagreement that might have caused all the

problems: the due date of the babies. They felt that perhaps the babies got sick because they had not been induced soon enough (p. 11). The wife said she was sure of this the second time through and that she had confronted the specialist with her feelings (p. 13). So the couple wanted to see whether the specialist would be responsive to their calculation of the due date this time. They offered various rationalizations at this point, such as, "technically, he's very good" and "you can't trade a team in midstream" (p. 14). The wife also emphasized that she felt very comfortable in this hospital (p. 14). Still, they both had a gnawing feeling of uncertainty along with a sensation of having to "hold a shotgun over him" (p. 16). While they knew that it wasn't "normal" for their babies to end up in ICU, they uneasily accepted that definition of the situation (p. 18).

After they had been to see the specialist, even though everything didn't go completely according to expectations, the husband appeared to shift over to the wife's feeling of "confidence" and announced that he would not have to accompany his wife after this (Int. #2, p. 5). Although they forgot to ask the specialist not to do an epesiotomy, the obstetrician had answered their main concern about the due date by

paying attention to their calculations, writing them down, and promising to induce on that date (p. 6). They now felt that everything was going to be alright because the baby was not going to be late (p. 8).

Finally, when the baby was delivered normally, the couple expressed complete faith in the specialist. This time, the wife said that even the husband could see "how professional he was" and was really impressed (Int. #3, p. 5). She claimed that she always had every confidence in him, but now she cannot say enough good about him - with a fourth child, she'd have absolutely no hesitation to go to him. Even the nurses had emphasized how well-respected he was, saying that he was their choice. The patient felt that the specialist had shown extra consideration by coming back to deliver her baby after he had booked off; even the epesiotomy she didn't want was only a "small" one (p. 3).

In this couple's discussion of their "guarded" trust in the specialist, it was clear that they kept close surveillance on his technical competence. The wife explained how a female resident had sewn up her epesiotomy with her first child too tightly, which involved a lot of pain (Int. #1, p. 9) and was partly the specialist's fault, because he "was in charge". Everything appeared redeemed when the obstetrician

sewed up the second epesiotomy, which involved "one-tenth" the pain (p. 10). But he sewed it up too loose this time, leaving a gap so that it had to be recut and stitched six months later. This incident had the patient concerned, since she remarked "some of them don't know how to stitch" (p. 15). She was also concerned that an unnecessary epesiotomy might be done just to make it easier for the obstetrician and she knew of a friend who vowed not to return to this obstetrician because he did an epesiotomy that he promised not to do. She even wondered if he would have done something about the loose epesiotomy sooner if she had been his wife (p. 15). Neither was this the only irregularity of competence - the obstetrician apparently did not get all of the placenta out with the second delivery and she "bled for 12 weeks after the delivery" (p. 16). And so the "guarded trust" of this patient and her husband was not wholly based on pressure from friends, but also on experiences with his abilities. The patient and her husband felt that they had to question anything that looked irregular. But ultimately, their babies lived, so that the patient's confidence in his ability was reinforced. When the specialist delivered her third child successfully,

renewed confidence appeared to wipe out the effect of the observation of these technical irregularities.

V. WHEN NEGOTIATION FAILS

What happens when GP and patient cannot work out accommodations of the type discussed above - in other words, when the patient does not "trust" the doctor's choice? Some of the strategies that were reported and demonstrated by patients in this study were: getting another GP to refer you to the specialist of choice; approaching the specialist directly, including going to the emergency department of a city hospital; and seeking alterative practitioners. In each case, negotiation has either broken down or has never taken place, and the referring doctor has been bypassed. These "breakdowns" of the referral system were investigated because they illustrate the importance of trust in maintaining referral. Further, they show that the patient can still "choose" a consultant even if the GP does not cooperate in this choice. In other words, it is argued here that these behaviours can only be understood as part of a sequence of behaviour in which the patient does not

trust the doctor to refer appropriately and takes matters into his or her own hands.

1. Getting Another GP

It has been pointed out in Chapter 5 that a failure of patient trust sometimes leads to patient-initiated referral. However, when the patient cannot get satisfaction through referral, or has lost confidence in the doctor to such as extent that s/he does not even want to "negotiate" about seeking a "second opinion" with another doctor, s/he may "divorce" the GP and seek another, as described in Hayes-Bautista (1976). GP 38 compared this behaviour to his "relationships with car repairmen - you know, I was going to one guy until he did something and my bumper fell off and I started going to another garage" (Int. #2. p. 14). This was more common in southern Ontario where GPs are more plentiful. In this study, Patient 1 reported having left a GP because he was an alcoholic (Int. #3, p. 9); Patient 2 reported having left a "pill-pusher"; Patient 4 left a doctor whom he felt ran a "revolving door practice"; Patient 16 left a "butcher" who failed to lance his boil; and Patient 20 left a GP who, he felt, was "ruining his feet" with

cortisone injections. In each case the patient questioned the competence of the GP and found a new GP who inspired more confidence.

In northern Ontario where the turnover and lack of accessibility to alternative GPs is greater, there was evidence of more "shopping around" than "divorce". For example, Patient 26 felt that a former GP had mismanaged her gynecological and obstetrical problems, but she stayed with him until he left the town. She is also a reluctant patient of her current GP, who, she feels, has not examined her ears properly. However, she checked her problem with another local doctor while he was away. GP 27 from a nearby town has also handled at least one "second opinion" for GP 25's patients. Patient 39 expressed profound distrust of her small-town GP, and considered aloud the alternatives, but decided that other GPs were too far away for her to change doctors.

2. Going "Off the Street" to the Specialist

A more attractive alternative for the northwestern Ontario resident who distrusts the local GP is not to try another GP or pressure for a referral, but to go directly to the closest specialist. While

many specialists will only accept referred patients in this region, the primary care part-specialties such as obstetrics/gynecology, pediatrics and some general internists, as well as specialists in ophthalmology, psychiatry and dentistry will accept such patients.

One illustration of the chain of visits to multiple specialists that can be set off by a patient who contacts specialists directly was given by the wife of Patient 4. While her husband was being seen by Neurologist 4, they decided to get a doctor on their own for a leg problem he was having and were quite perturbed at having to wait for the GP to return from vacation before getting this referral (Int. #2, pp. 6-7). At this time, this patient saw a number of specialists for her own problems (pp. 8-9). At first she contacted and went to the wrong specialist, who then referred her to another one. At the same time, she went to see a third specialist at the suggestion of a gynecologist, whom she had contacted herself (pp. 11-12). This woman, the rare, but classic "shopper", managed to engage numerous specialists at the same time with no satisfaction. She made clear that a failure of confidence in general practice lay behind her short-circuiting of her GP when she said: "[i]f I think there's something really wrong with me", she said, "I'd

rather go to the specialist than the family doctor" (p. 12).

The chronic patient may also short-circuit the GP by getting back in to see a specialist that s/he has seen before by calling directly. Most specialists said that after six months they ask the patient to go back to the GP for another referral, but Specialist 4 admitted that sometimes these patients get through to him the same way that GPs get some patients seen sooner: they "sweet-talk my secretary" (p. 7). One specialty in which there is a significant off-the-street chronic patient population is ophthalmology. In contrast to the angry reaction of GP 21 when the wife of Patient 4 went to a surgeon on her own (Int #2, p. 2), one clinic receptionist reported that she has been authorized to handle ophthalmological referrals without checking with anyone. Ophthalmologist 11, who said that about half of his patients were self-referred, explained that although the medical insurance schedules give him more money for a referral, it would be counterproductive to send a patient back to his GP when he calls the ophthalmologist directly.

A final way to reach a specialist directly in Ontario cities is to go directly to the emergency department, where a patient cannot be legally turned

away.[8] This strategy does not work in northwestern Ontario, however, where one is likely to run into one's GP manning the emergency department of the local hospital.

3. Seeking Alternative Therapists

Patients in this study reported seeking non-traditional therapies from chiropractors, osteopaths, faith-healers and fortune-tellers. In northwestern Ontario, they also consulted optometrists, but this was because of the lack of accessibility to ophthalmologists, just as the use of chiropractors was related to the shortage of orthopedic surgeons there. However, in southern Ontario, as well as northern Ontario, there was seeking of alternative medicine in areas that patients did not feel were handled competently by traditional medicine.

For example, a number of male patients who were not getting "satisfaction" from their doctors around the treatment of back problems sought out chiropractors through a lay referral network. Patient 12, for example, claimed, "I go to chiropractors more often than I go to doctors" (pp. 5-6). Other patients who reported going to chiropractors were the husbands of

Patients 5, 11 and 13 and Patients 17 and 20, all men. Patient 12 said that he went to the chiropractor because "I couldn't get any results from my doctor" (Int. #1, p. 5). Specifically, the doctor had refused to sign a compensation form and then, according to the patient, had warned him not to see a chiropractor because "[t]hey're not good for you". The patient is not sure why the physician treated him in this way, commenting that he was just acting "real ignorant" (p. 6). Now, the patient emphasizes, "I'd never go to a doctor for back problems".

Other patients knew that they were not supposed to discuss this type of care-seeking with their GPs. Patient 17, for example, saw a chiropractor whose advice he respected. He then waited for his GP to refer him to an orthopod as the chiropractor had suggested, without telling the GP that he'd consulted the alternative. Patient 13's husband was more fearful. This man, according to his wife, experimented with a chiropractor for back problems that have not yet been satisfactorily resolved, but gave up before long, fearing that it might do him some damage (Int. #1, p. 7). Unlike Patient 12, he and the husband of Patient 5 appeared to heed the GP's warnings.

More than any other participant in the study, Patient 19 gave a history of seeking a wide range of remedies, including reading about treatment for a yeast infection by a certain author (Int. #2, p. 4) to actually applying home remedies and going to alternative practitioners. She commented about these alternatives: "I used to believe it a lot. I still believe in it...[I]t's stupidity to ignore it if it works" (p. 4). She links the fact that she "grew up without doctors" in Ireland, where patients had to pay up-front to see a physician (p. 7) to learning to trust the "chemist" (pharmacist) (p. 9). After subsequently working in a pharmacy, this patient said that she is convinced that "[a] lot of what's wrong can be treated without major drugs" (p. 9). She also reported a good experience with an osteopath in England, who was able to fix back and leg pain that she experienced during after her first pregnancy. While her traditional doctors told her that it would clear up after the delivery, and she says, "you believe anything they tell you [as an inexperienced patient]" (p. 5), this "faith" was unjustified, the pain persisted and she was told that she'd "got it for life". But since she was only 25, she decided to pursue it and go to an osteopath, who fixed the problem (p. 5). As a child, she also

remembers such practitioners as "bonesetters" in the village, who fixed greyhounds as well as people. She tells of one who fixed her sister's collarbone instead of putting her in a cast for the summer.[9] All these experiences have reinforced her faith: "I'm a believer because it actually happened to me", she emphasized (p. 6).

What these arguments suggest is that patients do not restrict their medical care-seeking to traditional practitioners and that the "evidence" that they cite for the competence of alternative practitioners and the efficacy of their treatments is of the same type as that they observe for their traditional doctors. To the extent that patients can obtain a "second opinion" through the traditional referral network, they may not resort to these alternatives. But patients in this study consulted alternatives more than they cared to admit to their doctors and they did so because they weren't trusting or getting results from their doctors. Alternatively, they sought out traditional doctors after being disappointed with alternative practitioners, as in an illustration given by Radiologist 36. He described a patient with hemoptysis who'd come to him because "he tried the herbal medicine...and he said that medicine

doesn't work, so now he wanted to try other medicine" (p. 19). The radiologist thought that the medicine man or woman may be consulted by many natives, but with a healthy skepticism or "guarded trust" (p. 20). GP 38 argued that after a local chiropractor had hoodwinked a number of patients by diagnosing the same problem and the same cure, "[t]here's a far, far less use of chiropractors than there used to be" (Int. #2, p. 13). And he added, "I like to think that some of it's because we've provided some sort of stable care and continuity". The important point is that many Ontario patients attempt to be critical consumers of a wide range of consultants, just as patients in third-world countries do when a wide range of options are available (Ugalde, 1984; Feierman, 1985).

VI. SUMMARY

In summary, it was found that just as patient influence on the decision to refer has been underestimated in the literature, so has patient influence on choice of consultant been underestimated. Patients, represented in the literature as "passive" and incapable of making informed choices about where they can obtain the most competent medical advice, were

found to use a variety of strategies to justify the trust that they wished to place or that they had already placed in their medical advisors. In this, they resembled closely their referring doctors, who faced the same task of assuring themselves of their consultants' competence.

First-hand assessment of the consultant were preferred by both patients and doctors, and long-standing personal relationships with consultants were found to develop into relationships of "trust" that were extremely resistent to any negative evidence about the advisor that might come to light. However, in the face of sustained or unequivocal evidence of incompetence, the basis of the relationship might come into question, and patient or doctor might be forced to "divorce" the consultant, a phenomenon that has previously been described by Hayes-Bautista (1976). Often before reaching this extreme, patients or doctors would go into a hyper-vigilant state that has been called "guarded" trust here, because more attention is paid to the consultant's behaviour than would usually be the case.

Freidson (1970b; Freidson & Rhea, 1965) has made the detailed argument that the ability of the referring doctor to observe and assess consultants

first-hand is severely limited by lack of opportunity and lack of knowledge. This was supported in this study, where it was found that such opportunities were related to the referring doctor's career and geographical location as well as to the structure of specialties. Specifically, young family medicine residents had better opportunities to observe consultants recently and first-hand in the hospital, while geographically-remote practitioners and city physicians who seldom frequented the hospital were in the worst position to make such assessments. They were thus highly dependent upon the patients' appraisals of consultants.

Although both referring doctor and patient face limits on their opportunities to assess consultants, when approaching a new person, they attempted to do so by garnering evidence of technical skill; by assessing the adequacy of communication with the patient and in the consultant's letter; and by pondering the outcome of the consultant's intervention. When these methods did not provide conclusive evidence, they relied on their impressions of the "thoroughness" of the consultant and his or her manner of relating to the patient. Specifically, the "revolving door" treatment

was universally recognized by patients and doctors as a clue that the consultant did not deserve their trust.

When referring doctors or patients had no prior experience with a consultant, recommendations by colleagues were sometimes used or assumptions were made about the doctor's experience, position or reputation. Specifically, doctors who were older, had been in practice longer, who held important positions in the medical hierarchy, or who had had obvious experience in certain areas (such as women doctors with children) were all preferred by patients. Further, certain "addresses", such as the Mayo Clinic, were identified by most as providing good quality service by both patients and doctors, while other locations were favorably or unfavorably assessed, depending upon the reputations that had been generated about them. Both patients and doctors occasionally found these "reputations" unreliable, although they provided a rough guide as community assessments of the quality of care that had been offered in that location in the past.

Despite the traditional view that it is always up to the referring doctor to choose the best consultant, this study showed that patient assessments, when they were passed on to the referring doctor, were

taken seriously by them. Specifically, the patient sometimes suggested which specialist should be chosen, or debated with the doctor about this choice. Further, even when verbal negotiation did not take place, referring doctors sometimes tried to take their patients' views into account by "matching" them with particular specialists. Hampered as they sometimes were in assessing a consultant first-hand, they also reported putting weight on patient feedback about consultants, sometimes "divorcing" those who were rejected by their patients. Alternatively, they sometimes successfully facilitated the re-establishment of trust in a consultant, in an elaborate negotiation over time.

In addition to their influence on choice of consultant through referring doctors, patients were also found to bypass the referral system and choose their own consultant by "voting with their feet". Specifically, when they were unable or unwilling to satisfactorily negotiate a referral with their GP, they were found to circumvent him or her by getting another GP who would inspire more confidence or make the appropriate referral. They might also go directly to a specialist's office or the emergency department of a hospital. Finally, they might leave the system

entirely to consult an alternative practitioner. As research in third-world countries has shown, patients seek out a range of services over time, and do constant comparisons and assessments, so that trust is never established "for all time" (Feierman, 1985).

These patterns of care-seeking, which are reflections of patient confidence in local services, are probably not unique to Ontario. For example, Ugalde (1984), in a study of the experiences of 5500 persons in 18 hamlets in the Dominican Republic, found that patients bypassed local free primary care clinics to purchase their medical services in the town (p. 443). Although they were willing to pick up medicines at the local clinics, like many of their northwestern Ontario counterparts, these patients had a low regard for the young clinic doctors, whose competence was not judged to be as great as the town physicians. As in northwestern Ontario, there was frequent turnover of clinic doctors and patients judged their lack of commitment through their frequent absenteeism from their posts at the clinics.

NOTES

1. Long-standing relationships between patients and practitioners may be the basis of the "under-referral" discovered in the North Carolina referral study (Williams et al., 1960). In this study, "over-referral" from rural areas was linked to high turnover and poor patient-physician relationships.

2. GP 24, who had finally decided to go the the Mayo Clinic for his own health problems, agreed that since the Mayo Clinic is a "world centre", "it doesn't matter what it is, they'll be able to handle it" (Int. #1, p. 18). However, this positive assessment of "world centres" was not shared by all doctors. Surgeon 32, for example, suspected that much of the travelling done by northwestern Ontario residents for care outside the area was prompted by their being taken in by "the glitter of a university centre" (p. 11). Regarding the Mayo Clinic, Surgeon 39 suggested that if you go there "for a simple problem, you probably don't do as well as if you go to your own local centre...But if you have something really rare, then you'll probably do very well there. Their theory is that by testing people you can find out everything that's wrong with them. Which is probably basically in error. They overinvestigate" (p. 5). GP 40 agreed that to go to the Mayo Clinic, "you've got to have a fairly rare disease that they've got somebody there who's good at" (Int. #1, p. 4). Further, since "people see so many specialists there", "they're liable to sit the patient down and say, yes, you've got a brain tumour and there's nothing we can do about it" (p. 4).

3. This was a frequent reason for avoiding the emergency department of a hospital or the doctor "on call" for their family physician. Patient 32 remarked, for example, "You get used to one doctor and even now, when I have to go to another doctor, I'll postpone my appointment. If it's something I really have to

go to see about...I'm not going to see anybody else but [my GP] because he knows what's going on..." (Int. #1, p. 6). Patient 31's fear of hospitals, like that of Patient 36, was linked with negative experiences that she'd had, where, during one procedure, she believed that the hospital staff were going to kill her (pp. 22-26). She therefore prefers to stay with the doctors whom she knows and trusts.

4. This is a service organized by the Canadian National Institute for the Blind because there are no ophthalmologists in the several hundred kilometres between Thunder Bay and Winnipeg.

5. The example of Specialist 16 has already been described in Chapter 4.

6. This topic is treated at greater length in Chapter 8.

7. This patient's GP agreed with her assessment. In the area of obstetrics, he remarked that there were obviously more than the 25 referred births per year in his small northwestern Ontario town. Women there are "voting with their feet" by going on a self-referred basis to the closest city to have their babies delivered (Int. #2, p. 5). This GP spoke eloquently about there being a real basis for patient distrust of local services. According to him, "[t]he rats have moved into the ship and the good people move out. People move in, they see the kind of hospital here and they say, oh God, and away they go" (p. 5). He speaks with regret about a young doctor who left because she wanted a "rich medical life". What's left behind, according to this man, are GPs who don't want a challenge: those who are "recirculating chickenshit" and don't really want to upgrade the local services because they'd rather just stabilize a patient and send them off to the city (p. 5).

8. On the use of emergency services by patients with GPs, a great deal was said by patients and doctors alike. But since the problem was typically seen as one of accessibility rather than of competence, it will be discussed in Chapter 7. It should be mentioned here that

emergency services are used as an alternate to the GP in two ways: after hours, by patients who have GPs or in an emergency (as they were meant to be used); and by patients who do not have GPs. Since only patients who had GPs were included in this study, little can be said about the latter group, except that specialists in core-city hospitals such as Internist 4 complained that "patients in this area, especially, used the Emergency Room as a family doctor's office" (p. 10). Some of these patients are intercepted and "sent" to family physicians by the specialists, such as Patient 1, who was referred to a GP after going to the emergency department with a nosebleed. Patient 2 was also intercepted by a specialist, who gave him the name of a family doctor. It is worth noting that Internist 4 had a low opinion of the GPs in the area of this hospital and that these two patients had avoided GPs in the area whose competence they questioned.

9. One real attraction of alternative medicine, according to Patient 19, is its expediency. She says you have to decide whether, if you have a bone problem, you want to go on traction for six weeks and stay out of work for months when "you can go to a chiropractor...[and] can be back on your feet in two weeks and back to work in a month" (p. 7). A friend with scoliosis, she believes, is being treated successfully in this way: "[W]hen somebody tells you you're going to be on traction for two or three months...or you're going to be in casts, and you're going to be operated on and have something broken and reset, and it can go on and on, suddenly you think if you can just go to somebody who can just manipulate it back into place, then there's no need for all this stuff" (Int.#2, p. 7).

CHAPTER 7

GETTING TO THE DOCTOR

I. INTRODUCTION

In contrast to most of the literature on accessibility of medical care, which concentrates narrowly on the cost of services and how this affects utilization, this chapter examines more broadly the dynamics of getting to the doctor. After a look at the financial considerations facing patients seeking specialist care, the ways in which they and their referring doctors solve problems of geographic and temporal inaccessibility are discussed. Barriers to accessibility are traced largely to the ways in which specialists, working within the medical hierarchy and the political atmosphere of hospital organizations, structure their practices and careers.

1. Accessibility: Issues in the Literature

In Canada, the effect of universal health insurance in removing financial barriers to utilization of medical care has been the subject of numerous

studies (Beck, 1973; Enterline et al., 1973; Statistics Canada, 1977; Manga, 1981). By way of contrast, the effects of other barriers to accessibility such as geographical maldistribution of services and delays in getting to see the specialist have received less attention.

The maldistribution of specialists in Canada, while not approaching that of some third-world countries (cf. Navarro, 1974; Horn, 1985a,b), is serious enough that it has attracted attention from "manpower planners". It is typically assumed in manpower studies that needs can be quantified objectively and that underdoctored areas merely need to be brought up to the standards of urban areas with little investigation of the underlying dynamics of the problem. For example, a government committee on physician manpower in Canada came to the conclusion that since there should be one obstetrician/gynecologist for every 18,900 population, the country needed 168 more than it had in 1971 (Department of National Health and Welfare, 1975). However, as Pollett and colleagues have pointed out (1983; 1984), shortages of specialists in obstetrics and gynecology in Ontario might disappear if these doctors followed the British system of taking patients only by consultation rather

than the American system of a mixed primary care and consultant practice, which they have chosen. Their claim that there is not enough consulting work in Ontario is at odds with the claim that there is a shortage of obstetricians here. Clearly, the ways in which specialists structure their careers and practices need to be scrutinized.

On the issue of temporal accessibility, the literature is similarly disappointing. The serious problem of waiting lists under the NHS in Britain has been investigated in clinical studies, but this work does not analyze the process underlying the temporal inaccessibility. Fraser et al. (1974), for example, after documenting significant delays in admission to the East Midlands' hospitals where their study was conducted, as compared to other parts of England, merely urged GPs, specialists and hospital administrators to "get together on the problems raised in this paper" (p. 314). Carson's examination of delays in referral to hospital in Australia shows a similarly frustrating lack of analysis of what is going on. One clue about the pattern of delays, however, is given by an American internist practicing in Alabama (Burnum, 1973). He describes how, "as a practice matures, there is a snowballing accretion of established patients, who

use up most of the nutriment, that leaves less and less room for new patients" (p. 441). However, no link has been made in the literature between how this "saturation" of doctors is achieved and waiting lists- rather, the problems have been attributed to lack of manpower.

2. A More Comprehensive View of Getting to the Doctor

By taking a comprehensive view of medical referral as a silent negotiation among three or more parties, in previous chapters, the influence of patients on the decision to refer and the choice of specialist have been traced. At the same time, pressures to refer from the medical community have been outlined. This chapter concentrates on how the choice of consultant is influenced by specialist careers and practices. When the analogy between patients and referring doctors is examined, it is found that both are sometimes faced with making "tradeoffs" between choosing the most able or trusted consultant and the most available consultant, such that the quality of care that they obtain may be compromised. The effectiveness of the strategies that patients and

doctors employ to get around the barriers is limited, given the relative autonomy of specialists to determine whom they will see, when and where.

a. "Tradeoffs" Between Ability and Availability in Choice of Specialist

How do patients and referring doctors cope with the barriers to accessibility that they often face in consulting a doctor? One strategy pursued by both was to seek services farther afield, despite the costs that this entailed. This process of "shopping" involves moving outside a trusted circle of advisors, which may have negative consequences for referring doctor and patient. It also can be seen to have significant economic costs.

b. "Created Inaccessibility"

There is a great deal of sociological and clinical evidence that specialists structure their careers and practices in ways that do not necessarily match the needs of the community (e.g. Greenfield et al., 1983; Roth, 1972a,b; Sudnow, 1967; Wolfe & Badgley, 1973). In this study, it was similarly found

that career choices made by specialists had a profound influence on the availability of medical services. Specifically, deliberate choices of doctors to superspecialize in small areas of medicine or surgery were found to narrowly restrict choice of consultant by patient and referring doctor. Further, it was found that the decision of the "greedy" doctor to see "all comers" might result in the "revolving door practice". The "streamlining" of a practice by more established specialists, who can afford the luxury of super-specialization in an area of their choice, similarly had the potential to throw referrals in their specialty into crisis.

In contrast to the popular view that superspecialization is a reflection of the "developing science", the point is made here that, with the hospital community as a base, elite specialists are sometimes able to "build" a practice in an area of their choice, where none existed before, while demands for less desirable services such as abortion, treatment for back pain, and marital counselling are inadequately met or met by less prestigious (and perhaps less competent) members of the medical community. The consequences of this career structuring are felt throughout the referral system, but most acutely in

areas remote to the medical centres where superspecialization is supported.

II. BARRIERS IN GETTING TO THE DOCTOR

1. Financial Considerations

Doctors in this study felt that many patients abuse the "free" care available in Ontario, and a few advocated users' fees, at least in the emergency room. Only two said that they avoided referring patients to specialists who extra-billed.[1] In view of the attitudes of their doctors, it was surprising to find that a few patients in the study were deterred by or assumed substantial economic burdens in seeking care. One southern Ontario patient, a teenager on her own with a factory job, said that she would probably not return to an ophthalmologist who sent her a bill, nor will she be able to continue to see a dentist who charged her $110 for her last visit (Pat. 10, Int. #1, p. 6). She also claimed that her boyfriend could not afford to pay the insurance plan premiums and so did not have coverage.

All referrals in northwestern Ontario entail costs to the patient, because although travel grants became available in 1986 to defray part of the costs,

this does not include the one- to two- hundred kilometre trips that are involved for local referral. Further, even with travel grants, some cost is involved. For example, Patient 33 said that she received "$120 but the plane flight [to Winnipeg] was $138 and we had to stay there overnight. And they didn't pay for that" (Int. #1, p. 5).

Substantial financial outlays are faced by patients who choose to seek care outside of northwestern Ontario, or who are referred long distances. Patient 27, for example, bore the cost of her yearly trips to Toronto to see the rheumatologist who was monitoring her condition. "[Y]ou have to look at it as a vacation...The cost is borne by my vacation budget", she commented, "but I wouldn't be down there but for this" (p. 4). The elderly Patient 29 was not eligible for a travel grant when he decided to come home to Ontario rather than seeking care in B.C., where he became ill and required oxygen. He had to pay for three seats on the plane (one for the oxygen tank) plus about $170 for oxygen as well as arrange for his vehicle to be driven home.

Often the costs are prohibitive. For example, Patient 38 said that she would have felt more comfortable going to Winnipeg for a "trial labour"

which could be followed by a Caesarian if things did not go well in her delivery. She added that this "really meant spending three or four weeks...And financially speaking, with two children at home, and we don't know anybody at all in Winnipeg...it would have been financially impossible" (Int. #1, p. 10). Even by going to the hospital in a nearby town, her husband found it difficult to "trek down to visit [her]" (p. 12). Afterwards, she waited several months in "a lot of pain" for a gall bladder operation, "because my husband's a teacher and I had to be with the kids" (p. 10). Patient 39, in deciding where to have her baby, said, "I wouldn't mind going to the States, except for the expense" (Int. #1, p. 11). Because of complications, she ended up in a hospital two hours' drive away, and her husband "had to run back and forth to two hospitals, with his dad in one and his wife in the other" (Int. #3, p. 2).

OHIP remunerates patients for care sought in other provinces or countries that cannot be provided locally, but only according to the Provincial fee schedules. However, patients who choose to bypass local specialists and visit the Mayo Clinic on their own may pay thousands of dollars in American fees. GP 24 thought that even more people would seek care in the

U.S. except for this deterrent. He commented that, "they know that if they go there, they're going to have to pay an awful lot of money" but recalled that one of his patients "went down there and had vascular surgery done on his neck and the bill was $19,000. OHIP paid 10,000, but he's still stuck with 9,000" (GP 24, Int. #1). The man had rejected the offer of a local neurosurgeon to operate on him. Patient 31 similarly decided to go to the Mayo Clinic after local orthopedic surgeons were unable to help her with her knee. She had calculated that it might cost more to go "back and forth" in Ontario to specialists than to go to the Mayo Clinic once. But she worried,

> if I go down there, and this thing costs 10 or $15,000, well, I can't go to school...So far it hasn't cost anything because I got it done in Ontario....But if I go to Ontario anywhere, they're going to keep making me come back and forth...I know $10,000 is a lot of money but my health is worth a lot too.
>
> (Int. #2, p. 5)

A previous trip to the Mayo Clinic for diagnosis of her skin disease had cost her "about $1500", of which OHIP paid about $400. However, she had chosen this alternative because "it was gnawing at me enough that I was going here and going there. I thought about all the money that I've spent on this doctor and that doctor and medications and cremes, and to tell you the truth,

it didn't work" (p. 9). In order to cut costs, she had come back to Ontario to have the treatment that they had recommended administered by her GP (p. 10). Patient 38 suggested that all northern patients weigh the costs of going to one centre or another, and decide accordingly where to go (Int. #1, p. 15).

Some of the travel costs of patients have been reduced by having specialists visit small towns on a regular basis. GP 32, for example, reported that a team of orthopedic surgeons and a dermatologist from Toronto visit his town every three months. As Cardiologist 35 pointed out, such visits suffice for chronic patients who can be seen every six months or for "reassurance cases" (p. 1). Since he doesn't "like flying in small planes" or "driving in winter", these patients have to wait for spring or fall (p. 2). The once-a-year visit of the CNIB "eye van" to northern communities also saves patient travelling for a diagnosis, since "ophthalmologists in Winnipeg will take these people on a surgical waiting list on [an eye van ophthalmologist's] recommendation" (GP 38, Int. #2, p. 16). However, patients typically have to travel to the specialist if more urgent follow-up visits or testing are needed (GP 38, Int. #1, p. 2; GP 34, Int. #1, p. 3). Pediatrician 34 said that his visit to the patient

is typically just to decide which tests should be set up to be done in the city (p. 3). Further, most of these visitors fail to return when they acquire enough patients in the city that they need no longer travel. If the visiting specialists come from Manitoba, they must have an Ontario licence to provide care; otherwise, they can only receive patients to be treated in their own jurisdictions.[2] More important, there may be no financial incentives if the adjoining province pays a lower fee for the service (Obstetrician 34; GP 37, Int. #2, p. 1).

2. Geographic Inaccessibility

As these examples indicate, geographic maldistribution of consultants introduces substantial inequalities even in the system of "free care" that exists in Canada. Little is known about geographic patterns of referral, partly because referral studies have tended to be restricted to single clinics or small numbers of physicians in cities. In this study, it was found that many towns in northwestern Ontario do not have a resident GP, and others go without for long periods of time after someone retires, leaves or dies. Further, "southern" GPs who come up for <u>locums</u>

(arranged through a central office in Toronto) are often not qualified to perform all the procedures that a northern GP might be called upon to perform, such as deliveries (GP 24, Int. #1). However, there did not appear to be a serious problem in access to primary care: travelling a half-hour to an hour to one's GP was not uncommon in southern Ontario either - Patients 5, 10, 11, 15 and 19 all reported that they did so - as a result of continuing to see a GP whom they trusted after s/he, they or both had moved.

Accessibility to specialists in northern Ontario, on the other hand, is considerably different than it is in southern Ontario. There is a hospital every 50 or 60 miles along major highways in the north, but only a few have resident general surgeons and some hold out no hope of attracting any on a permanent or even part-time basis (GP 27, Int. #2, p. 4). General surgeons are also in short supply in northern cities, because outlying regions compete for services (GP 29, Int. #1, p. 1). When neighbouring towns try to lure small-town surgeons or other specialists to visit their town, a scuffle over the specialist may ensue (GP 38, Int. #1, p. 2; GP 32, Int. #2, p. 7). When the surgeon is away, patients wait, or - as Surgeon 32 puts it- "[w]hen I'm hunting moose, they have to go elsewhere"

(p. 6). In some cases, GPs double as obstetricians (as in the case of Obstetrician 39, who had not written his specialty exams); optometrists fill in for ophthalmologists; and nurse-practitioners staff doctorless hospitals in the far north. Because the U.S. suffers the same type of geographical maldistribution of specialists, Internist 40 remarked that patients come to him from as far away as Utah.

For emergency treatment by a specialist, local GPs depend on an "air ambulance" that serves the north shore of Lake Superior and the northern reserves. Alternatively, a relative may have to drive hundreds of miles to a hospital (Patient 38, Int. #1, p. 18). Patients are thankful when a local surgeon can perform an operation that avoids this type of ordeal (e.g. Patient 36, Int. #1, p. 15).

General internists are rare in northwestern Ontario outside of cities, and even in cities, many subspecialties that are "overrepresented" in Toronto are not represented at all. For example, there are no rheumatologists in northwestern Ontario but "[t]here's virtually no hospital in metropolitan Toronto that doesn't have at least a rheumatologist. And many of them have more than one" (Spec. 27, p. 6). GP 29 in a northern city reported that he sends such patients to

Winnipeg, Toronto and Duluth (Int. #1, p. 2). Neither were there any dermatologists in the northwest for several months, so that patients had to be sent to Duluth (p. 2). As GP 24 exclaimed, "You know, that's in the United States!" Further, there are no respirologists or neurologists. GP 25 said he only knew of one or two people who did cardiovascular specialization in addition to general internal medicine, a situation he called "ridiculous" for an area with a population in excess of 200,000.

Until recently, there were only two ENT specialists in northwestern Ontario. GP 25 complained, "I don't have <u>any</u> choices [in ENT referral]" (Int. #2, p. 3). Optometrist 33 observed that ophthalmologists in Winnipeg were failing at the impossible task of trying to serve "a population of a million people in Winnipeg and us in northwestern Ontario too and as far west as Saskatchewan" (p. 1). As an optometrist, he covers an area of several hundred miles and is booked four months in advance (p. 3). Optometrist 38 in a border town refers patients to the U.S. and is lobbying for surgery done there to be covered by OHIP, since "it's an awful long way for someone to go [to Winnipeg] if they could just go across the river" (p. 2).

One psychiatric hospital with seven psychiatrists serves a catchment area that is "half the Province" and a psychiatrist from this region reported that general hospitals may refuse to admit psychiatric patients if they are "difficult" (Education Rounds, McMaster Univ., April, 1986). Similarly, there is such a shortage of obstetricians, gynecologists and maternity beds that Specialist 26 got referrals from across the vast area stretching from Wawa at the east end of Lake Superior, up through Hearst, Kapuskasing, Geraldton, Manitowadge, Marathon and all along the North Shore and west to Atikokan, Dryden and Sioux Lookout (p. 4). Patient 36 noted that there is only one maternity bed and not enough equipment in her town, so that almost all deliveries are sent out to Winnipeg (Int. #3, p. 4). Patient 39 had to drive two hours every time she visited her obstetrician (Int. #1, p. 2). One large border town has no obstetrician, and the resident pediatrician is often pressured to do obstetrics, which he cannot do (GP 37, Int. #1, p. 1).

Inaccessibility to specialists is felt more acutely by the native population in northwestern Ontario, which is scattered along secondary highways and on reserves with only air transportation. Their health care system is administered federally, and some

federally-salaried personnel travel to the reserves where there are nursing stations, but OHIP is billed for doctor visits.[3] Optometrist 33 regretted that he had recently decided to no longer visit the thousand or so people living in nearby reserves, because he had enough business in town (p. 5). Ophthalmologist 38 said that of the 160 people that he saw on a three-day visit on the eye van to an area heavily-populated by natives, he saw only three, with the remaining patients being "the white mining residents of the town" (p. 1). Obstetrician 25 chuckled about native patients in labour missing their planes if the weather is bad (p. 4). Cardiologist 35 agreed that natives often miss appointments when they are unable to get on the plane, and that he had participated in efforts to arrange a transport system for them (p. 7). GP 37 explained that there are a number of problems in getting a native patient to the city to see a specialist:

> [The first] problem is how do they get there?...Then there's the problem of when they're there, where do they go [when] they land in the city...[Y]ou need a nursemaid to take them by the hand and lead them every step of the way...[Y]ou have to make two or three appointments before you eventually get them there.
>
> (Int. #1, p. 11)

The epidemiology of disease on the reserves resembles that of a third-world country, with high rates of

infectious disease, diabetes and pediatric problems (e.g. GP 34, Int. #1, p. 1). Since these problems are dealt with by specialists in Canada, access to them is crucial.

By way of contrast, a Toronto surgeon emphasized that there are few accessibility problems in his city. He hardly ever has to refer a patient outside his hospital:

> I wouldn't even refer to [another nearby hospital], for example. There's nothing that we can't offer in the hospital locally...apart from a special thing like a liver transplant ...[With] first-rate university centres there's no need to refer anybody to the States. Absolutely none. Our OHIP, I think, wouldn't sanction any of that. (pp. 14 - 15)

In smaller cities than Toronto, where a single hospital does not have a good representation of all specialists, referrals are made all over the city (as Modrow, 1976, showed for the city of Windsor). In this case, geographical accessibility may become a problem for patients who do not drive or for elderly patients who are hesitant to use public transit. These difficulties were experienced by Patients 1, 2, 3, 4 and 19 in this study. Patient 2 claimed that he had to miss an appointment with his respirologist one day because he was too unwell and out of breath to walk up the two or three mile hill to the hospital. Patient 10

missed an appointment with a dermatologist which was a three-quarter hour drive away, probably deciding that her skin rash not a serious enough complaint to warrant the inconvenience. Patient 3 also considered skipping an appointment with her ENT specialist that would take a "$6 taxi".

These patients did not complain to their GPs about inconveniences and the GPs did not seem to be aware of their patients' difficulties. GP 2, for example, said that she waits for the patient to raise the issue. GP 5 thinks about it a little more often: he comments that "only about 20 percent will ask me for a specialist that is close. Most of them, I think, know I'll give them someone near here...[but] most of them get driven." (p. 23). In his practice, in contrast to clinic patients, only "the odd one" lives alone. GP 1 was aware of the importance of convenience to city patients when he commented that "[g]eography has a lot to do with it, I mean, people won't go a long way. You know people won't go and see a guy in [a distant suburb] but they'll see someone here" (Int.#1, p. 10). In rural areas, he pointed out that referral has to be for more serious problems: "you can't be sending someone down to the city for [anything]. It's got to be something fairly substantial, because...you've got the

person having to find accommodation" (p. 11). On the other hand, he did not appear to be aware of the problems that his patient had in reaching a specialist in part of the city distant from his home.

3. Temporal Inaccessibility

a. The "Waiting" Room

The word "patient" connotes how the seeker of care is expected to react to delays in seeing the doctor both in getting an appointment and in getting in the office. But not all patients suffer this inconvenience gracefully, and may divorce a GP who becomes too inaccessible.[4]

There are fewer options if the offender is a specialist. One solution by a patient who knows that she can wait for two hours to see her specialist is to "phone in advance" to monitor when he is able to see her (Patient 37, Int. #1, p. 14). Optometrist 38 explained that he is sometimes able to get an appointment with an opthalmologist in a distant city which allows a connection with the bus schedules by phoning and explaining the situation - but, he adds, "mind you, sometimes for those appointments you do have to wait a fair amount" (Int. #1, p. 5). Patient 18, a small businessman, tried criticizing an orthopod who

kept him waiting for two hours in the office, pointing out, "I know you are busy, but so am I" (Int. #1, p. 3). This prompted an apology, but since the man was kept waiting again, he could only assume that the complaint was not taken seriously (pp. 5-6).

Patient 33, a teenage girl, was similarly upset about being put in one waiting room for about half an hour, transferred to another room for 20 minutes, and finally put in the ophthalmologist's office for 15 minutes more. After then spending two minutes with her, he indicated that he would have to look at her through another machine, whereupon he left her "in this other waiting room by this other door. And he went and looked at his other cases, I guess. I saw about 10 of them going at a time" (Int. #1, p. 5). Finally, he looked at her briefly again and predicted a 30 percent improvement in her eyesight in three to four months "[a]nd then he walked out of the room" (p. 5).

b. Delays to Appointment

More problematic is the delay to appointment time, although most patients reported that they could be seen earlier by their GP if they exerted some pressure. Patient 30, for example, explained that if

you make an appointment through "the desk", you would be put off three to six weeks. However, when she calls his nurse-practitioner, an old schoolmate with whom she is the "best of friends", she is able to get in the next day (Int. #2, p. 2). Patient 33, on the other hand, is used to waiting "two or even three months" to see her GP (Int. #2, p. 1) and Patient 39 reported a six month wait for a "physical" (Int. #3, p. 9). In this particular town, the local optometrist says that he can "call over to the clinic or write a note that I want them to be seen right away" so that they don't have to wait so long for eye problems (p. 8).

Delays to see the specialist, again, are more of a problem. GP 21 commented that, "some [city] people think there's a problem if [they] can't see [the specialist] tomorrow. Why can't I see him tomorrow?" (Int. #1, p. 12). Many patients (e.g. Patient 29) are used to "phoning...[the GP] and [getting] in the next day, at the latest" (Int. #2, p. 2), and thus are unhappy that they must wait longer to see a consultant. Patients in this study with chronic rather than critical conditions complained about delays, such as Patient 20, who waited six months for an orthopedic operation, Patient 26, who waited three months with an earache, and Patient 37, who waited three months for a

pediatric specialist.[5] The delays increase as the referring doctor tries to send a patient to one of the "better known ones", commented GP 21. In such cases, this GP says, "I'll pick up the phone and try to get in touch with him and it's not always easy" (p. 12).

Referring doctors agreed, however, that lengthy delays, such as the seven months to one year that some patients must wait for a cataract operation or the two to three months' wait for cardiac stress testing in one city, are serious problems (GP 32, Int. #1, p. 2). For ophthalmology, in the north, "[y]ou can't even get anybody in on an emergency basis", complained Optometrist 33 (p. 1). Internist 29 said that he was even "a little concerned" about the few weeks that Patient 29 had to wait for a biopsy of his lung. However, he had decided that it was not so "overwhelmingly urgent that I want to step in and say it can't wait" (p. 5).

From the perspective of the referring doctor, access to a consultant within a reasonable length of time is second only to considerations of competence in influencing the choice of consultant. In explaining why he chose Dermatologist 21 of all the available dermatologists in the city, GP 21 said, "[b]ecause he's first of all in the building and convenient to send

patients to him. And...[t]here's no delays" (Int. #1, p. 2). The GP used to refer to the senior dermatologist in the city, and then to one who'd been a GP, "but since I am here in this building", he says, "I have switched more and more to [Specialist 21]" (p. 2). He is also happy that the feedback from this specialist is "immediate": "at least within a few days I can have a report back and I know what's going on. I'm very satisfied" (p. 2).

FFS specialists are acutely aware of the importance of temporal accessibility in maintaining their referrals. Gynecologist 19, for example, explained that she has five or six GPs "who refer to me everything", using her "exclusively" (p. 4). "And they also know they can call on me. Day in and day out"."[I]f they want me to do something, I will do it. Because they are counting on me and I can't let them down", she added (pp. 2-4). Neurosurgeon 28 recognized that GP 27 must be using him consistently because the GP has gone through a trial and error period of sending him cases and has been happy at his availability. Comments the neurosurgeon, "He knows that if he needs me...he can fall back on me" (p. 5). If a referral is made through his secretary, a patient will wait three months to see him. But if the physician calls directly,

as does GP 27, the neurosurgeon will see the patient as soon as he can.

In their own referrals, specialists find temporal accessibility to be of great importance. Orthopod 18, for example, who has one internist for all his pre- and post-operative patient care, chose this man because he is available during the day to do investigations when labs and other support systems are open, while some other equally competent internists might try to pursue the cases in the evening when the labs are closed. Further, the chosen internist is always available in the hospital, whereas a GP would not be (p. 7). The internist has specialized in "preop" (p. 10), unlike other internists whom the surgeon is forced to consult when the preferred man is away.

In view of the importance of temporal accessibility in referral, then, problems in this area are particularly perplexing for both patients and referring doctors. The traditional explanation for minor delays, offered by a Toronto surgeon, is that "[w]ith some specialties, they have to spend an hour examining a patient...So they're much more time-constrained. They can only see four, maybe five patients in an afternoon, whereas I'll see 20" (p. 10). To explain delays of several months, however, such as

those in orthopedics and neurology, requires a closer look at the way specialist careers are structured. After a consideration of how referring doctors attempt to get around these barriers, the effect of specialist careers on accessibility is examined.

III. GETTING AROUND THE BARRIERS: MAKING TRADEOFFS

Financial, geographical and temporal inaccessibility place both patient and doctor in the position of having to "shop" for better service. In the process of "shopping", both have to make decisions that involved tradeoffs between getting the best and getting an available consultant. However, the fact that patients pursued strategies similar to their doctors in dealing with inaccessibility was not appreciated by most doctors, and most patients were unaware of the "tradeoffs" being made by their GPs.

1. "Tradeoffs" Made by Patients

Patients drew attention to the fact that there were "two kinds of doctor": those you can see right away without waiting a long time, including the "revolving door" types; and the ones that you wait a long time for and spend a long time with, but whom you

really like and trust. Some patients in the study reported having chosen to leave this kind of doctor and to seek the "other" kind for reasons of convenience, recognizing as they did so that they might be in a tradeoff situation between ability and accessibility.

Couples who had "split allegiances" - that is, the husband saw a different GP than his wife - are the best illustration of the "tradeoff" situation. Although the majority of married couples in the study (23 of 29) went to the same GP, in a few young urban marriages, one or other spouse had opted for a more convenient doctor, thus trading off something they valued for increased accessibility. The husbands of Patients 14 and 15 had remained with the old family physician while their wives switched to a female GP. The wives in couples 11 and 12 remained with the old GPs while their husbands switched for convenience.

Patient 14 had wanted "someone young" to follow her children (Int. #1, p. 6), but her husband remained with his old doctor, whom they both feel is "the best doctor they ever had" (p. 26). The husband's reason for remaining was that since the old family doctor is "the best", he is willing to wait for him (p. 4). The wife switched because even though her husband's doctor is a "wonderful doctor", "who's got time nowadays?" She

comments that, "it was worth giving up" because, for one thing, it's very difficult to wait for hours in a waiting room with little children (p. 6). Also, in the wife's GP's practice, other doctors cover for her, another point of convenience.

Patient 15 and her husband have similar split allegiances, although the wife manages to see two different doctors, depending upon the nature of her problems. She likes her female GP so much that she has retained her despite moving to the other end of the city (Int. #1, p. 3). Her husband prefers his mother's GP, who, like GP 5, spends a lot of time socializing with the patients and knows them "like the back of his hand" (Int. #2, p. 1). Although neither husband nor wife have time for this kind of socializing, both say they like this doctor (p. 12). The wife's doctor is clearly more sufficient and not necessarily less competent. The wife, a nurse, who is concerned about convenience, acquired a second GP for her respiratory problems. He was "closer" and thus useful to consult for less important problems, while the woman doctor was retained for the important problems around her pregnancy (Int. #1, p. 3). The male doctor dealt with her "upper half" and the female doctor dealt with her "lower half", a practice that is reported as

commonplace by female GPs. This patient feels that her two-timing is justified by the lack of geographical accessibility of her original GP (Int. #2, p. 9).

Patient 11 was in the process of "divorce" from a GP that everyone in her family likes (Int. #1, pp. 5-6). As with Patients 14 and 15, she had to choose between a well-liked doctor and a convenient doctor (who will see her within an hour). The well-liked doctor was always willing to take his time and talk to her and make sure that he has answered her questions. But convenience is important - she works. Now her family, and she, belatedly, are switching to a closer doctor (p. 4). She still finds it convenient to see the former GP after work for a prescription, but she would have to switch entirely if she had to go more often because waiting "three hours" is too inconvenient. "I usually take my books because I manage to do a lot of reading", she jokes (p. 5). She is sure that her old GP will understand and even appreciate her gradual defection.

By way of contrast with these examples, Patient 19 refused to trade off someone she trusted for convenience. When she first moved away from the neighbourhood of a GP with whom she had developed a trusting relationship, she opted for convenience in

switching to a new female GP near her new home, but this woman proved unresponsive, giving her an appointment four weeks into the future (Int. #1, p. 4). Despite the recommendation of a neighbour for this new doctor, the bad experience made her decide to go back to her current doctor, even though it involves a $5 taxi, since she doesn't drive, or "slogging through the snow with three kids on the bus". Reflecting on her move away from the GP's neighbourhood, she said, "I was very sorry I'd left there, because I had small children and I had to be able to walk to the doctor" (p. 4).

Patients in remote areas might be unhappy with the ability or accessibility of their local GPs, but they do not have the options of young urban patients. In this region, it is the GP who moves and the patient who remains. Patient 38, from Manitoulin Island, experienced a different doctor "every two or three years because they didn't stay" (Int. #1, p. 17). Patient 25 had been seeing her current GP for six months and the previous GP for only a while longer. She'd had four doctors for her son, who was only two years old. She knew of two longstanding doctors in the next town 15 miles away but avoided one for reasons of competence and the other she found inaccessible. For convenience, Patient 26 kept in touch with a GP whom

she felt had mismanaged her obstetrical and gynecological problems. She liked her mother's doctor in another town, but decided that the one- to two-hour commute to his office would be too far to travel on a regular basis. A number of other patients opted to see their local doctors rather than travel further afield, and GPs sometimes expressed concern about this (e.g. GP 34 regarding the "complacency" of native patients, Int. #1, p. 2).

Patients in remote areas also make financial tradeoffs to get access to specialists. The case of the Mayo Clinic has already been discussed. Another example has to do with specialists who extra-bill. For example, Optometrist 33 explained that even though one ophthalmologist that he refers to charges "$200 an eye", "there are a lot of people willing to pay that to get cataract surgery done by him" (p. 4). Further, as GP 32 points out, "if the patient is referred by the optometrist to the ophthalmologist, then the patient does not get their travelling expenses" (Int. #2, p. 4). However, presumably to avoid waiting months to see the GP, some patients will pay the travelling expenses.

2. Tradeoffs Made by Referring Doctors

Like their patients, referring doctors sometimes find themselves "trading off" choosing the most trusted consultant vs. the most accessible consultant. In the urban situation, where the referring doctor has available a number of equally competent consultants in a field, little is given up in choosing the most convenient consultant. Specialist 1 believes that this is why he was chosen out of a number of possibilities:

> [T]here's not much to choose between one gastroenterologist and another one [here]. All of us do the same procedures, with about the same amount of skill. So from the specific technical point of view, there's nothing to choose between us. People therefore tend to make their decision on the basis of the service they get ...Now this [GP] admits to another hospital and therefore it is more or less unusual for me to get referrals from him. On the other hand...there's almost no referral to my office that gets an appointment that's more than two weeks away.
>
> (Int. #1, p. 3)

Although Specialist 1 did not know the waiting period of every other gastroenterologist in the city, he knew that his "colleagues at the medical centre, in spite of the fairly large number of them, have waiting periods of up to six weeks. Now in my opinion", he says, "even

two weeks is often long...[T]he nature of the problem is that we should get on with it" (p. 3). He attributes the delays to "style" of office operation, adding "I have a policy that whenever my book is getting past two weeks, then my secretary and I have to sit and review it. And I'll introduce an extra office just to get it back to where I'm happy with it" (p. 4). Cardiologist 35 and Surgeon 39 described similar practices to keep down their waiting times. The surgeon said that his experience in the NHS in Britain, where "[f]or varicose veins, you could wait two, three, four, five years", had taught him that "waiting was a bad thing", and so he promised himself "never, ever to have a surgical waiting list" (p. 7).

Considerations about convenience were involved in the referral of Patient 17 to a specialist in another hospital, although in this case, the referring doctor clearly gave something up in not referring to an older, closer orthopedic surgeon who has a good reputation and a good working relationship with the GP. The older consultant had even seen the patient before, but the GP didn't want the patient to wait two months to see him. An orthopod in a different hospital gave him an appointment within two weeks (Pat. 17, Int. #2, p. 2). The new orthopedic surgeon had no idea why he

was chosen, noting with concern that this GP has never referred to him before and that he has no privileges at this GP's hospital. The GP admitted that he had some concerns about the orthopedic surgeons operating out of this distant hospital, but was willing to "try out" this particular man. He has been forced to make a tradeoff here - when blocked in referring to the "guys he grew up with", he must look further afield for someone accessible.

On the other hand, like patients, doctors will often put up with some inconvenience to keep a good consultant. GP 32, for example, talked of a visiting specialist from over 1000 miles away who was giving his patients such good service that he would not switch to a closer consultant (Int. #1, p. 2).

Alternatively, tradeoffs are made in which the referring doctor has qualms about the competence of the chosen consultant but refers because he is the only accessible man. This situation arose in northwestern Ontario where there were few alternative specialists. GP 25, for example, reported that he had been referring all cases of a particular type to Toronto until recently, when a new specialist had arrived in the area. However, he was "disappointed" with the result of the first case that he had sent this new man (Int. #2,

p. 11). Specifically, he had found the feedback from the consultant's letter "negligible". In the city, he probably would have avoided this man after getting off to such a "bad start", but here, because of the lack of availability of alternatives, he will continue to send cases and hope for the best.

GP 29, in a clinic where most referrals were made within the group, said that he preferred the internist to whom he'd referred Patient 29 because he had fewer patients and spent more time examining the patient (Int. #2, p. 2). The specialist himself admitted that another doctor actually had "extra training in [this specialty] more recently than I have" (p. 1). While perhaps there were other choices with more ability, however, he "worked hard at having a short waiting period" (p. 2). Thus the referring doctor had made a tradeoff.

Like patients, for minor problems, referring doctors are not so particular about their choice of consultant and, in these cases, considerations of convenience may predominate. For example, GP 32 says that he will send patients to the travelling eye van in the summer "for little things that you don't want to make a special trip to Winnipeg" (Int. #2, p. 5).

GP 27 in northwestern Ontario felt that he had to maintain contact with specialists who don't have the best reputation just because of their promptness in giving him appointments. For example, there is a "nasty" orthopedic surgeon who will see people quickly - in a week - and will see them at inconvenient times. Thus if the consultant is accessible in a situation where alternatives are relatively inaccessible, s/he will still get referrals in spite of a bad reputation. This GP's alternative is to send patients further afield to "big city clinics", but then he is in a position of not having first-hand knowledge of the consultants and worries that his patients will be treated "like numbers". This in fact appears to have been the experience of Patient 28 in Winnipeg.In the case of his Patient 27, on the other hand, the patient, GP and the specialist all agree that it is worth the maximal inconvenience of having the patient travel over 1000 miles once or twice a year to receive care from one of "the best". As the specialist explained,

> if you take off...the health economist's what and say if <u>you</u> had an illness which was unusual...like hers- would you want to have an opinion from somebody who's seen, maybe, 200 of those or from somebody who's seen two?
>
> (Int. #1, p. 3)

The process of specialization increasingly puts referring doctors in a position where they must make decisions involving tradeoffs between competence and accessibility. The most unsatisfactory tradeoff of this type in the study occurred with Patient 19's referral to a thyroid specialist. The specialist speculated that the GP may have chosen to refer to him because the original GP in her group practice had referred to him for 30 years. However, the GP indicated that this was not the case. Like GP 2, she said she wouldn't refer anybody to this man. She was worried about his bedside manner, commenting that he was "downright rude with patients, he hates fat people and he basically tells them as much" (Int. #1, p. 6). But she also had no regard for his ability, commenting, "I don't think that his clinical judgement has necessarily kept up with the times" (p. 6). The real reason for the referral was that there were limited alternatives. There are only a few men in the area who have a license to administer the type of treatment that this patient needed, and when the GP referred the patient to her favourite internist, he referred the patient on. Although the consultant wasn't her choice, she had to go along with it, although neither she nor the patient were satisfied. When another specialist suggested that

the patient needed to go back to the original specialist, the patient refused to consider it, insisting that there was "no problem" at that time and adding, "I need him like I need a hole in the head". This prompted the other specialist to calmly comment, "If you don't like the goods in the store, you shop in the next store" (Pat. 19, Int. #2, p. 2). However, given the superspecialization in the area and licensing of the treatment, the alternatives were limited.

IV. GETTING AROUND THE BARRIERS: THE PROCESS OF SHOPPING

1. Shopping by Patients

In the previous chapter, a breakdown of trust between doctor and patient was identified as the reason for a patient seeking another doctor. Patients may also decide to seek medical services elsewhere for reasons of convenience. Patient 31, for example, explained that instead of travelling around Ontario to various specialists, she would rather go to the Mayo clinic where "the average person is in and out in a day", and

she might be there "a week" at the most (Int. #2, p. 5).

Patients who change doctors are called "shoppers" and are anathema to some GPs, such as 16 and 21. Rather than recognizing that these patients are struggling with the same kind of tradeoffs between ability and accessibility that they themselves face when seeking a consultant, they instead choose to see the patients as opportunists. The bitterest comments were reserved for patients who "crash the gates" by calling an ambulance or by going to the emergency department to be seen right away. Doctors in northwestern Ontario tended to be more tolerant of "shopping" - Surgeon 32 even suggested that it was good to have two clinics in his town because "if the patient gets dissatisfied with one, they can go to the other. And nobody minds it, you know" (p. 5). Patient 36 similarly reported that there was no problem switching GPs - "you can see whatever one you want", she said, and if it bothers them, "they haven't said anything" (Int. #1, p. 2).

On the issue of the emergency room, GPs in this study felt that most problems that patients sought emergency services for after hours could probably wait until morning. Patients themselves perceived a lack of

accessibility to their GPs after hours, a phenomenon that has also been reported in Britain (Cartwright, 1981). Patient 32, for example, reported that she didn't call her GP when she thought she was having a heart attack because "they won't come to your house anymore...They'd say, go to Emergency" (Int. #1, p. 13). In this particular case, the GP was unavailable, and so the patient went to see a surgeon that she had seen previously. Patient 35, a native woman with documented heart problems, reported that she called an ambulance but that it "didn't come right away anyways", so that she had to get her son to drive her to the hospital (p. 5).

The fact that patients can "short-circuit" the system by going directly to a specialist or to the emergency department provoked comments from both GPs and specialists. Specialist 5, for example, said that he received many inappropriate calls from patients when they could not get in touch with their family doctor, even when the problem was not related to his specialty:

> [T]hey call you because they can't find any other doctor. They don't try hard enough. They call the answering service and the answering service says so-and-so is looking after his practice tonight, and they say...I never met him before...[Y]ou try and reassure them that they should either go to the doctor who is related to their

> operation or go to emergency. But you get lots of calls like that.
>
> (Int.# 1, p. 14)

Specialist 13 had no sympathy for patients of his who showed up at the ER, whom he saw as involved in a kind of "power play" (p. 7) which he gets around by having emergency staff see them.

This hostility towards "after hours" patients was shared by GP 21, who believes that persons who abuse the system in this way should be charged for visits:

> They should pay for it. Because the patient always says, I didn't know this wasn't an emergency. But he has been working until five, and then he goes...When it is convenient. So here, for my investment of one dollar, I get a $100 reward...If I took a throat swab for everyone that had a sore throat, my gosh, it would go into the millions in no time!...At the hospital [the patient] gets a blood count, he gets a urinalysis, he gets a chest X-ray, he gets, God knows, an IVP, ultrasound and so on, and so on, and he'll say, ha, ha, I got everything done...[Y]ou cannot say this is not an emergency!...[Y]ou blow your head off, every second or third case, but 70 percent is not an emergency.
>
> (Int. #1, pp. 15-16)

Most urban GPs spoke of trying to discourage patients from using medical care after hours. For example, GP 19 said that she has taught patients to take responsibility for fevers and diarrheas at night but has had trouble with patients of the elderly physician

in her group practice "who are very used to just walking in even without appointments" (Int. #1, p. 11). The three other younger GPs in the practice try to discourage people from seeking care at night, but GP 19 knows that when the patients are told that they will be seen in the morning, they probably go to the ER (p. 12). Her own patients sometimes go there and she only finds out later. GP 14 noted that her night calls have dropped "drastically" in the past few years since her patients have somehow gotten the message that primary care after hours is to be obtained from the ER (Int. #1, p. 21). She speculates that patients are afraid to bother the GP after hours in case the GP "holds it against them" (p. 22). But she finds the situation mysterious, given that her office has "24-hour coverage".

There were a few patients in southern Ontario who thought of calling their GP in the event of an emergency. Patient 13 said that she and her family always called their "old style" practitioner after hours, since he would respond personally, even setting broken bones (Int. #2, p. 8), a task not typically performed by urban GPs. Patient 16, who also had a good relationship with his "old style" GP, checked with him first about his chest pain, waiting several hours

before going to the ER. Another patient of this same GP knew that the doctor wouldn't be available and went directly to the ER when he was involved in an accident. The specialist tried to redirect him back to his GP a couple of days later (Int. #2, p. 2), but the patient thought of the GP as an unnecessary step in the process.

Most young urban patients were unaware of the hostility of their physicians towards them seeking out such care after hours. Patient 14 and her husband, for example, perceived that an "answering service" was an indication that the GP was "out of bounds" and felt that their behaviour in consulting the ER was quite acceptable. They had to drive right past the GP's house to get to the ER, but wouldn't think of "bothering them". Only once did the husband speak to the doctor in front of their house "because the[ir] baby might die" (Int. #1, p. 4). The couple felt strongly that GPs should only be consulted between 9 and 5 because that would be the way they would like it if they were GPs. Besides, they argued, the ER is "there for that purpose" - if you went to the GP with a child with a fever, the GP would just refer you on anyways and it would be "one more step" to waste time (p. 23). When the wife broke her arm during pregnancy, she went

straight to the closest hospital (not their GP's hospital). She realized that this caused problems for their GP, who still had not received a report on the incident two weeks later. But this was an emergency and there was no time for the GP (Int. #1, p. 1; Int. #2, p. 3). With her grandmother's suspected heart attack, the patient also rushed to the hospital. On the other hand, for something less serious, like her first miscarriage, the patient was content to call her GP first (Int. #1, p.8) and to go to the GP's hospital, which is farther away than the one she went to for her broken arm (p. 3).

Patient 15 went to the ER when she began to bleed during pregnancy, arguing, as in the broken arm situation, that it is silly to go the the GP who will only send you to the hospital anyways (Int. #1, p. 1). She also went to the ER later with premature contractions (p. 2). She thought about asking the GP whether a trip to the ER was appropriate, but got someone "on call", so she told him she was going to ER rather than asking.

What were the GP's feelings about the three visits of Patient 15 to the ER during her pregnancy? The GP felt she could have handled the first two ER visits, which involved just some minor bleeding and

contractions (Int. #2, p. 5). She was a little disappointed that the patient is a nurse but still does not know that such symptoms are not particularly serious. She imagines that the patient may have just panicked. A threatened abortion may have been indicated if the bleeding was bad enough, but it was not a legitimate visit, according to the GP, because nothing can be done for a threatened abortion. The GP knows that "emotion" takes over in such cases: "you don't totally use your rationality" (p. 6). The third visit to the ER just before the birth is still a mystery to the GP, who has no record of it, but she thinks this visit may have been appropriate, because the patient was admitted overnight.

Because this was not a study of emergency room usage, it is difficult to say whether physician complaints about widespread inappropriate use of these services is warranted. The complaints only occur in urban areas where GPs seldom meet patients in the ER after hours, and the problem might be solved if the GPs, like their northern counterparts, assumed these duties.[6]

2. Shopping By Referring Doctors

In an ideal world, all of the consultants chosen by a referring doctor would be competent and responsive in giving appointments. However, sooner or later, all GPs are faced with having to shop for a consultant who is more accessible. As GP 1 put it, "[p]eople have a network. You have a number of people that you send folks to first, and if you can't get them around a common problem, you send to someone else" (Int. #1, p. 7).

Shopping involves difficult situations, as illustrated by GP 30's statement that he is not prepared to take the "cover" of his first choice of consultant if the first choice is not available (Int. #2, p. 15). Obstetrician 34 made the remark that when he and his wife chose an obstetrician, they looked not only at the obstetrician but the person she shared call with, avoiding consultants who had "jerks they share call with" (p. 16). GP 30 maintains "preferred" consultants to whom he "will send certain types of surgery or certain types of problems", but "wouldn't send all problems to one in particular" because in his city, "you don't have the number of surgeons that you can send all of your hernias to one and that sort of

thing" (Int. #2, p. 15). He had two "preferred surgeons" for the breast lump problem presented by Patient 30 and beyond these two, he was agreeable to going further afield because he knew that the problem would not be appropriate for the other surgeons in town. His strategy for most areas of referral is to "twin but to keep enough of the other avenues open that you're covered...so you don't have to resort to taking your turn in the line" (Int. #2, pp. 15-16).

While such "shopping" is generally considered to be unacceptable when done by patients in Ontario, it is a necessary part of the clinician's practice of referral. GP 5 describes how he recently shopped for a case that he considered to be an emergency:

> I pleaded with the nurse - see [who] you can get...[One neurosurgeon] was away, he's always away, so I got [another] and I said, please see him early, but they gave him an appointment for six months. So I said, that's ridiculous. I said [to the nurse], tell them what the fellow's got and to see him earlier. And sometimes if they can't, they'll say, get someone else to see him in the next three or four weeks.
>
> (Int. #1, p. 18)

Specialists report that they usually schedule their time so as to leave room for such exceptional cases, although they are unhappy when they are "second choice" at an inconvenient time. Specialist 1, for example,

noted that a few "high profile people" infrequently refer to him but tend to call at inconvenient times when they are unable or unwilling to call their regular consultants and are shopping (p. 8). He says that he cannot say no to these shoppers:

> [I]f it is a Friday and if at 5:00 I get a call saying...Dr. So and So wants you to call him, I more or less have to call him. It's not very easy to say, no, I don't wanna see your patient. But it's a great irritation, especially when the disaster turns out to be something that could have been more appropriately booked into my office and wait for two weeks.
>
> (Int. #1, p. 8)

Specialists who are building their practices are generally tolerant to such requests. As Specialist 1 points out, the requests are often justified, and, in any case, appropriate or not, they are "business", that is, "how we all make our living".

Receptionist 2 brought out a box of cards to explain the mechanics of "shopping". These cards, sent out by new specialists announcing the opening of their offices, were used regularly by the GPs in the study, and could be found taped to the walls of their offices. Ophthalmologist 38, for example, said that he sent out "six or seven hundred" of these cards (p. 12). The receptionist pointed out that they worked well for

awhile until the new specialist built up his practice and became as inaccessible as established consultants.

Cardiologist 8, who had just begun practising and was still building up his practice explained that, "in your first six months of practice, you can see some people usually within two or three days" (Int. #1, p. 12). However, since you "tend to build quickly", this drops off after awhile, but you remain responsive to emergency cases. On the issue of waiting time, this cardiologist did not see local cardiologists competing with each other to get patients by reducing their waiting times. Instead, the young cardiologist believes that since "there's a lot of work to be done" and "people are pretty busy" (p. 11), a more cooperative system prevails among these specialists. For example, they cover for each other in emergencies. Ophthalmologist 38 is also a new practitioner building his practice who points out

> that a lot of people will start off in a situation like me, taking anybody who wants to be seen and then once they get busy, or they see their referrals going up and they start booking further in advance, then they cut it off and say, OK, referrals only.
>
> (Int. #1, p. 10)

GP 1 argued that in most specialties in the urban location,

> there's not much competition. Not unless the competition comes from the really younger guys who provide...a faster consultation and have a much better knowledge of CME activities, and then there are the older fellows who have been around for a while and don't need the business as much. (Int. #1, p. 8)

Ophthalmologist 11 agreed that the orderly practice of allowing new practitioners to "pick up the slack of the older ones" until their practices are full up, prevailed in his specialty. As in cardiology, the distribution of referrals was cooperative rather than competitive, with senior consultants often suggesting the names of new practitioners to referring doctors (p. 4). A more competitive arrangement among opthalmologists exists in another city that was studied, where Optometrist 38 reported that he encountered difficulty in finding another opthalmologist. The optometrist had been having problems referring patients to an ophthalmologist who was "very gruff" to them and was unable to get any recommendation of who else to see. He said, "if you ask if there's someone else you could recommend, [they'd say] no we can't recommend anyone...I can't give that information out" (p. 5). He felt that in such a competitive situation, "if you're not happy with one,

you don't really know where to start to get another one" (p. 7).

In some specialties, shopping is not an occasional event but a chronic and crisis situation in which no consultant can be found who will see patients with certain problems within a reasonable time. GP 21 claimed, "an appointment in orthopedics is very difficult to get. It might be weeks and weeks and even months" (Int. #1, p. 11). He said that he couldn't even get appointments for patients with back pain and thus often had to refer to whomever was on call. One way to insist on an appointment is to call the orthopedic surgeon directly, but the GP does not do this in every case, because, in his words,

> I certainly do not want to press them into something: he has to be seen tomorrow. If it is urgent, there is an orthopedic clinic at [the hospital] where every day, someone is on call, and I do send a person there and say, look, we have to look after them right now. Not in a month. (p. 11)

However, he admits that he makes more phone calls to orthopedic surgeons than he does to other specialists. In cardiology, by way of contrast with orthopedic surgery, patients

> can be seen, if it's necessary...the same day. Or if they can get an appointment within a few days, I don't think you make much of a fuss. And I

> wouldn't refer them if there's no need to, they know me. (p. 12)

GP 10 also says that he waits two to six months for orthopedic appointments and often "ends up with someone in another hospital, where you're dealing with someone you don't know" (Int. #2, p. 3). GP 14 agreed that orthopedics was in a class by itself because of the unreasonable delays for appointments and nastiness to the patient (Int. #1, p. 15). Like GP 14, GP 5 explained that the situation in orthopedics was so critical that he "dives" onto any new practitioner:

> [W]e use [new orthopedic surgeons] as fast as we can! Right away! They're not new very long. This came up a little while ago (he picks up a card and reads a name). Unless you phone 'em up right away - he's booked up solid now too. And nobody really wants to do backs because most of them are unrewarding...[O]ne back a day, one back a week. That's all they want to see...[I]f you got in five more orthopedic men, ten more orthopedic men, they'd all be busy right away, but nobody'd have any operating time... They're only allowed so many hours a week to work...
>
> (Int. #1, pp. 19-20)

Similar problems exist in psychiatry in the urban location, about which a number of GPs complained. GP 14 commented that she did considerable "shopping around" until she discovered a local clinic to which she could make psychiatric referrals:

> [W]ith psychiatry people you wait quite a while. Yeah, and I think there's a bit of a problem there too because it's one area where the specialists have their likes and dislikes. A lot of them have honed down and do not necessarily want to do all aspects of psychiatry ...A few of them do <u>not</u> want to do marital counselling. A lot do not want to treat any kind of drug-alcohol problems...[I]f you're talking about an emergency...they can't see them...There's a class distinction. They're not going to see the young girl who's living common law who's being beaten by her husband - they don't want that...You have to go to the community clinics...I do not know any person medically that I can really feel good about sending them to. It's a real problem.
>
> (Int. #1, p. 16)

Shopping for a new specialist is thus difficult and hazardous. In the hierarchy of medical tasks, popular specialists perform the most desirable ones, while "backs", abortions and counselling of drug problems are handled, if at all, by less popular clinicians.

V. SPECIALIZATION AND ACCESSIBILITY

How do the ways in which specialists structure their careers affect accessibility to care? Most basic is the decision to accept referrals-only. In cities, the operation of groups limits referral choices, and the superspecialized world of the medical centre affects not only urban, but more remote referral

patterns. The decision to accept only patients with certain interesting disorders further limits accessibility.

1. Referral-Only Practice

Accessibility to medical care in Ontario has been fundamentally affected by the fact that the fee schedule rewards referred rather than off-the-street consultation of specialists. Thus specialists might be expected to structure their practices so as to maximize their referrals. However, this basic fact was almost never mentioned by participants in this study. Instead, they talked about a specialization that they had developed to attract referrals in a particular area as a "career choice". When the trend was discussed, it was linked to geographical location. For example, one specialist explained that it was not practical to "close" a practice to "referral only" in large cities: "no one sets up consults-only...It's just a question of supply and demand. The more [specialists] there are [of a particular type], then the more competition. And the more you take in patients [directly]" (Spec. 30, p. 18). Optometrist 33 agreed that "in a city...a lot of people directly refer themselves to ophthalmologists

...[but not in] small towns" (p. 3). In centres smaller than large cities, referral-only has become a predominant mode of practice in Ontario and specialists in this situation reported that they had been encouraged to "close" their practices to referral only by colleagues.[7]

2. Specialist Careers and Geography

a. City Practice

In two of the cities studied in this research, a few multispecialty group practices involve financial commitments to refer patients within the group. This may have been a hold-over from pre-OHIP days when patients were scarcer, and most GPs in this study emphasized that they were not involved in such restrictive arrangements. However, while this is no longer enforced "within the major groups", as GP 30 explains, even when it is not, "they have a token suggestion that you refer within the group" (Int. #1, p. 1). GP 29 agreed that three-quarters of the referrals in his clinic were made to within-group specialists, with the remaining referrals to specialties that are not represented within the group (Int. #1, p. 3). This arrangement is reminiscent of

Hall's (1948) description of the referral systems within Chicago hospitals. GP 30 says that it is disappearing, because to the extent that a practitioner is "established", "they don't worry about the security of their position and they refer anywhere" (p. 1). However, he admits that even after acquiring several thousand patients, he still occasionally thinks twice about not referring patients to the local orthopedic surgeom "who had a lot to do with encouraging me to stay within the local area" (p. 8).

Financial partnership is also now avoided by many northern specialists. As one man who was just opening a practice commented, "I don't want any restrictions being put on me". He had heard that referrals in his city are polarized such that for "specialists of which there are more than one, [each specialist] tends to get [patients] referred by one group or the other" (p. 6). He thought that there might be an advantage to such arrangements if there was a great deal of competition among practitioners of his specialty: "if I was the fifth [man] in here...I might have rethought going privately and may have gone into one of the clinics" (Specialist 30, p. 2). However, he noted that even in cities where there is no shortage of specialists, new practitioners seem to have no problem

getting referrals and so he did not want to be limited in this way (p. 3). Obstetrician 34 felt a commitment to the northwestern Ontario GPs whose referrals got him started, but he foresaw a gradual withdrawal as he builds up his city practice (p. 5). He has been blocked from getting referrals in his home city, where new GPs are actively "recruited" by specialist-dominated clinics, but has been able to build up an off-the-street practice along with his rural visiting practice (p. 12).

Even if GPs are not financially or socially committed to referring to consultants within their clinic or hospital, there is still a preference for referring within a group. Specifically, if the patient is going to be hospitalized, referring to a consultant who practices in the local hospital makes it easier for the GP to visit the patient. As GP 1 puts it,

> it's a real pain to go to more than one hospital. I mean if you can imagine how many hospital patients you can see in a period of time and you've got four or five hospital patients, it can take half a morning.
>
> (Int. #1, p. 7)

Neither does the specialist wish to undergo the inconvenience of having patients in several hospitals, whether he practices in a city in southern or in

northwestern Ontario. As Radiologist 36 points out, when he visits one town in northwestern Ontario with two hospitals, it can "really waste a lot of your time" just wandering from one hospital to the next (p. 18).

Specialist 3 recalled that "at one time, I could start out my day by doing a couple of cases at [one hospital], then up to [another] for another case or two, and then over to the [third] for another case or two, and it was completely chaotic..." (p. 7). Since the city hospitals have asked specialists to choose a single hospital, this specialist no longer gets as many referrals from GPs in other parts of the city, who send to their local specialists unless these consultants are away. He suggests that admitting a patient locally means "the family doctor will be more inclined to be able to come in and see them" (p. 8). However, where it can't be helped that a patient must be admitted to a distant hospital, he feels, the GP's presence can be dispensed with. "[I]f they come in, it's just to cheer the patient up a bit", he points out (p. 8). What is most important to him is that <u>his</u> patients are nearby. This geographical segregation of specialists and referring doctors sometimes means that the patient cannot have both GP and specialist involved with the case. Patient 31, for example, recognized that she

could not be operated on by the orthopedic surgeon of her choice with her GP present, because they worked out of different hospitals (Int. #1, p. 21).

Specialist 25 explained that obstetricians in the north and south ends of the city in which he operates also divide the city into segments: "the patient populations are to some degree separate" (p. 5). Perhaps the obstetricians "should work more closely together" to conserve resources, but they prefer not to cover for each other because it's a half-hour drive from one end of the city to the other. They are "too far apart" so they "deliver their own". In contrast to his patients, many of whom travel hundreds of miles to him, this man is "less than a mile away" from his hospital, so that he "never misses a baby" (p. 5). Obstetrician 34 argues that a coalition of obstetricians in a third city have also been unable to work together - they are "antisocial individuals" (p. 13).

b. Remote Practice

The nature of the referral system in remote areas is also largely determined by the ways in which physicians structure their practices and careers. Most

fundamentally, physicians decide where they will practice in Ontario, and few choose rural practice. The resulting acute inaccessibility that exists, for example, in northwestern Ontario, has been described above. In some cases, only physicians from the third world can be attracted to practice in remote areas (GP 30, Int. #1, p. 6). In terms of referral, a "boycott" cannot be maintained because there are no alternatives in many specialty areas.

A less visible effect of the decision on the part of most doctors to practice in urban areas has been what a few physicians called "two tier medicine". As Specialist 36 emphasized, practitioners find it threatening from a medicolegal standpoint to practice with unsophisticated equipment beyond their narrow specialties, as is typically required in remote areas. In his specialty, "everybody does ultrasounds" but there is no ultrasound equipment where he visits in the north. Surgeons there may enjoy "the challenge" of general medicine where "there is never a dull moment"- "it is the attraction, but it's also a detraction" (p. 10). Surgeon 39 agreed that ,

> The world is changing, and what people don't realize when they get things like CT scans, is [that] as the big cities develop and become more sophisticated, it becomes more and more

> difficult to diffuse that down to the periphery.
>
> (Int. #1, p. 9)

The consequence of this process, according to Ophthalmologist 38, is that,

> [Y]ou may have some overworked general surgeon up there doing the urology, doing the orthopedics - he's been in practice 20 years and hasn't had the time or perhaps the inclination to keep up..." (p. 11)

Government policy does not address this problem, and may actually foster "two tier medicine" by attracting a type of practice to remote areas in which the emphasis is on making money quickly. Any physician who chooses rural practice can be assured of what GP 30 called "a good volume practice almost instantly" (Int. #1, p. 6). In addition, government offers generous financial incentives to practice in the north (Spec. 29, p. 14; GP 34, Int. #1, p. 3). In the view of Specialist 36, this may have selectively attracted physicians more interested in "money" than in a "commitment to service" (Int. #1, p. 7). Lack of commitment is evidenced by frequent turnover that further disrupts referral.[8]

Government policy with regards to native health care has also contributed to an irrational referral system in northern towns where there are two separate sets of consultation systems for natives and

whites, side by side. In one such town, the GP noted that the situation was "very political" in that most visiting specialists only see one type of patient or the other (GP 34, Int. #1, p. 4). The local surgeon pointed out that visits by specialists are so uncoordinated that the town may, for example, go for weeks without a radiologist, and then have two arrive on the same day (p. 9). Further, although Winnipeg is closer, provincial policy prohibits most of the closest specialists from visiting the town, and specialists and their residents are instead flown up from southern Ontario universities. Further, each side is in the process of acquiring duplicate equipment (Radiologist 36, p. 15). In another town, where primary care is offered at a provincially-operated clinic and the federally-operated hospital, staffed by nurse-practitioners, is a few miles away across the water, it is almost impossible to coordinate services (pp. 16-17). While it is "crazy" to have the two systems juxtaposed, the two sides are in a deadlock, because neither the federal nor provincial government want to take full responsibility for native health care. As it stands, consultants who see natives tend to be salaried academics from southern Ontario, while white consultants tend to be FFS specialists from

neighbouring regions. There are no federal funds to encourage northern doctors to visit the reserves as there are for visiting white hospitals (GP 37, Int. #2, p. 15). The latter group would like the business, but are largely blocked by the existing structure, which is a coalition of government, medical schools and the natives themselves. Will the stalemate ever be broken? Radiologist 36 suggests that it will "only be broken by a politician going against their wishes" (p. 14).

There was also evidence that specialists already in northwestern Ontario influenced referral patterns more directly by discouraging recruitment of new physicians in order to maintain their monopoly in serving the white population in the area. For example, GP 30 reported that it was "the cited intent of the hospital here [in northern Ontario] not to recruit a neurologist to the area" although for chronic headache problems, which are "fairly common", "you can't get a really competent answer from a neurosurgeon". The fact that local neurosurgeons cannot deal with this problem is discovered by trial and error: "[i]t takes a few years to see what their limits are. And anything outside their limits, you send to Toronto" (Int. #1, pp. 6-7). GP 32 similarly felt that his town needed another surgeon who had skills in the areas not covered

well by the surgeon already there, but the man in town insisted that he would not tolerate anyone else and that he was handling everything quite well himself (p. 13). A similar situation existed in a large town in this region where the few specialists form a clique "on the board of the hospital" from which they "run the show" (Patient 37, Int. #1, p. 9). In a smaller town with only a resident surgeon, the surgeon decided to leave when another surgeon was recruited (GP 34, Int. #2, p. 2). The second surgeon, with third world medical experience, had made the commitment to stay full-time in the town, and did not want to push the first (part-time) man out, but, as the GP put it, he felt "that his territory [was] being encroached upon" and told the new surgeon not to come (p. 3). Surgeon 34, in addition to having a practice in this town, had a practice in another town in northwestern Ontario, a commitment to the federal government in northern federal hospitals and a practice in the northern U.S. (p. 7). Another man who worked as an obstetrician, but who had not written his specialty exams, said that the town had stopped looking for an obstetrician because "they don't need to - they've got me" (Obstetrician 39, p. 6). The main onsequence of this restricting recruitment is the maintainance of inaccessibility.

3. Inaccessibility as a Byproduct of the Process of Specialization

In urban centres as well as remote areas, inaccessibility can be traced to the ongoing process of specialization, which is driven by the career choices of specialists rather than more directly by the needs of referring doctors and their patients. In 1932, when GP 23 opened his practice, he had only three consultants: a general surgeon, a general internist and a pediatrician (p. 6). The general internist used to receive the bulk of non-surgical referrals before the current proliferation of subspecialties. Now, GP 23 quips, there are "so many fine specialties...they've got so fine, that you have to ask, which nostril are you working on, the right or the left?" (p. 12) GP 7 recalled, "we used to send cardiac cases to [general internists] but we don't send them anymore" (Int. #1, p. 13).[9]

The proliferation of general internal medicine into subspecialties has taken place as part of a career change of already-practising generalists or as part of an early decision to subspecialize taken by new practitioners, depending upon what the local market would bear. Specialist 1 was able to subspecialize early in his career. He was attracted to

gastroenterology for a number of reasons, not the least of which was that "it was still a fairly young specialty and therefore the job opportunities were a lot better". He added that, "[i]t's becoming a bit crowded now...but...still has fairly good practice opportunities" (p. 7). Like other specialists, he made clear that the process of specialization was guided by opportunities to practice.

In the first urban location that was studied, specialization has proceeded even beyond the stage of subspecialization, as, for example, with the rheumatologists in town who individually specialize in certain areas such as lupus or rheumatoid arthritis. Members of this group try, as much as possible, to refer cases of interest to individuals cooperatively within the group (Rheumatologist 20, Int. #1). Ophthalmologists in another city similarly specialize exclusively in glaucoma, cataracts or retinal work. Optometrist 33 believes that this is a trend across Canada in ophthalmology, which he describes as "more and more spread out" and "more running into specializing in certain work (pp. 4, 8). As a consequence, referring physicians are often in the position of having no real choice of consultant. GP 7, similarly, had to refer his patient to a particular

consultant because neurosurgeons in the city had divided up their area of specialization so that one handles pediatric cases, another does vascular surgery and another tumours (p. 6). Patient 7 eventually saw a clinical fellow because the appropriate neurosurgeon was constantly out of the country. Where all or most of the consultants in an area choose to specialize to the extent that they refuse to see a particular kind of case, a selective inaccessibility may result. For example, even with a surfeit of neurologists, orthopods and psychiatrists, it may still be difficult to locate a consultant who will deal with problems such as migraine headache, back pain or marital counselling. In other areas, there may not be a complete inaccessibility but only a long wait to see a particular kind of specialist.

In general surgery, there has also been fragmentation into subspecialties, so that even so-called "general" surgeons specialize in hernia repair, cancer surgery, and so on (General Surgeons 20 and 30). Unlike some branches of medicine, however, limiting factors are the amount of operating time and "beds" that each hospital allots a specialty. For example, as Specialist 8 explains, three cardiovascular surgeons in the city must share a certain amount of OR time and

beds allotted to cardiovascular surgery. "[Y]ou can't infringe" on other surgeons' beds and time, he emphasizes (Int. #2, p. 6). This partly explains the cooperation rather than competition for clients that has been noted above.

Neither does it appear that the process of specialization in cities can be reversed. Career choices lock the urban specialist into a narrow band of competence. As Patient 11 explained, with respect to her occupation of lab technician, the types of lab tests done in the city are split among the city hospitals, so that only one set of specialized equipment exists in that area. In big cities, technicians (and doctors) are narrowly trained and know only how to do one or two tests. In smaller hospitals, a technician might have more general skills, having to work in, for example, three departments. But this particular lab technician believes that she is already too specialized to work in such a setting. Similarly, country GPs have more general skills than urban GPs. And specialists have increasingly specialized skills depending on the size of the centre. They are thus locked into practising there, much like the lab technician (Specialist 36, Int. #1).

4. Meeting the Demand

At the beginning of a career, the specialist building up a practice may be willing to take "all comers" and to give them prompt appointments. However, after a cadre of patients or referring physicians has been built up, s/he faces the decision of whether to continue to build or whether to restrict the practice in some way.

Pressures to see more patients are particularly acute in the north, and specialists who are used to a more leisurely pace of life ultimately change their mode of practice to suit this situation. GP 38, for example, reported that the young Internist 40 in a nearby town used to spend an hour with each patient, but has recently dropped down to 20 minutes so that he is able to see more patients (Int. #1, p. 1). The internist said he had trouble with this because at "the university, you always had however long you wanted" (p. 2). Specialist 30, conversely, had booked himself solid for the first few weeks of practice in the north, and then decided that "35 new patients in an afternoon is a lot" and reduced it to 25. But this man recognizes that he must keep up a brisker pace in the north than

in the city: "if I was seeing less patients in a week, it's a problem." (p. 16).

In certain specialty areas, being over-subscribed with patients was alleged to be not so much a response to overwhelming demand, but a situation "created" by the specialists themselves. For example, noting that orthopedic surgeons never appear to meet the demand for their services, Internist 29 said,

> Orthopedics is a big mystery to me. You know, our orthop[edic surgeon] is now taking referrals for [eight months from now]. And he's only been here a little over two years...[One local clinic] got one orthop[edic surgeon] and then they got another, and I thought, gee, they won't need another, but they got a third one and then they had a fourth one for awhile. He's left, but not for lack of work. They seem to be able to generate any amount of work.
>
> (Int. #1, p. 2)

GP 37 similarly observed that in his town, where 10,000 people were being served by five physicians, when the number of physicians doubled and then tripled - still, with "everybody doing useful stuff" (Int. #2, p. 2)- suggesting that work is somehow "created".

If oversubscribed doctors opt for a "revolving door" mode of practice, patients may not "wait", but they spend very little time in the office. As Internist 29 pointed out, a specialist need not make less money because s/he spends less time with patients: "[T]he OMA

tarriff has something in it called a "limited consultation" - if it takes you less than half an hour, you should charge the limited consultation. But I don't think many internists do that" (p. 4). Short appointments are so commonplace now - even Cardiologist 35 said that he only spends "20 minutes with a new consult" (p. 14) - that the OMA guidelines perhaps need revision.

Obstetrician 14 ran his office in this way. He had so many appointments booked that he was squeezing in patients 15 minutes apart all day, and Receptionists 2 and 19 indicated that patients have recently refused to go back to him. There were concerns about how he had handled the referrals of Patients 14 and 15. For example, he didn't respond to the GP's original question about an abnormal ultrasound reading for Patient 15. Patient 14 and her husband didn't have time to satisfy themselves with regards to all their questions about previous pregnancies, in 15 minutes. As GP 27 explained, such men are temporally accessible, but something is lost in choosing them as consultants.

5. Limits to the "Revolving Door" Practice

In surgery, there is a structural limit to the number of patients that can be seen in the form of hospital beds and allotted operating time. Surgeons may be able to do large numbers of operations, but they must work within these constraints. For example, Ophthalmologist 38 points out that in one southern Ontario city where he worked, "they have a fully-equipped OR...which is empty. It's not used because they don't have enough money on the budget to staff it" (p. 8). The waiting time for eye surgery is over a year for some ophthalmologists in that city whose assigned operating time is filled by demand, and they can't get any more OR time, even if they are popular. The allocation of beds and operating time are political matters provincially and within hospitals and this political process not only slows down the "revolving door" but it may also force referring doctors to make tradeoffs in referral.

When faced with OR restrictions, one option is to "streamline" a practice by restricting the types of referrals that will be taken. Orthopod 18, who made this choice, noted that because of streamlining, his office is "seldom overflowing like it used to be" (p.

2). He feels that the overflowing style of practice is partly due to the "financial needs that doctors have created by their lifestyle", such that they are willing to take all comers (p. 2). When a consultant operates in this way, he points out, the patients can't be scheduled into a normal day. Like GP 16, he can now be critical of "greedy", "revolving door" doctors, including many local orthopedic surgeons. According to GP 16, these young specialists are qualitatively different than those who entered medicine 30 or 40 years ago and who "loved medicine". At that time, "money was a problem, collection was a problem", but now, with OHIP, "whatever you do, you get paid well. And more and more young people go with medicine. Not because they are very much interested in medicine ...but it's easy money. An easy income" (p. 9).

Another limitation on the revolving door practice is fear of medico-legal consequences. Gastroenterologist 12, like some GPs, had built up a backlog of cases, with long delays to appointments, by spending a great deal of time on each case. He made clear that his practice of being thorough with each case was related to always having an eye on potential medico-legal problems, in addition to the satisfaction that such thoroughness gave him.

In rejecting the "revolving door" style of practice, Orthopod 18 was aware that he was protecting his reputation as well as making himself less accessible. The basic "cause" of his change of practice was a limit on his operating time - so that a case of elective surgery that he generates today must wait five months, since he can only operate once a week (p. 3). Complaining about the fact that he had just lost two hours of his time to a new orthopedic surgeon who had to be accommodated, he remarked that the meting out of operating time is done by an "autocracy". In an ideal world, the best men, men with patients demanding their services, would have more operating time. But as it is, the time is equally divided and the popular consultants can't keep up in operating room time what they are generating in their offices (pp. 3, 10). This is why Patient 20 waited from February to July for his operation. Further, Patient 17 could no longer be seen within a time period that his GP thought was reasonable and was referred to another orthopod. Faced with this situation, the senior orthopod decided to cut back and pick and choose the kinds of patients that he would prefer to see. He established a "quota system" for "things you have seen enough of", including patients with back pain. He cut down the amount of

operating room time that he generated by filling some of his time with medico-legal cases (Receptionist 18, p. 5). The medico-legal cases have "cut our patients in half", observed his secretary (p. 6). A real need is met in the community - a kind of "public service" that this orthopedic surgeon has decided to provide, but it is also a lucrative business that does not generate surgery and is preferable to the dreaded "backs". The secretary attempts to "weed out" cases by suggesting alternative orthopods (p. 9), but the old GPs <u>like</u> us, she says, and some are willing to wait five months because they "don't want to take a chance with their patients" (p. 9).

Like Orthopod 18, Gynecologist 19 was at the point in her career where she wanted to reduce her caseload to a manageable level and to concentrate on the kinds of things she liked. This specialist pointed out that after a while, "you can gear your practice to what you want" (p. 6). Specifically, she doesn't mind the patients who come in for regular check-ups for reassurance - in fact, she prefers just her regular patients. Her strategy is to stay with her cadre of five or six referring doctors. "I have the same guys that referred to me when I started and I have the same guys now and I'm loyal to them and they're loyal to

me", she points out (p. 7). This strategy inherently involves streamlining, because, as the gynecologist observes, "[M]y GPs come to the state where they don't want too many patients. So if they don't have too many, then I don't get too many either! And it works very well" (p. 7). Surgeon 30 reported a similarly stable "core of referring doctors that I've had since I first started" (p. 13).

Unlike Orthopedic Surgeon 18, who has chosen a superspecialization that he enjoys to the exclusion of other types of cases, Specialist 19 says that she wants time to do things other than medicine: "There are other things in life than this...I have to spend some time doing things that I want to do...working in the garden...[or] doing nothing sometimes!" (p. 8). Her streamlining does not focus on a type of patient but on her "regulars". "[Y]ou get attached to your patients", she says (p. 3). So to them she cannot say no and is always accessible, but she warns new patients that they will have to wait two to six months to see her. Neither does it bother her if a new GP gets angry about a six-week waiting period - "send them someplace else", she'll recommend (p. 3). Cardiologist 35 reported limiting his practice and leaving academia for similar reasons, so that he works "only three afternoons a week

now", with the remaining days for "paperwork" (p. 9). His reason for streamlining his practice was for "independence" - he'd begun to feel as an academic specialist that he had "no control" over his career, and wanted the freedom to schedule his own time (p. 10). By scheduling any extra consults in a week into an extra day, he is able to keep his waiting list to three weeks (p. 12).

Another strategy for "streamlining" is that of accepting uncomplicated self-referrals while being relatively inaccessible to referring doctors with more difficult cases. For example, Patient 31, who had a knee injury as a result of a car accident, found it "funny" that she was referred to an orthopod by a local ski equipment salesman "within a week", while her GP had been "trying to get [her] in but...couldn't get [an appointment] in a month or two" (Int. #1, p. 17). As it turned out, the orthopod cancelled a number of appointments with her (p. 18), and finally became upset when he discovered that she was actually an example of the more difficult medico-legal case that he had presumably been trying to avoid by accepting "ski" referrals.

6. Consequences of Streamlining

The decision on the part of specialists in a discipline to restrict what type of case they will accept has repercussions in the referral system. Roth found a similar situation in the emergency room that he studied, in which emergency physicians were able to control the type of case that they saw, which involved making undesirable patients wait longer times before they were seen, treating them abruptly or rudely, or relegating them to be seen by junior staff (1972a, b). Similarly, in this study, "undesirable" referrals were described as facing delays of months or being taken up by young or unpopular practitioners - including those with reputations for nastiness or revolving door practices. For example, GP 30 pointed out that orthopods in his city "limit their practices in certain areas. All the knees go to [Dr. X]. And all the backs to [another] one [and so on]". Further, "they don't cooperate in a group" such that "they cover their call often without an orthopedic surgeon available". As a result, "[o]rthopedics [here] is a very long wait referral". (Int. #1, p. 9)

Although it might at first appear that long waits in some specialties are due to "shortages", the

inaccessibility may actually be "created" in the process of streamlining. For example, Specialist 27 explains that at his downtown Toronto hospital, a patient will have a four- to five- month wait to see someone, although, perhaps, "young guys outside Toronto" might give an earlier appointment (p. 6). This specialist believes that there is a shortage of rheumatologists because a six-month wait is "unconscionable" (p. 7). However, he adds that a patient can be seen sooner if they are seen by a teaching fellow, or, if their illness is acute, they can be admitted to hospital (p. 7). Ophthalmologist 38 reports that a similar situation exists in a major southern Ontario city where he practiced, where, "for some of the surgeons...you would wait over a year" (p. 8).

One difference between the downtown Toronto specialist and the more eager out-of-towners is that the former is a salaried specialist in a big-city regional tertiary care centre while the community specialists are remunerated by fee-for-service. It was often noted by participants in this study that FFS-paid consultants are more responsive to their referring physicians. FFS consultants are usually seen as more responsive because they want to increase their income,

while salaried doctors can choose to see only the cases that interest them. However, the situation is somewhat more complex than this. As Obstetrician 34 pointed out, he actually gets paid less for visiting remote areas in Ontario, but has done so as a source of income because referrals are locked into city clinics (p. 4). Further, in explaining inaccessibility to salaried specialists, Specialist 27 insists that, "it's not the salary - the disincentive for most of us is that we see patients only one, two, two and a half days a week. Because we teach and do research" (p. 7). He denies that this system creates inaccessibility, since, according to his calculations, "[i]f you take the number of patients I see plus all the patients seen on my behalf by the fellows, and the trainees, it probably amounts to at least the equivalent of a practicing rheumatologist" (p. 7).

A similar argument can be made for the way in which teaching hospitals "cover" rural and remote regions by sending out trainees. Cardiac Surgeon 4, for example, explained that in his specialty, trainees are sent out to handle cases in rural areas so that the centre is not overwhelmed with referrals (pp. 13-14). "We're putting out trainees from our system now in [two rural towns] hoping that they'll...stop sending

[patients] here", he commented (p. 13). But there is usually not enough business in such small communities, and the trainees don't get enough experience. This surgeon in fact believes that there are two referral systems, one consisting of rural referrals to tertiary care centres and a second "within city" system using FFS specialists (p. 14).

From a sociological perspective, what is happening here is that the senior, more popular specialists are able to relegate less desirable cases ("dirty work" in E.C. Hughes' terms) to their junior colleagues. In both the FFS and academic systems, there is a hierarchy of accessibility in which the junior members handle the uninteresting or otherwise undesirable cases. As Internist 4, who is just building a practice, points out, junior men like himself are also likely to get the "5 o'clock Friday" referral (p. 9). Ophthalmologist 38 went for a three-day stint on the eye-van that visits communities in northern Ontario for "a little extra income" (p. 1). Specialist 34 observes that he was recruited to become a visitor to northwestern Ontario communities when he could not compete with established elites in his home city. "I think if I had been busy here and they had approached me, I wouldn't go", he emphasized (p. 3) Although he

is disgusted by salaried consultants, whom he feels "aren't as keen and aren't as progressive" (p. 3) - he looks forward to the day when he can "build up a whole practice" in the city and be autonomous on his own (p. 4). In his city, since he is unable to get the more desirable obstetrical referrals, he has built a practice of gynecological referrals of older women (p. 12). Specialist 38 also has a plan to stop doing dirty work later in his career. He remarked, "I think ultimately I would close my practice just because there's a lot of routine refracting and routine examination which probably can be looked at by others" (p. 11).

7. Limits to Streamlining

FFS consultants indicated that there was a limit beyond which it would be unwise to streamline a practice, lest financial security be threatened. Specialist 3 is resigned to the fact that he must see some "filler" cases for this reason:

> [T]here are <u>interesting</u> things that one deals with, but I suppose if you're a professional, you have to deal with the <u>other</u> kinds of things as well. I talk to lawyers who <u>hate</u> being involved in setting up a mortgage and so on, but they do it. They do it well

> and they do it faithfully for the client. (Int. #1, p. 11)

Neither can a FFS specialist even in a remote area be so inaccessible that s/he loses business. Specialist 26 argues that if the priority of referred problems is sorted properly and if GPs share the responsibility, he is able to "control" his appointment system for emergencies and keep his waiting list "reasonable". "There's no use waiting six weeks for somebody that's got pain inside their ear", he says, "six weeks is a little too long". Specialist 30 in Toronto expressed horror when he heard that Patient 30 had to wait several weeks to have her breast lump investigated in the north, when patients in Toronto would get an appointment "within a week" (p. 10). In some specialties with long delays, Specialist 26 speculates that the travel grant program will make northern specialists more competitive. Referring doctors will ask, why wait six months for a northern specialist when you can see one in Toronto in three months (pp. 8-9)?

Outside the FFS system, however, it is unclear where the limits of physician autonomy to structure their careers lie. GP 5 reported avoiding consultants at the university hospital because "the patients ended up seeing someone on call there". Thus, along with the senior GPs 8 and 12, he now refers only to those who

are "still independent" and "not university-oriented" (Int. #1, p. 16). GP 8, who used university consultants extensively, now uses only three or four salaried consultants. He finds academic psychiatrists particularly unhelpful and makes all his psychiatric referrals to a private psychiatrist. In his cardiology referrals, GP 12 has also switched his cardiology referrals from the university hospital to the city hospital, where their "response time is much faster" (Int. #2, p. 13). However, this "boycott" has no effect, since the university specialists are still on staff.

GP 16 rejected the account of the proliferation of specialties as a result of the "developing science" (a view was outlined by a number of physicians e.g. GP 8, Int. #1, pp. 5 ff.). GP 16 maintained that there had been no demand in his city for cardiac surgery until such a "superspecialist" arrived. This suggests that the view that superspecialists can only practice in large centres with an appropriate-sized population base to generate demand is "backwards". Since such superspecialists are not accountable in the funding system, they are free to "create their own" clientele (Int. #1, p. 12). In practical terms, what happens, says the GP, is that they have a "nice life" seeing the

interesting cases, doing research, giving talks, etc., acting as the elite of the profession. Cardiac Surgeon 4, for example, is on hospital staff, receives a protected salary and is thus at least partly immune to the pressures of referral to which FFS specialists and most GPs (excluding those who teach in the clinic) are subject.

"Research based" specialties such as rheumatology and neurology that are concentrated in medical centres are particularly inaccessible. In explaining why there are no neurologists in northwestern Ontario, Neurosurgeon 28 argues that this is a limitation imposed by the nature of the discipline. Neurology has to be based in a tertiary-care centre, he says, because it is research-based. This is why it is impossible to attract neurologists and also rheumatologists to the north. GP 40 said that he sometimes had to refer patients from his town, on the border of the U.S. and Manitoba, to Hamilton and Montreal (Int. #1, p. 9). Rheumatologist 13 argued that there were not enough research rheumatologists outside Toronto, but even in Toronto, the wait for neurological referrals is six months (Surgeon 30).

Even outside the "research-based" specialties, "created inaccessibility" may occur near concentrations

of academic specialists. In gynecology, for example, GPs had difficulty referring patients for normal pregnancies in an area near a university hospital that specialized in high-risk obstetrics. In psychiatry, GP 16 complained that, "we got better service when there were six psychiatrists in the city than now there are 60", referring to the establishment of a department of academic psychiatrists who do not see mundane cases of marital discord. These GPs know that it is inappropriate to try to refer such cases to a regional tertiary-level referral centre. However, they are questioning the concentration of "undersubscribed" tertiary-level specialists in an area where they feel that the demand for less sophisticated care is not being met.

VI. SUMMARY

Accessibility to the consultant is second only to evaluations of competence in choice of consultant from the perspective of referring doctor and patient. When access to the specialist is blocked, patient and doctor may "shop" for better service, and, in the process, make "tradeoffs" between getting the best and getting an available consultant. Specifically, when

trusted advisors are not accessible within a reasonable time, more convenient ones are consulted. Alternatively, considerable inconvenience may be suffered to stay with a trusted advisor. Further, patients may have to make significant financial outlays, even in a system of universal health care, to reach doctors who are concentrated in urban areas. Making these decisions is an everday aspect of referral for doctors, both in urban and remote areas, but they sometimes criticize patients for shopping, particularly those who consult the ER after hours.

The major argument in this chapter has been that when a broad view of the dynamics of accessibility is taken, it can be seen that "shopping" and "tradeoffs" are consequences of the ways in which specialists structure their practices and careers within the broader framework of hospital organizations. Specifically, specialists make themselves inaccessible to patients directly outside of large cities, where they can choose to operate on a referral-only basis. Further, a segregation of specialists and referring doctors may result from historical associations of doctors in clinics, or for reasons of convenience, such that the choice of consultant is no longer "free". Geographical maldistribution of specialists is also

directly related to the choice of consultants to specialize in narrow areas in urban centres, which then "locks" them into that mode of practice. Generalists in more remote areas can be seen to be practicing a qualitatively different type of medicine than their big-city counterparts, which makes it increasingly difficult to attract specialists to these areas. Further, they may be attracted for reasons of easy accessibility to operating time or equipment, rather than commitment to service. Finally, encumbent specialists may block recruitment of those who might threaten their business. The general significance of the resulting inaccessibility is that choices are reduced and the possibility and/or effectiveness of a "boycott" to maintain quality are reduced.

Tendencies towards "revolving door" practice among specialists are mitigated to some extent by lack of facilities and medicolegal considerations, but the alternative mode of practice, where the popular specialist "streamlines" his or her practice also has negative consequences. Specifically, the "dirty work" of seeing cases rejected by these more popular consultants is picked up by their less experienced colleagues. Alternatively, where everyone in a region superspecializes in areas of a particular discipline,

the referring doctor may have no choice of consultant. In a FFS system, big-city specialists facing more competition for referrals might be expected to offer the referring doctor some alternative in such situations. However, in research-based specialties populated by salaried consultants, there may be an almost total inaccessibility.

NOTES

1. It was still possible at the time of this study to "extra-bill", i.e. bill a patient more than the fee covered by the Provincial insurance plan for a service. The rural southern Ontario GP 12 said that he avoided such consultants to save his patients the extra costs. Another rural GP in the northwest also said that he avoided the closest ENT specialist who extra-billed, preferring to send patients hundreds of miles to Duluth, Sudbury or Winnipeg. Extra-billing, mainly practised by specialists such as orthopods and ophthalmologists with the highest incomes and the highest-volume practices (Wolfson & Tuohy, 1980), was outlawed by the legislature in Ontario in June, 1986, at the time that this study was being conducted in northwestern Ontario. This provoked a doctors' strike, one of a series that have occurred over funding issues in Canada (see Taylor, 1978; and for a discussion of events leading to this legislation, see Vayda and Deber, 1984). The strike "petered out" and did not appear to interfere with "business" in most of the locales visited in this study. It was followed in 1987 by a generous fee settlement which was not publicly disclosed, but was reported to surpass what would have been charged via extra-billing.

2. GP 40 explained that "there's no difficulty" getting an Ontario license - "it just costs $400 and a lot of bookkeeping" (Int. #1, p. 7). Alternatively, "if the town is small enough and they don't do it often enough, they can claim ignorance and get away with it...[but] if [they] got caught for malpractice, it wouldn't be covered. And there's a whole raft of trouble" (p. 7). The scarcity of visiting specialists is thus not due to licensing restrictions.

3. The federal system of health care services for natives in Canada has a long and unsettled history that has been documented by Young (1984). The facilities and administration vary

markedly from region to region, with some areas having a more organized referral system, and others less organized (with patients mainly presenting at Emergency or relating to a "community health representative" with "no central health coordination") (GP 37, Int. #2, pp. 14-16). GP 37 complained about the low political priority for native health care: "[W]e lobby the government for things like extra social workers on the reserves to coordinate patients moving to Winnipeg back and forth, sorting out the multiple psychological and social problems on the reserve, alcohol problems - and do you know what they send up instead? They say, no, we don't have money for that. But we'll send up Telemedicine instead. You know, it's a load of horseshit! ...Every physician in town wrote off [to the Ministry of Health], we do not need telehealth. We do not need telemedecine. What we need is more bodies to help us organize patients, particularly on the reserves. And they wrote back that there was no funds available for that. And that we would be receiving Telemedicine. And we've now got it" (Int. #2, p. 13). Later he remarked that there was no incentive for him to visit the reserves to provide primary care: "The federal government has no interest in me going down to service the native reserves. They have no interest in anyone going to the native reserves" (p. 15). In spite of this, three local physicians visit the largest three about once a month (p. 16).

4. In a few cases, it was difficult to determine whether patients clung to their GPs because of a trusting relationship or because they wished to have a physician who spoke their language and could find few alternatives. Such patients, particularly those of GPs 5 and 10, suffered very long waits in the waiting room. Specialist 16 saw a kind of "matching" between patients and their doctors in which patients for whom English is not a first language "tend to rely on authority" (p. 16). However, this psychoanalytic concept that some patients "need" authority is not necessary to explain why they endured these hardships. Their longsuffering with these GPs seems more related to the fact that some patients will drive

hundreds of miles to see a doctor who "knows their culture" and speaks their language (Patient 11, Int. #3). There was a similar kind of affinity between some female patients and their female family physicians, along with a willingness to endure accessibility problems in return for a closer doctor-patient relationship.

5. Referring doctors and patients typically do not agree on the urgency of the problem. Patient 41, for example, was perturbed about waiting three weeks to see a surgeon regarding his hernia (the same surgeon who'd insisted that he had no waiting list) while his GP remarked that he could have easily waited several more months. However, in the case of Patient 37, the GP had met the patient in the distant city by chance and had attempted to have her seen in a clinic by one of the remaining residents in the now-closed residency program at that medical centre, with no success (Int. #2, p. 5). X-rays and other lab tests cannot be transferred across borders for readings by specialists in other jurisdictions because this would involve the public health system billing across borders (GP 37, Int. #2, p. 12), and these regulations, for example, forced Patient 37's husband to "take a day off work" to drive her to Manitoba, just for an x-ray (Int. #1, p. 6). As well as taking "months", these arrangements are the source of other problems, as illustrated by an example given by GP 37. He had attempted to screen the family of a native child for allergy to a muscle relaxant used during operations before operating on the child. The tests had to be sent to London, Ontario to be read, over 1000 miles away, and the boy's were lost. The GP has been unable to contact the family about this, because they are on a reserve. He often deals with this problem by "go[ing] into Winnipeg for a day and into a lab [to] do it myself...But you see, I'm not remunerated for that" (Int. #2, p. 13). GP 39 blamed the fact that a urine test took three days to get for his mistake in diagnosing Patient 39's ruptured appendix (Int. #2, p. 1).

6. This is unlikely, given the progressive withdrawal of the family doctor from the hospital in urban areas, a phenomenon that will be discussed at length in the next chapter.

7. Alternatively, like Specialist 30, when a clientèle is assured by the scarcity of specialists, s/he may immediately restrict the practice. After two weeks in town, this specialist has already decided that "regular patients will wait five weeks" despite the fact that "you feel bad that you keep people waiting two months" (p. 11). It is argued here that economic considerations affect the decision to take "all comers". However, GP 5 was an example of a doctor who failed to limit his practice, probably not so much due to greed as to failure to address the problem. As he admitted, "I'm not the most organized person in the world. I don't rigidly structure everybody" (p. 8). He claimed, "I could make much more money than I do if I would bring them all in for 10 minutes and send them out. I could see another 25 people a day like that...I [may] spend an hour talking to a guy, or three-quarters of an hour listening to Mr. A. 55 times...the same story...I don't mind listening to neurotics or some of these depressed people" (p. 8). He rationalizes the situation of having scores of patients waiting several hours in his waiting room by arguing that there is a social dimension in the office for these patients: "[T]hey come here to have fun. I think it's part of their social hour" (p. 23). GPs such as the young woman GP 3 philosophically rejected this mode of practice: "if they're seeing 50 people a day - well, that's their choice. I don't need to work so hard. I like the job, but I don't like working overtime. It's in conflict with a lot of the traditional ideas of the profession. But...women have done one of two things in the medical profession. They either just entrench themselves in male behaviour. They go and make the same mistakes that men do...Or what they do is they come in with a fairly fresh outlook" (Int. #2, p. 17). In this woman's view, she will make less money but will not end up like the traditional family doctor who worked until he literally "dropped dead".

GP 19 operates a similar kind of practice, which she admits may sometimes make her inaccessible to her patients - it is "totally selfish", made for her convenience in raising her family (Int. #1, p.11). The traditional GP 16 was highly critical of this more relaxed style of practice, asking,"Why are there so many girls? Many of the girls will be forever in a part-time position. They should and they will get married and they are all looking for soft jobs. They will have children. There are a number of them in general practice, not that many, but most of them are really looking for a good income and a good job where they can take time off when they want and that they can come back to. If a child comes, they can take off for a year and they will have something to come back to" (Int. #2, p. 9).

8. A further incentive is that there is less accountability in remote areas - for example, as Specialist 34 pointed out, there are "no litigation worries" in treating native patients in the north (Int. #1, p. 4). As Freidson (1970a) has argued, freedom from accountability sets the scene for possible abuse. In the north, autonomy and the opportunity to "make money" were factors reported by a number of specialists in their decision to practice there. Surgeon 32, for example, explained that he will "take anybody extra anytime" (Int. #1, p. 7), despite the concerns expressed by GP 32 that this surgeon should be referring patients with problems outside his area of surgical competence. The surgeon, however, was pleased with the facilities available locally that allowed him to operate so rapidly and efficiently, and with the "comfortable living" that he was making as a result (Int. #1, p. 6). Like Specialist 30, he spoke happily of the extensive hospital privileges, personal equipment and preferred working hours that he was able to negotiate as part of practising in this underdoctored area. Similarly, GP 25 was unhappy with Specialist 30's intention to use these facilities to do the cosmetic surgery that interested him, but the specialist is in a position to dictate how he will practice regardless of local need.

9. Because the referring doctor sometimes picks the wrong specialist, one general internist in the study advocated that GPs might better thread their way among the myriad specialties by "twinning" with a general internist for 80 percent of referrals (Spec. 16, p. 7). Like cards, he suggested, you should "learn to play with one person", not seven, a person who would depend on your referrals and thus serve you better. A GP in this position, according to this specialist, could feel as comfortable as a patient feels in allowing the internist to make the choice of specialist. However, he admitted that GPs seldom refer through generalists any more and noted that young subspecialists were "begging, borrowing and stealing" away their patients, leaving the old internists to go "down the pipe" (p. 7). There was some evidence that GPs used "first-line" specialists to make tertiary referrals to the appropriate consultant, but the first-line specialists tended not to be general internists.

CHAPTER 8

SHARING RESPONSIBILITY IN REFERRAL

> The only real answer is for the primary care physician and the consultant to know each other well enough to know what each other is capable of doing.
>
> -GP 40, Int. #1, p. 7

I. INTRODUCTION

This chapter focusses on how doctors "negotiate" with other doctors and with patients, the splitting of responsibility for referred cases. The key aspect of this process is identified as mutual assessment of competence. In cities where specialists are dominant, the GP tends to be seen by the consultant as less competent than in communities where GPs have some political presence. Urban GPs may be "squeezed out" and/or "abdicate" responsibility for referred cases, or may become militant about where the lines of responsibility lie. Patients similarly either passively submit or make active attempts to assume responsibility for their care. Where no party clearly assumes responsibility, each has a tendency to "lose

track" of what is going on, in a process that Balint (1957) has termed a "collusion of anonymity".

1. Sharing Responsibility: Issues in the Literature

The first clinical studies of referral (Balint, 1957; Williams et al., 1960; Clute, 1963) identified problems in the coordination of responsibility for the patient as the central issue to be addressed in the referral process. Beyond this initial documentation of a problem, however, there has been little exploration of how coordination or lack of it is achieved. Commentary in medical specialty journals suggests that increased referral and fragmentation of care are unavoidable consequences of increasing specialization (Bomalaski et al., 1983; Gonnella & Veloski, 1982). On the other hand, advocates of the new specialty of family medicine emphasize that it is the role of the referring doctor to make sure that the patient does "not fall through the cracks created by the divisions of health care among subspecialties" (Barnett & Collins, 1977, p. 665). Studies of some family practice units report that their members rarely or almost never surrender full responsibility for a patient to a

consultant (e.g. Geyman et al., 1976; Glenn et al., 1983). However, there are no clinical statements in the literature to suggest the conditions under which responsibility should be surrendered or retained.

In the sociological literature, some perspective is supplied by Mechanic's (1971) comparison of the American and British systems of referral. He argues that in both countries, increasing specialization has fragmented the care provided to the patient, but the fragmentation occurs in different parts of each system. In the U.K., where the GP coordinates outpatient care, but surrenders responsibility to the specialist for inpatients, there is a discontinuity between primary and hospital care. In the U.S., where the doctor first consulted by the patient is more likely to be a specialist who can admit the patient to hospital and care for him or her, this problem is minimized. However, the American patient often contacts more than one specialist, and has no co-ordinator of primary care.[1]

While Mechanic's comparison suggests the structural determinants of the splitting of responsibility in referral, Freidson's (1975) analysis of negotiation between generalists and specialists around cases of referral highlights the social

psychological process whereby the doctors define the boundaries of their competence relative to one another. What is missing is the ground between Mechanic and Freidson: how do mutual assessments of competence and negotiations about the division of responsibility relate to the context in which care is delivered?

2. A More Comprehensive View of the Negotiation of Responsibility in Referral

Ontario provides a natural laboratory within which to address this question, since in big cities, the British tradition of the specialist taking over inpatient care while serving only as a consultant for oupatient care predominates. Coexisting with this, in smaller centres, is the American model of the generalist admitting and caring for the inpatient, or, at least, retaining the major responsibility for the case. Finally, this study adds the element of the patient as a key participant in the negotiations.

a. Sharing Responsibility and the Mutual Assessment of Competence

Just as the referring doctor and patient make assessments of the consultant's competence, the consultant is in a position to make judgements about the competence of a referring doctor based on the type of cases that are sent. If the specialist feels that the referring doctor cannot handle a particular case, he or she may "take over". Often, however, there is some ambiguity about how far to go, and, where the referral has been initiated by the patient in the first place, there is a basic question about the competence of the GP involved. If too many inappropriate cases are sent, the specialist may suspect the GP of incompetence and/or "dumping". The consultant may also take over if s/he has medico-legal concerns.

Since the specialist has only incomplete information with which to judge the GP, mistakes can be made. If the specialist takes over and the GP did not intend this, he or she may accuse the specialist of "stealing" or "dredging" (Chapter 5, pp. 204-208). In such cases, it is difficult to tell whether the specialist has reacted legitimately based on an assessment of the referring doctor's competence, or

whether s/he has economic or academic interests in acquiring the patient. If the specialist "backs off", and hands the case back to the GP without taking enough responsibility for the case, the GP may express frustration that the consultation has been of little value. This response was often attributed by specialists to economic motives, since, for a busy specialist, follow-up visits do not "pay". Alternatively, as suggested in the previous chapter, the specialist with a surfeit of patients is in a position to choose to see particular types of cases that interest him or her and may "back off" or even refuse to become involved in treating other types of problems.

b. The Shrinking Boundaries of General Medicine

It was found in this study that there was more of a tendency for specialists to "take over" a case in big-city specialty-dominated clinics or hospitals. Structurally, GPs in big cities are excluded from many procedures by the limits of their licences and hospital privileges, and so are not in a position to gain competence in many procedures. One current example of this growing exclusion is in the area of obstetrics

(discussed in Ch. 5, pp. 178-184). Patients are aware of their lack of competence and feed into pressures on the GP to refer. In teaching hospitals, GPs must compete with medical residents to care for patients, and operating schedules are not set up taking their routines into account. Most practitioners reported that it was easier to find things to do in their offices than to try to overcome the barriers to participation that they faced in such organizations.

Even in outpatient care, where patients were referred to specialist-dominated clinics, GPs lost track of their cases, since specialists tended to assume that they did not wish to participate. Not all GPs accepted this situation passively, and a number reported "militant" tactics, such as boycotting specialists who "stole" their cases, making fewer referrals, and, occasionally, where possible, attempting to block the hiring of specialists to join growing cadres of specialists.

In sharp contrast, in a few rural hospitals, where small numbers of specialists and GPs worked together closely in local hospitals, such as those scattered across northwestern Ontario, co-ordination of responsibility was personally negotiated and unproblematic. GPs systematically built up areas of

competence through their interaction with local specialists and were able to assume more responsibility for their cases. Systems of visiting specialists reinforced the pattern of the GP maintaining primary responsibility for cases. Inevitably, however, referrals had to be made to the big city, where the referring doctor faced all the problems of his urban colleague - compounded by distance.

c. The Patient's Participation in the Process of Referral

When the analogy of the patient seeking advice and the GP seeking advice is explored, it can be seen that the patient who brings a problem to a doctor invites an assessment by the doctor in just the same way that a referral by a GP invites an assessment from the consultant. Doctors generally had low opinions of the competence of patients to handle their problems, and tended to "take over" in the same way that specialists "took over" referrals. Just as specialists were generally unaware of the extent to which GPs wanted to remain involved with their cases, doctors tended to be unaware of the extent that patients wished to participate in their own care.

Ironically, experienced patients, like experienced referring doctors, who were unhappy with the course of their care, reacted militantly, just as some of their GPs did in a similar situation. Specifically, they passively withdrew from consulting the doctor (the equivalent of the GP's boycott); they actively sought out doctors who might give them more satisfaction (which might include pressuring for referral or circumventing the GP); or they complied selectively with the advice they obtained.

II. COMPETENCE AND THE DIVISION OF RESPONSIBILITY

1. "Negotiating" the Division of Responsibility

The reason that no specific medical guidelines about which cases should be referred can be found in clinical journals is that the lines are constantly, mostly silently, negotiated. As Specialist 5 observed, "[s]pecialties are man-made arbitrary lines" (p. 9). Even the simplest consultation, such as a request by a GP that a specialist merely do technical testing and report the results back, contains elements of ambiguity about boundaries of responsibility. For example, when exercise testing was requested to assess the heart problems of Patients 8 and 9, the specialist

was aware from past experience that the GP wanted to maintain control of these cases, but he was also aware that the patients expected him to inform them about the results of the tests. In threading a line between these two, he reasoned,

> [I]f the patient's just referred for a procedure...it's really up to the physician who is in charge of the patient [to inform them]...[Y]ou're not looking after the patient, you're just doing a test...I think it's courteous to let the patient know what the results were, but for the implications of it, I think they should go back and speak with their family doctor.
>
> (Int. #1, p. 6)

This is why he merely gave Patient 9 some nitroglycerin pills for cardiac pain and asked both patients to return to the GP. As it turned out, both cases later became "full consultations", and the specialist felt free to give them a little more information. Initially, however, their future relationship was not clear. If the results of their tests had been normal, it would have been safe to assume that the GP could take over. If the tests had been abnormal, the specialist would have had to decide, based on his knowledge of the referring doctor, whether s/he would feel able and willing to take over.

The ability and willingness of the GP and specialist to participate in handling a particular

problem vary considerably, and both doctors must assess this, often without direct knowledge of where the other stands on the issue. When one doctor is known well by the other, they can sometimes guess correctly what is to be done. However, there were many complaints in this study about specialists not assuming enough responsibility to be helpful, as well as about specialists assuming too much responsibility to the point that the GP lost track of the case. At the same time, specialists complained about GPs who assumed too much or too little responsibility. These referring doctors were characterized by Specialist 2 as those who "see people for three minutes and then get their index finger out into the phone", who are "just referral agents" (p. 3) vs. others who "isolate themselves and [try] to do too much. And won't refer" (p. 8). Specialist 3 also complained about "the other side that'll send everything along without any kind of thought about it...[with] the majority in the middle ground" (p. 12). What determines what a particular referring doctor and consultant will negotiate?

2. Lines of Responsibility as Lines of Competence

The argument was made in Chapter 5 (pp. 144-148) that a GP's willingness to refer is based on his or her experience with a particular type of case. Specifically, some experienced GPs develop a self-confidence in their ability to handle all but the most difficult cases, which they described as "ego investment". These physicians earn the respect of their consultants because they refer "appropiately". Specialist 5, for example, acknowledges his healthy respect for senior family physicians of whom he says, "when they call you, you better get off your ass and see [their patients]" (p. 11), because they tend to refer only the most challenging cases.

A similar process can be identified around the sharing the responsibility once a referral has been made. As GP 16 describes it, the sharing of a referral between GP and consultant reflects the extent to which each is asserting his or her competence. Speaking of his relationship with one of his consultants, he comments,

> we have respect for each other. I know that he knows that I know what I am talking about...We never discuss what I think of him and what he thinks of me, but you know it.
>
> (Int. #2, p. 7)

The specialist to whom he referred Patient 16 confirmed that he indeed has high respect for this GP's competence and the GP said that he knew the specialist would give prompt and serious attention to referrals from any GP who demonstrated that they "care" (Int. #1, p. 16).

3. How the Specialist Assesses the GP's Competence

The ways in which a patient and referring doctor assess the competence of a consultant have been described in Chapter 6 (pp. 247-262). The specialist goes through similar processes in judging the competence of the referring doctor and, based on this judgement, makes decisions about assuming responsibility:

> It depends on the GP. If the GP's good and approachable and reliable, then I'll call him and he and I will work something out. If the GP's not good, then that will be the rare patient that I'll continue to follow and keep sending letters to the GP until such time as I think they can handle it or they say that they can handle it.
> (Internist #4, p.7)

Orthopedic Surgeon 18 speaks of assessing <u>who</u> the family doctor is and "whether they have that aptitude". He says that he "makes a judgement call as to whether [he thinks] the family doctor should be looking after

it" (p. 6). He may assume responsibility if he decides that the GP is the type who can't be trusted because s/he won't read to the end of a letter, even if it has been constructed so that it is easy to read; alternatively, responsibility may be assumed if it is known that the GP feels uncomfortable handling problems of this particular type. In such cases, the orthopod says, he usually sends a letter back beginning, "there are complications and I have arranged for..." (p. 7).

How does the specialist make assessments of the GP, since the GP cannot be observed directly? Some of the ways that were identified in this study include gauging the GP's competence by observing how fully s/he "works up" a case, thus indicating his or her willingness to participate; the adequacy of the referral letter; whether the consultant's advice is followed; and what the patient reports.

a. Thoroughness

GP 16 identified the basis of Specialist 16's respect for him in the comment, "I don't refer junk to him" (Int. #1, p. 7). All of his cases, he claims, are "worked up" in the painstaking way that he describes of following the "whole natural evolution and solution of

the problem" (p. 8). This experienced physician advocates acting like a "detective" and doing as much as you can on your own, before referring, as a way of maintaining interest and responsibility for a case rather than handing it over too soon. "[I]f you have somebody that you don't know what's going on, then you don't work at all", he argues (p. 8). Orthopedic Surgeon 18 agrees with this, commenting that a few GPs show up at the hospital to scrub in with him because they like surgery and have the intellectual curiosity to which GP 16 is referring. This assumption of responsibility is assessed positively by many specialists. As the surgeon puts it, "[i]f I was a family physician and I had referred a patient, I'd kind of like to see the pathology that I had diagnosed and maybe missed" (p. 4).

b. Adequacy of Communication

A second way in which the specialist assesses the GP is by his or her referral letter. The widespread failure to send referral letters by urban GPs, argues Internist 12, is really an example of the GP abdicating responsibility.[2] As the internist explains, it is the same group of GPs who don't show up

at the hospital, who don't send referral notes and who expect the specialist to take over cases that they should be able to handle.

c. Outcome

Another more difficult way in which Gastroenterologist 12 has learned about his referring GPs is by a process of double-checking after a referral to see if they have followed his advice, much as some doctors check on the compliance of their patients (p. 6). This specialist says that he has learned throughout the years that he cannot just return patients to their GPs to be followed, because he cannot be sure they will do what should be done (p. 5). He is not even sure that they read his letters. On the other hand, he adds, there are referring doctors for whom you can "see the patient once, send them a note, and you know it's going to be taken care of". Although the busy specialist makes more money by seeing new patients rather than follow-ups, as this specialist explains, when a basis for mistrusting the referring doctor has been identified, for medico-legal reasons, it may be wise to "keep" a case.[3]

Occasionally a direct observation of outcome can lead to the specialist maintaining some responsibility for a case, perhaps in response to a patient's concerns. For example, it is likely that the surgeon who operated on Patient 39's gangrenous appendix, which had been missed by her GP, saw her several times on follow-up because he did not trust the GP with this task (as alleged by the patient, Int. #3, p. 1). The GP reported that the patient wanted to be discharged before the surgeon felt comfortable that she should be, so that the surgeon called him and asked him "to follow up on her" (GP 38, Int. #2, p. 10). However, the patient reported that the surgeon had questioned the "water pills" that the GP had prescribed for her after she was discharged from hospital, and then insisted on seeing her again.

d. Patient Feedback

Finally, the patient may tell the specialist, or indicate by his or her behaviour, that s/he does not trust the GP (as in patient-initiated referrals). As described in Chapter 5, specialists are resigned to accepting this type of case which technically, very

often, the GP should be able to handle. With Patient 3, for example, the specialist complained that,

> the family physician is getting out of the business of removing wax from the ears. Traditionally they all did it or their nurse did it...[P]eriodically, a family physician that's done it will rupture an eardrum and then he'll never do another one after that. (p. 11)

He goes on to comment that Patient 3's problem might have been handled by the GP, "but then you never know...[about] their credibility" (p. 12). Presumably if a GP makes too many of this kind of referral, s/he is suspect. Further, just as a GP avoids a consultant about whom patients complain, so too will a specialist become wary of a GP about whom patients complain.

4. The Limits of Specialist Assessments of GP Competence

In making judgements of GP competence, specialists often have less information than the GP had with respect to their competence and no method of assessment was entirely satisfactory. For example, Internist 12 said that he used the "visibility" of the GP in the hospital as an indication of his or her interest in maintaining responsibility:

> Family physicians who come into the hospital regularly tend to be the ones who want to keep that kind of control. But the vast majority don't come into the hospital, and they wouldn't care too much about how the patient was managed.
>
> (Int. #1, pp. 2-3)

While this rule-of-thumb may "work" in general, it has limitations - for example, even though GP 12 expressed willingness to keep control, his rural practice is too far away for him to be in the hospital when certain specialists might see him. Consequently, a specialist may incorrectly assume that he does not want to be involved. In making these characterizations about GPs as a group, the specialists have "typified" them in a Shutzian/Weberian sense, but in reality, the behaviour of the GPs is not so homogeneous. Because the two "pass in the night", specialists may take a long time to learn who can be trusted and who cannot. GP 30 thought that it was up to the GP to set the specialist straight, as he tries to do - "[t]he surgeon who takes [my lack of visibility in the hospital] to mean that I'm not interested in my patients soon learns very quickly that that's not what I meant" (Int. #1, p. 18). However, the GP may not be aware that s/he is being judged in this way.

There were a several examples in this study where the lack of visibility of the referring doctor to

the specialist was related to the specialist underestimating his or her involvement and interest. Internist 4, for example, was unaware that the attending family practice resident of Patient 4 and his supervisor had visited the patient in hospital. Neither was GP 7 given credit for all the responsibility that he took for Patient 7 in the specialist's account of the case. The specialist gave no indication that the GP had made any input beyond attendance at the patient's biopsy, but the GP reported that he did some homework on the case (Int. #2, p. 6). He had looked up the patient's history of malignant melanoma from five years back, and suggested to the specialist that a craniotomy might be unnecessary because the case may be hopeless. According to the GP, that was why the decision was made to do only a biopsy, but the specialist failed to give the GP credit for this, implying in his description of the case that the workup and operation was entirely his decision. It is possible that the specialist, who was a resident, just didn't know about the GP's involvement because his supervisor did not tell him. He admitted that he was not used to the GP having this degree of influence in a case.[4]

III. GEOGRAPHY AND RESPONSIBILITY

The process of mutual assessment of competence by consulting doctors and patients takes place within a variety of settings in which the specialists have more or less non-negotiable control over what types of cases must be referred (see Chapter 5, pp. 188-196). While GPs still do the majority of inpatient care in small hospitals in Ontario, most urban hospitals require that virtually all patients admitted to hospital must be referred. Even where this is not a hospital policy, GPs may be excluded by their limited licences; by their inability to compete with medical residents in teaching hospitals; by the inconvenience of surgical schedules; and by pressure from outside agencies. The concern that urban GPs are taking less and less responsibility for patients, even in ambulatory care, was a central theme in physician accounts in this study. An insight into what is happening can be gained by a comparison of how referrals are handled in the two settings.

In Ontario cities, when a patient is admitted to hospital, maximal specialist involvement is usually expected. As Specialist 16 put it, GPs have "no business" admitting patients to hospital, and, as services are regionalized, GPs are effectively cut off

from all responsibility for inpatients when their patient enters a hospital at which they have no privileges. In the hospital of Cardiologist 35, GPs may admit patients to the hospital, but they cannot participate, for example, in cardiac care:

> [W]e have what's called a "closed unit". That is, when the patient is in the unit, even if [he] is admitted to the hospital under another doctor as [his] "family doctor" or "family internist", in the unit, they cannot write orders there. Only myself or my house staff can write them...[T]here are no GPs practicing at that hospital at all...[but once he leaves] Coronary Care, I no longer have the responsibility for that patient.
> (Int. #1, pp. 11-12)

This restriction on cardiac inpatient care is true even in northern cities where GPs have more control over inpatients than their southern colleagues (GP 29, Int. #1, p. 1). However, outside of big city hospitals, the GP in Ontario still takes a great deal of responsibility for inpatients. In northwestern Ontario, GPs perform a variety of hospital procedures that they would not in the south, such as gall bladder operations and surgery of various other types, as well as care of heart patients. As GP 25 remarked, the GP is "king" in this area - "number one on the totem pole", and medical students look forward to placements in this area because of the experience it gives them.[5] In very

remote areas, such as rural B.C., the Yukon and N.W.T., Caesarian sections, appendectomy, vasectomy and other surgery is routinely done by GPs. Even in northern cities where the hospitals are run by specialists, many GPs still routinely assist in surgery. GP 24, for example, had been "assigned" to assist with cataract and other surgery, even for patients that were not his (Int. #1). GP 32 assisted Surgeon 32 in the removal of a breast cyst for Patient 32 in the small local hospital. As the surgeon explained, he always tries to operate "with the GP as anesthetist" (p. 3).

Because it is still possible for the GP to do inpatient care in Canada, a few physicians suggested that Canada offered more options to the GP than other countries. Specialist 26, for example, said that he had British friends who were GPs who came to Canada to practice because they were concerned about having no say in the patient's care once the patient got admitted to hospital in Britain. However, there are others who are quite happy not to be involved with cases. As he summarizes it, in Canada, "you practice medicine just the way you want to" (p. 6). Specialist 1, also from Britain, made the same point when he said that in Canada "the family physician still is more of a

community-based doctor than he is a hospital-based doctor but he almost invariably has hospital privileges and can do as much hospital-based care as he likes to do or as he's competent to do" (p. 7). GP 25 agreed that, "what we have privileges for determines what we refer", with northern GPs having a wider range of responsibilities from which to choose.

Rural GPs also take considerably more responsibility than their urban counterparts for outpatient referral. As GP 24 describes it, "[a]nybody that comes up here to practice, they very quickly have to be prepared to investigate [anything], because you never know what you're going to see next" (Int. #1). GP 34, in a small, northwestern Ontario town, explains that GPs in remote areas often have to deal with problems that urban GPs would ordinarily refer- everything from acute rashes, since the dermatologist only visits every three months, to pneumonia and Caesarians, since there is no resident internist or obstetrician (Int. #1, p. 2). Further, although the local surgeon does some orthopedics and gastroenterology, GPs set bones, assist with GI investigations and manage these cases, whereas they would be referred in the city (GP 34, Int. #1, p. 3; GP 38, Int. #1, p. 1). GP 24 explained that although a

southern GP might never see a fracture because patients with broken bones go to the ER, in the north, "you treat everything that happens in the first instance". As the doctor covering the ER, "[y]ou see acute medical emergencies coming in at all hours of the night or day" (Int. #1, p. 10).

Explaining that he routinely assumes responsibility for certain chronic conditions that southern GPs might refer, GP 40 exclaimed, "I've never in my life referred a migraine headache!" (Int. #1, p. 9). He added that he seldom referred to a dermatologist because he considered this "to be primary care, not consultative care" (p. 9), claiming, "I'm a pretty well-trained internist myself" (Int. #2, p. 1). For psychiatric cases, he explained, "we handle what we can't refer" (p. 9). GP 38 reported that most of of his ENT problems were dealt with locally (p. 2). Even Patient 35, with a heart arrhythmia, who would be in the care of a cardiologist in the south, was being monitored by her GP (p. 5). GPs 25 and 32 explained that in their small towns, most cases of angina and heart attack are handled by the GP (GP 32, Int. #1, p. 2). Finally, when patients are referred long distances to the city, the GP makes a greater effort to coordinate the event. As Cardiologist 35 points out,

"[w]hen it involves patients travelling, the onus is on [the GP] to make sure that the questions are asked...whereas in the city, they can [just] send them to see you" (p. 3).

Northern GPs are critical of the attitude of some southern GPs that they would like to limit the number of patients and responsibilities that they assume. GP 24 thought that such people shouldn't "really be in medicine. If there's enough people like [that], then I don't know what's going to happen". He added that you "can't say well, my cultural interest is the violin and go fiddle your violin". Although southern GPs come up and think that a high volume practice is a "dirty word", he commented, they have to change, as did GP 25, who is now "willing to take on as much work as he can handle" (GP 24, Int. #1).

The fact that rural GPs take more responsibility for their patients does not mean that they refer less. Surgeon 39 commented that "95 percent of X-rays that are taken in this town are probably acted on without the benefit of radiological interpretation" (p. 4), but, as, Radiologist 36 points out, rural GPs may refer more than their urban colleagues to the specialists who are available. This is because, in radiology, for example, they are faced with reading

X-rays that orthopedic surgeons, gastroenterologists and respirologists would ordinarily read, because they have little access to these specialists. As an alternative, they consult the radiologist directly (pp. 3-4). This situation sometimes gives the northern specialist more freedom to suggest how the referral should be handled, as Radiologist 36 points out:

> [W]e feel more free up there. Which I don't feel down here. Like I wouldn't say to a doctor down here, you should send this patient to an orthopedic surgeon. But up in the north, I'd feel perfectly free and the doctor would appreciate that...I'll say, you know, there's a 10 degree angle of deformity and that's just about five degrees too much...you'd better [refer] that patient...And because the work is done mainly by GPs whereas here it would be done by orthopedic surgeons, they welcome that.
>
> (Int. #1, p. 4)

In the case of Patient 33, for example, the GP telephoned a distant ophthalmologist to ask him whether a referral was appropriate. Optometrist 33 explained that local GPs will often "call the ophthalmologist and describe what's there and ask what to do" and the ophthalmologist will suggest a particular medication or other treatment, while a referral would be arranged in the south (p. 11).

The specialist as well as the GP in northwestern Ontario assumes more responsibility than

his urban counterpart for a broader range of care. This is because there are no residents in the hospitals to do general internal medicine; further, the volume of patients in a narrow specialty would not be enough to support a practice (GP 30, Int. #1, p. 8). Specialists also unwillingly sometimes do primary care where there is a shortage of GPs (GP 37, Int. #1, p. 2). Further, as small-town Surgeon 39 comments,

> you have to be more versatile a person than in practices in the big city...[I]f I cut somebody open, I have to be able to deal with <u>anything</u> that I find. Whereas a big city surgeon always has the option of calling somebody else.[6] (p. 2)

In the city, a general surgeon will handle "abdominal surgery which includes hernias, breast surgery and varicose veins", but an orthopedic surgeon will be called for any bone problems and a urologist for any urinary tract involvement (p. 3). In contrast, the local rural surgeon will tackle all of these as part of seeing accident cases. This can be exciting, says Surgeon 39, because "you have an opportunity of doing something, and then you see how it turns out, rather than having to send it to the big city" (p. 4). In general, northern surgeons are so anxious to take all comers that there were occasional complaints that they refused to refer on cases that they could not handle

and that patients had to go around them to be referred to the city (e.g. GP 38, Int. #1, p. 3). Surgeon 32, for example, claims that he can do "almost everything", limited only by lack of equipment (p. 4). However, all rural specialists insisted that they "try to avoid family practice as much as we can" (Obstetrician 39, p. 5), since there is enough surgery alone to support them. As this obstetrician comments about northern patients,

> they bring their kids in with sore throats and scraped knees and all the rest of it. And now virtually anybody can deal with that. But you don't want to start dealing with that in the middle of an afternoon of prenatal care and gynecology. (p. 10)

GP 40 points out that it is a deliberate policy of his northern clinic for the GP to take as much responsibility as possible, referring only those patients that absolutely cannot be handled by them:

> If you're lucky and you get a specialist that wants to work really hard, a group practice is a very good environment for it, because you get everything screened out here, there's no rubbish. Everything in the preliminary workup is done [so our surgeon's] surgery is at least twice the Ontario average. I mean cutting surgery. So he's very busy. We don't send him nonsense...And similarly [our other specialist] doesn't get any easy problems...[They] never keep any patients and we really would get upset if [they] did...If we let them pick up caseloads of their own, they would not

> be able to function. They wouldn't be able to respond to my urgent referrals. (Int. #2, p. 3)

Internists in northern cities, while seeing a broader range of problems than their southern counterparts, similarly only get the "complicated problems" referred to them (GP 24, Int. #1). Even where this is not a clinic policy, the specialists try to "save themselves" by avoiding any procedure that a GP could do. For example, GP 24 commented that if one of his patients went to a local gynecologist, he might say "they need a D. and C. and send 'em back to me [for it]" (Int. #1).

The effect of the specialist insisting that the patient see a GP for minor surgery, as GP 24 points out, is that it "prop[s the GP] up so that you're in authority" (Int. #1). Surgeon 32 claims that the GPs who assist him as anesthetists in surgery are "as good" as specialists - and that even cases that they turn down, "they could probably handle" (p. 10). As well, "they do lots of work here which would be done by internists [in the city]" (p. 10). Optometrist 33 explains that this means that patients in the north are quite trusting of GPs to do a variety of procedures, such as take foreign bodies out of the eye, whereas, in

the south, the GP would be "sticking his neck out for a malpractice suit if something went wrong" (p. 11).

In general, the fact that GPs take more responsibility in the north is reflected in the greater respect that both patients and specialists show for their abilities in cases of referral and consultation. Patient 40, for example, described the GPs in his local clinic as "semi-specialists" in various areas such as orthopedics (Int. #1, p. 7). Speaking of Pediatrician 34, GP 34 explained that "he respects us to do primary care which in teaching hospitals, doesn't happen". In the south, he continued, GPs are treated like "dummies" (p. 7). Cardiologist 35 confirms that he is more likely to take over a case for his city referrals than for rural ones, adding the caveat that he avoids monitoring them "too closely, [or] they start coming to you as their general physician" (p. 8). This is not so much because he does not trust the GPs - as he says, "the proportion of [GPs] that can't do the managemement is very small. Who I don't <u>trust</u> to do the management" (p. 8). Instead, he "takes over" these patients because he is responding to a subtle message from city patients that they would rather have a specialist monitoring this problem - "it's not completely a medical assessment, it's from a psychological point of

view". In addition, like other academic specialists, he sees them "for [his] own interest as [much as] any benefits to them" (p. 9).

The exclusion of urban GPs from areas of responsibility that rural GPs take for granted is thus a complex process that comes about from both specialist and patient taking GP competencies into account. Pediatrician 34 admits that he often arranges follow-ups that might be considered "unnecessary" from a medical point of view for this reason:

> [Y]ou're taking a little bit away from the GP...[when] you see [a patient for follow-up] nine months or a year later. You're probably not doing anything that the GP couldn't do, but somehow Mom expects you to reassess the child, and you feel more comfortable reassessing that child.
> (Int. #1, p. 4)

In fact, city referrals differ from rural referrals in this way, he points out. In the city, "90 percent of [the pediatrician's cases involve only] well-baby care" (p. 12), while rurally, referrals tend to be pediatric emergencies. In the city, "you're much more likely to be called to reassure a mother that her child with a fever is just a viral illness" (p. 11), he says, whereas, in rural areas, referrals are "all reasonably well screened by relatively energetic, enthusiastic

GPs", and are thus more likely to be cases that fall clearly within the specialist's jurisdiction.

IV. DYNAMICS OF GP ABDICATION/EXCLUSION

1. Are GPs "Abdicating" Their Responsibilities?

Many hospital-based specialists saw urban GPs as abdicating their hospital responsibilities as well as many of their outpatient responsibilities. Often the "abdication" was put in economic terms. Orthopod 17, for example, claimed that GPs no longer write letters or come down to the operating room because "it doesn't pay" (p. 4), nor will they perform certain outpatient procedures, such as removal of casts, for the same reason (pp. 5-6). GP 19 reported that she ran into a disagreement with a consultant who insisted that she should be able to put on a cast (Int. #1, p. 5). One GP who agrees that family doctors may be shedding too many of their responsibilities, comments,

> A lot of my colleagues tell me they don't do deliveries because - the reason is really greed - it is that they don't pay...[T]hey're stopping them because it doesn't pay...That's why most people quit. And yet we're

> supposed to be general practitioners, you know. We're giving up with one hand and trying to hand on with the other.
> (GP 5, Int. #1, pp. 14-15)

He lists the areas that GPs have abdicated: "they don't do tonsils, they don't do D. and C.'s. They don't fix too many fractures. They become pocket psychiatrists" (p. 15). Orthopod 18 also points out that the GP can generate more income by seeing patients in his office than s/he can in the operating room (p. 3). It is easier to phone the specialist at the hospital than to come down (p. 5). Specialist 29 pointed out that this was the trend even in northern Ontario:

> [R]eferrals are much more frequent ...[T]he population of this area has not changed that much...[I]n our group, we have four internists who are surviving to a large extent on referral work whereas there were two of us here when I came in '58...but there were very infrequent consultations ...There are various reasons for it. One of the most important is technological advance. But medico-legal considerations are very prominent. And then willingness to slough.
> (Int. #1, p. 13)

2. Or Are GPs Being Excluded From the Hospital?

Orthopedic Surgeon 18 outlines more complex reasons underlying the failure of GPs to show up at the hospital that relate more to the organization of medicine than to economic incentives, although these

are interrelated. While it is still "possible" for urban GPs to "practice medicine as they wish" - since they are not completely barred from participation even in big city hospitals -physician reports suggested that a combination of psychological pressures and practical considerations really leave them no choice but to concentrate on their office practice.

Gynecologist 19 said that although she is streamlining her practice, she understands that she must become involved with her patients and leave her GPs free to concentrate their practices in their offices. Deliveries involve leaving the office, she points out, and "when [the GP] comes back, he's got an office-full of patients...complaining" - "it is less of a hassle for them...if they just stay in their office and look after all those patients" (p. 8). Patient 11, a hospital employee, whose brother and sister-in-law are GPs, similarly argued that it is unfair to expect that the GP can handle such a heavy outpatient load and then also take responsibility for the patient in the hospital. "I think it's a bit <u>much</u> for the GP", she says (p. 8).

a. Restrictions of Licences and Hospital Privileges

As GP 7 remarked, younger GPs tend to be discouraged from taking more responsibility when,

> [t]hey get in the hospital and you can't do this any more and you can't do that any more. And this is purely for a surgeon and this is purely for another specialist and so on.
>
> (Int. #1, p. 14)

When they get a hospital staff appointment, as most GPs now do, they receive a card on which to list procedures that they would like to do. "[All] you can do is apply for it. And there is a Provincial committee that says, OK, yes, he can do this, he can do this". However, it is unrealistic for many GPs to apply for many procedures, he adds. For example, he knows that he wouldn't get obstetrical privileges because "if you do less than about four in a year, you're not really up to date" (p. 14). For obstetrics, a family medicine residency would be assessed favorably, but a period of supervision would still be required. The hospital is justified in this firmer line, according to this GP, "[b]ecause the hospital gets in hot water if you mess it up" (p. 15). He argues that this state of affairs is preferable to situations that he recalls in the past in

which he had to undertake procedures that he wasn't comfortable with, and that are now done by specialists.

However, a few doctors felt that some hospitals had gone too far in placing restrictions on GPs. According to Gastroenterologist 12, "we're wiping them right out of the hospital". He recalled that, a decade ago, at his hospital, the GP and the general internist shared responsibility around patients. Now, at this hospital, the GP can no longer even admit a patient without a subspecialist. GP 12 explained that technically, there are two or three beds for GPs to admit patients at this particular hospital, but that over the years, subspecialists have "claimed" more and more beds (Int. #2, p. 10). GP 16 thus calls what some specialists term an "abdication" of GPs really a "squeeze" in which GPs are being excluded from the hospital (Int. #1, p. 8). GP 30 commented that even where GPs have a strong presence, in northern hospitals, they have to "guard their power" because,

> Internal medicine is very jealous of the powers of general practitioners, and they'll attempt to block admitting privileges, or on referrals...they attempt to monitor what they consider 'their' beds in the hospital.
> (Int. #1, p. 16)

In technical terms, GPs no longer are able to perform some of the procedures that are routine. GP 24, for

example, explained that over time, he has done less and less surgery because "in the old days", he "just did the same thing as the surgeon did" (Int. #1). For a perforated ulcer, this used to involve resuscitation, closing the perforation and patching. Now, however, the surgeon does a vagotomy and other procedures beyond the GP's competence. The GP therefore finds himself more and more in his office, referring patients whom he used to be able to treat.[7]

b. Competition with Medical Residents

Complicating the situation at teaching hospitals is the presence of medical residents, who are supervised by specialists, and who balk at "backing up" a GP, since GPs are not their teachers. Gastro-enterologist 12 claims that in such a residency system, even he cannot do anything for a patient where the residents handle things on a day-to-day basis. (This appeared to be the situation for Patient 7.) If a GP tries to visit a patient in such a hospital, s/he is usually unable to get information about what is going on, unless s/he talks to the patient or the nursing staff, since residents are seldom available for consultation when the GP arrives. A few GPs also

reported difficulties in dealing with medical residents. GP 19, for example, said that she lived through a rough period in the transition from "student" to "doctor on staff" where she had been dealing with residents but then had to relate to former teachers as colleagues. When she tried initially to work through a resident when she was on staff, the resident would "try to think of any excuse not to see the patient" (Int. #1, p. 8). Gastroenterologist 12's conclusion about this situation is that visiting a patient in hospital, for a busy GP, is a "total waste of time". He adds, "I wouldn't do that" (p. 8).

If GPs try to participate in surgery, Orthopod 18 points out, residents assist at surgery and GPs are often put in the boring, redundant and non-lucrative position of "second assist", which they may find discouraging (p. 3). In general, says Specialist 5, a residency system has the effect of reducing the number of side-by-side contacts between GPs and specialists, and the situation may be difficult to reverse. For example, one young staff specialist noted that the progressive withdrawal of the GP from his local hospital has thrown it into a state of crisis, because there are now government cutbacks on the numbers of

residency positions and staff members (such as himself) are now called upon to do what residents once did:

> [A]s resident numbers get down, and residents aren't involved in all the cases in hospital anymore, it makes my life much more difficult, because it further increases constraints. Because...I have to do routine primary care follow-up on patients in hospital. (Internist 4, p. 11)

Prior to the arrival of residents, he explained, GPs took a lot more responsibility for their patients, and staff men have now inherited more direct care responsibilities than they used to have. Because of this, he says, they "are looking at ways to get the GPs more involved again. So that some of the work can be shared around" (p. 12). He is not optimistic that local GPs will be interested, however. As he explains, "they're going to be resistent, because they've grown to like being home at night and not getting phone calls. And they've also lost some of the skills involved that they need to do the inpatient care. But basically, we can't do it all." (p. 12). He believes that a more threatening stance will have to be taken:

> [Y]ou just have to lay it on the line with the GP and say, look I am not going to cover your patient if he needs a laxative at four in the morning. I'm going to tell him to call you and <u>you're</u> going to deal with it. Or whoever is on call for you. And

> we're in the process of trying to work that out. Obviously you don't want to piss off all the general practitioners. You have to do it, you know, in a slow and tactful way.
> (Int. #1, p. 12)

He adds, "I think it's going to be a major issue in the next few years" (p. 12).

The other side of this issue is illustrated by GP 10's claim that he recently sent a patient to the ER who did not get treatment, so that he ended up treating her himself some days later (Int. #2, pp. 13-16). He denies that it would have been appropriate for him to insist that the job be done, but since "this was my referral to Emergency", he feels that they should have taken responsibility for it. He sets aside the issue that he knew what to do in this case because it is not a problem that can be dealt with in the family physician's office. He could have given the patient something for pain, he said, but her problem had to be investigated in the hospital. Staff men, rather than residents, were involved with this case. But the real culprit, in the GP's view, is "the hospitals", who have taken GP privileges away. This has led to a loss of skills and a feeling of not wanting to be involved where one is not wanted. On the issue of declining night calls and the problem he encountered with the patient sent to ER, GP 10 commented that prior to the

establishment of the residency system, "I would've admitted [the patient] and [the specialist] would've seen him in the morning" (p. 15). However, in the current situation, ER staff become angry about such admissions.[8]

Urban GPs freely admit that developments at their hospitals have reduced their workload. In the words of GP 7, "[l]ife is much easier now. Much easier" (Int. #1, p. 14), despite the frustrations of some younger GPs about what they are not allowed to do in the hospital. GP 19 also says that she is aware that in northwestern Ontario she would have to go to the Emergency Department with a patient and stay up all night with him or her. But while this would improve her skills, it would "disrupt her sleep" (Int. #1, p. 14). She explains that this "abdication of responsibility" has its benefits - she sees this as a tradeoff, commenting that, "in many ways, I suppose, things have been taken away from us as a group, but overall, as a group, we've asked for it" (p. 15). Where you do all the work, she adds, you keep the responsibility (p. 15). The drastic reduction in night calls is part of this withdrawal of responsibility - which this GP, and GP 14, both experienced a few years ago with the establishment of the residency system (p. 13).

c. OR Constraints

Another constraint that limits GP participation in surgery at the urban hospital is the establishment of a "block booking" system by which surgeons are assigned a specific block of time per week within which to perform their surgery. As Specialist 5 explained, this system reduces the chances that GPs will show up for surgery because, for example, if a surgeon is assigned four operating hours on a Wednesday morning, referring family physicians may have office hours at that time. They may only be able to participate if there is emergency surgery booked at 10 o'clock at night. Alternatively, if a surgeon is unreliable and runs behind time, the GP may not be able to wait around. They can charge for such delays, but this is generally not a productive way to spend time. Orthopod 18 admits that he has been guilty of this and that many GPs have been discouraged from working with him. As he says, "they'll know if a surgeon is on time and they're more likely to show up" (p. 4). He has therefore tried to be more prompt and to recruit new GPs and surgeons to fill the gap.

One GP who was able to show up for his patient's surgery explained that he has more time

because he no longer carries a full patient load, and so is more able to attend surgery when it is scheduled at hours when normally a GP must be at his office in clinic (Int. #2, p. 7). This GP says that surgeons who don't have residents will ask GPs to scrub in, but more typically, the "situation" of scheduling actually discourages the GP from attending the surgery. Now "surgical assistants" and "cardiovascular teams" are filling in for the missing GP in urban hospitals. GP 7 is unhappy about this situation because, as with Patient 7, it means that he tends to lose track of inpatients. He believes that specialists don't mind having GPs around (although Specialist 7 said he'd rather not have them around). Instead, he passively accepts the blame, insisting that the problem is "mostly the fault of the family physicians", who hide in their offices where they feel more "comfortable" (p. 8).

Specialist 5, who sees a crisis in his surgical subspecialty which has to do with decreasing GP participation (pp. 7-8 and 10-11), worries that "we are losing out on this good kind of family doctor" and sympathizes with the patient who has to "take off his shirt to every new face", referring to residents and medical students. He also suggests that there is more

duplication of tests because of the extra layer of physicians. Specialist 5 himself is short of residents, so that often, like Orthopedic Surgeon 18, he has to depend on GPs to "scrub in" with him. About what GPs are allowed to do, he claims that this is not always clear. Even he is restricted in what he can do, and for example, he would not remove tonsils except in an emergency. However, the strict drawing of lines of specialization, he points out, does not make sense in terms of good patient care. Further restrictions on GP participation are introduced by localizing certain services in one hospital of a region for efficiency. These arrangements exclude most GPs from participating in tertiary inpatient care for geographical reasons alone.

d. Preop "Referral"

In city hospitals, internists are now called in routinely to do a general examination of patients, particularly elderly patients, before surgery. Pre-operative assessments might be seen as primary rather than tertiary care work, but both Internist 16 and Orthopedic Surgeon 18 emphasized that they use internists rather than GPs partly for medico-legal

reasons. According to the orthopod, this type of "referral" is felt to be necessary because the GP in southern Ontario no longer has the time to do it nor the skills. If the GP does it, the orthopod worries, there might be medico-legal consequences. GPs in northwestern Ontario said that this sort of assessment wasn't too difficult to handle and that they did so routinely, but city specialists are much happier to have a skilled internist handle complex cases such as post-heart surgery (Orthopedic Surgeon 18, p. 7). Because he has an internist who regularly does all these assessments for him, Orthopod 18 tends not to ask GPs who they would like to do preop assessments on their patients. In fact, he sees this as his business. As he puts it, "one tends in life to try and simplify" (p. 8). GP 40, in northwestern Ontario, on the other hand, felt that having an internist do a preoperative medical assessment "is an abuse of the internal medicine service. We can't afford to have primary care done on referral" (Int. #1, p. 6). In his own case, he feels, he has "lost the battle", because the city where he sends his patients for surgery is too far away for him to travel for pre-operative assessments.

3. General Practice and Outpatient Responsibilities

As GP 23 recalled, before the advent of national health insurance in Ontario, "you didn't go out of town in case you'd lose a patient" (p. 10). It was so difficult in the 1930s, when he began practising, to set up a practice with customers that would pay, he said, that you had to wait for another GP to "drop dead" in order to buy his practice. In keeping with this fiercely competitive situation, physicians of this period tended to "work until they dropped". All this implies that the "golden age of general practice" of the first half of this century in Canada (Shortt, 1984) was probably not based on the GP's altruism so much as on attempts to maintain a tenacious hold on a source of income. Dedication to one's patients resulted in fewer referrals, with the GP tending to take as much responsibility as possible, because he wanted to keep the patient. GP 23, for example, was so upset about losing track of some patients when the local medical school first opened (p. 7), that he took a long time to trust them and refer again. Although the days that he spoke of have passed and he has had to take partners to

handle his patient load, he still voices concerns about losing patients (p. 5).

a. "Stealing" Patients

Are his fears about specialists "stealing" patients justified? The results of this study suggest that there is some justification for his concern, but that "stealing" is very selective. That is, in teaching hospitals, patients of particular academic interest may "disappear" within hospitals or large clinics. The case of patient 7, who was to have had a device implanted to filter her blood as teaching experience for the resident involved was an example of this process. A number of academic specialists also admitted that they continued to see outpatients with interesting diseases not solely for the patients' benefit.

Occasionally the specialist advocated involvement in a continuing and comprehensive way well beyond what the GP had originally envisaged, and not just for casual followup. For example, Patient 2 underwent respiratory treatment that involved visiting a respiratory clinic every few days for extensive testing and changes in medication over several months, even though the referring doctor had only asked for

"assessment" of his condition. With this type of treatment, the specialist commented, as in the case of asthma and other respiratory disorders, "the specialist is a manager and a teacher and facilitates bringing all other kinds of services together" (p. 4). After complaining about the lack of responsibility generally taken by GPs with this type of case, and suggesting that GPs actually refuse to send him patients because he "steals" them, this specialist adds that when patients finally get to his clinic, they receive the "total individualized educational package so that they become independent of the physician" (p. 4). Regarding Patient 2, it is clear that the GP "lost track" of the case, since she was not able to answer the patient's questions about medication. She received one three-page letter from the specialist in the first few weeks of the referral, but it was not enough to keep informed about the details of this case.

Is there any danger that FFS consultants will take over a GP's outpatient? It was suggested in Chapter 5 that an occasional dishonest practitioner who was "short" of patients for one reason or another, might "dredge" patients, not for teaching or research purposes, but for profit. However, this approach may backfire if GPs decide to send no more patients. It

appears to be more of a danger in specialist-dominated outpatient clinics where specialists tend to refer to other specialists within the clinic without checking back with the GP. For example, Patient 29 was referred on by an internist to an anesthetist and a surgeon for a lung biopsy (which the patient did not want) without consulting the referring GP (Specialist 29, p. 9). The internist said that this was typical of this clinic "once it's into this level of care" (p. 9), and that he would only get the GP involved if he were making a referral outside the clinic (p. 10). He felt that not consulting the GP in this case was justified because the biopsy decision was part of the responsibility that he was supposed to assume for this case (p. 11). Ironically, the GP involved emphasized that he had "no patience" for consultants who did not keep him informed about the progress of a referral, although he was aware that specialists in his clinic persisted in doing this (Int. #2, p. 4).

There was also the occasional specialist who insisted that patients were generally better off under his, than the GP's care. Specialist 16, for example, said that he never shrinks from taking over cases, e.g. by taking responsibility for drugs by asking patients to bring all of them in and by discontinuing whatever

he feels should be discontinued (p. 18). He says that he doesn't bother fighting with the GP over such "silly things", and sees the split of responsibility between him and the GP as "not problematic" (p. 19). This man, in the later years of his career, has major concerns about "losing" referrals to younger subspecialists, so that it is probably in his self interest to "hang onto" patients.

The allegations about "stealing" are difficult to prove, however, since multiple specialist visits in this research often appeared justified by the weeks that took to put a patient through numerous tests, as in the cases of Patients 8 and 12; or by the specialist's "thoroughness" in trying to deal with a difficult case, with concerns over medico-legal matters in the background. Further, in a few specialties, such as ophthalmology, GPs did not have the training or inclination to remain involved, and were quite happy to hand a case entirely over to the specialist, even for a two or three year period. An example in this study was that of Case 37 where the GP admitted "I refer all squints" because "I have very little experience with ophthalmology" (GP 37, Int. #2, pp. 3, 7).

b. The Tertiary Referral Problem

One of the most common complaints from GPs around referrals was not about the specialist who "steals" patients but about the one who refers on a patient to a tertiary consultant without consulting, or even notifying the GP. GP 7, for example, complained,

> [M]aybe I'll send somebody who has a heart problem...Next thing they refer without me knowing to somebody else to look into this GI tract or GU tract or so on. And I don't think this is right...They should at least put in a call to see who you prefer. Many do that but not all. They just kind of pass it on to the next specialist.
> (Int. #1, p. 13)

He added that he had often already taken care of the problem (p. 14). GP 1 suggested that this takeover of a case by a specialist reflected an assumption that the GP is not aware of, not competent to handle, and/or not interested in the problem. As he comments,

> I think they do it when it's outside their area of expertise and your consultation note...may not have addressed that particular issue, and they think it's an unresolved problem. Sometimes the patient doesn't put a very succinct case forward to the extent that you're dealing with the problem.
> (Int. #1, p. 10)

Specialists confirmed that they believed that most GPs did not care when a tertiary referral was

made. As Specialist 13 said, GPs "don't want to spend their day on the phone making referrals" (p. 2). Although he occasionally hears complaints about going ahead on his own, he observes that "the same people tell me at other times, why the hell are you bothering me? Why don't you just do it?" The compromise he has worked out is to go ahead and then "tell them" in the consult note that he's taken the initiative and referred.

The consensus of specialists is that the consultant should check with the GP on surgical referrals "out of courtesy" (Internist 4, p. 8), but that this is not that important in other areas. As Internist 12 comments, "I don't think that most specialists have the time to sit down and call a family doctor and ask him whether he would agree to that. Most family physicians, I think, are agreeable to this sort of arrangement" (p. 2). There is the "odd GP" that wants to be consulted, according to this internist, and you just keep a mental note of them and oblige. Specialist 16 agrees that "straightforward" tertiary referrals, such as those to ENT specialists, do not require a call to the GP. The general rule that he follows is to ask the GP to arrange a consultation around a problem that he discovers that is not related

to the original referral, but to refer himself if the problem is related to the original request (p. 19).

4. Responses to the "Squeeze": Passivity and Militancy

A few GPs in this study appeared to passively accept their progressive exclusion from certain areas of hospital and outpatient care. As pointed out in Chapter 6, GPs who have been away from the hospital for a few years are at a disadvantage in assessing the competence of their consultants and they appear more willing to hand over responsibility to the specialist than the GP who has an opportunity to assess competence first-hand. GP 14, for example, has a rule of thumb that she lets the specialist direct the treatment (Int. #1, p. 10). This includes drug prescriptions, which, she emphasizes, "we would not change". If she had any questions, she says, she would call the specialist or book another appointment to have the situation reviewed.

This is a different approach than that reported by more experienced referring doctors, such as GP 8, who said he was quite critical of what he got back from the specialist and that he was willing to change drugs,

discard other advice, or make whatever modifications he felt appropriate. GP 14, on the other hand, left virtually no room for any disagreement that she might have with the specialist's advice. Neither did she see any technical problems if the patient called her for advice on, for example, a drug reaction when she was not aware of what the patient had been given. Her solution would be merely to call the specialist (p. 11). She added that she if she wished to alter a specialist's treatment, she would only do so long after the consult. Even family medicine residents seem more critical of their consultants than this GP, perhaps because they have first-hand knowledge of these men, as suggested in Chapter 6.

GP 16 predicted that GP 14 would become more like him as she gains more experience and wants to give away less responsibility to the specialists (p. 7). Then she will earn the respect of consultants, he expected. But, he predicted, if respect is never gained, communication will be poor and the GP will further lose control of her cases. He spoke of being vigilant about guarding GP responsibilities around referrals, complaining that, "even I lose track because there are all sorts of subspecialists lurking around the corner" (p. 8). He sees referral as involving a

battle that he wages with the specialist for control of the case. In keeping with the "battleground" metaphor, he talks about specialists "squeezing" GPs, whom they consider to be incompetent, out of the hospital. He theorizes that with individual cases, the specialist "takes over" (i.e. informs the patient himself or refers the patient on without consulting the GP) if s/he detects "inertia" on the part of a GP (p. 8). This inertia may be related to the GP's perception of his or her own incompetence to handle a problem, perhaps because of the inadequacy of his or her training. However, the assessment may be wrong, and if so, it must be corrected. When a neurologist recently tried to refer a patient of his on to a cardiologist, for example, this GP let the specialist know that he had stepped on his toes, and pointed that the consultant had missed the original problem for which the patient had been referred. The consequence of allowing specialists to take over patient care, warns this GP, is "an overall disintegration...of what I consider good family care" (p. 8). In such a situation, he adds, the GP no longer "holds all the cards" - but neither does the specialist.

GP 12 was another middle-aged GP who thought that with increasing experience, GPs would learn to be

critical of and challenge consultants and the technological approach they represent. This man, like other rural GPs, performed procedures such as the setting of bones, that urban GPs did not feel comfortable with (Int. #1, pp. 12-13). He also seemed more willing to take on the specialist when he disagreed with him or her. For example, he spoke to the staff at one hospital about an alcoholic patient of his whom he thought was being treated in an undignified way. He had once reminded a staff person who let a patient bleed for a week that, "you are the responsible physician", not the attending resident. One case that upset him involved a specialist who wanted to continue care on his patient, when the man wanted to be left to die in dignity. He had debated about taking this example of pushing technological medicine to the extreme to an ethics committee.

A third middle-aged GP who jealously guarded his responsibility for referred patients was GP 27 from northwestern Ontario. This man, called an "old style" family physician by his patients, was clearly the responsible physician for Patients 27 and 28, who were referred to Toronto and Winnipeg, respectively. When Patient 27 made the mistake of going to see her rheumatologist without talking to the GP first, as she

put it, "I got my ass booted". In other words, she was reminded that her GP wanted to remain in the picture. In this case, the GP had emphasized to her that "professionals talk to professionals" (p. 16). As the patient says, other GPs may abandon a patient, saying, "No, I've seen you, I can't do anything for you, the other guy will take care of you" (p. 17). But her GP "doesn't want to be told by another doctor that this is what's happened" (p. 16). The patient labels contacting the specialist directly an honest mistake, because, as she says, "I'd rather go to the top. But you have to follow steps...And then everybody's happy and everybody knows what's going on" (pp. 16-17).

GP 29 from northwestern Ontario agreed that, "I don't feel we should bow at the feet of these exalted human beings that call themselves specialists", adding that "if consultant's habits [around here] were really derelict, people would be on to them pretty quickly" (Int. #2, p. 6). A few very militant GPs, however, thought that a boycott was more effective than mere negotiation. For example, GP 40 commented,

> [I]f I refer a patient to a specialist...I do not expect that specialist to send them on to somebody else...[T]his is all part of the...team spirit, as it were, between referring doctor and consultant. And if a consultant sends my patient to another

> doctor without asking me, I won't send him any more patients!
>
> (Int. #1, p. 5)

While he admits that certain conditions require immediate attention and tertiary referral, he feels that most situations do not fall in this category. For example, it is just "common sense" to refer back patients who might need cataract surgery, so that he can discuss the decision with the patient (p. 5).

GP 30 similarly reported boycotting specialists and clinics who "internally cycle patients without consulting the referrer" (Int. #1, p. 3). This included "about a quarter of the specialists in town" because "they don't allow enough participation by the general practitioner. They tend to ignore the general practitioner's role in interpreting what is to be done for the patient" (Int. #1, p. 17). This GP decided on this policy after one of his patients, by tertiary referral, reached a man "who has continually been at odds with me on diagnosis and management" and the patient "ended up going to the Mayo Clinic because they got fed up with all the haggling" (Int. #1, p. 3). This GP suggested that where GPs still have some power in local hospitals, they can block the hiring of specialists who might be recruited into networks of specialists who favour the squeezing out of local GPs

(pp. 10-11). In his city, two factions have developed: the "we want nobody but subspecialists" vs. the "we want general internists" groups, and every new specialist who comes to town gets drawn into this battle (p. 16). By definition, the former group is bolstered if a subspecialist is recruited to the hospital, and it is up to GPs to keep them out.

According to most of the specialists in the study, GPs such as 8, 12, 16, 27, 30 and 40, who are both respected as being competent and enthusiastic about assuming responsibility for their referrals, are very much in the minority. Neurosurgeon 28, for example, makes a contrast between the amount of responsibility taken by the more numerous urban vs. rural referring doctors and older vs. younger ones. He says that in his experience, it is the older GP who may force a specialist to take over responsibility for a case, and be more likely not to be bothered - perhaps because they haven't had as rigourous training as some of the younger GPs who now take family medicine residency training (p. 4). Also, rural GPs tend to take more responsibility, as in the case of Patient 28, where the GP has a "central role" as a 'coordinator" (p. 3). In a small city, the neurosurgeon explains, GPs and specialists see each other every day in the

hospital, and so he may be consulted more often by the faltering GP to see what he thinks (p. 6), but borderline GPs are able to hang onto the responsibility for their cases longer only because they know he is there as a backup and that he will see their patient right away if they run into difficulty (p. 7). Specialist 27 described a similar situation in Toronto (p. 3).

In assessing the comments of these specialists, the point should be made that it is likely that just as the patient's influence and desire to participate in care is underestimated by the physician, so the GP's intentions are underestimated by the specialist. However, GPs also dichotomized themselves into "passive types" - who refer more because they have symbiotic "political/social/economic" relationships with specialists - and those who refer less because they are more independent. GP 30 suggested that passive types might be attracted into specialist-dominated group practices because they are "less independent or less able or ready to pursue problems far enough along the way" (Int. #1, p. 18). GPs like this would be considered an asset to the clinic "because it generates more referral" (p. 18).

V. THE "COLLUSION OF ANONYMITY"

Although physician reports emphasized that referrals ran into difficulty when one or the other doctor involved took too little or too much responsibility, a more common problem in this study was the situation in which no doctor appeared to take the initiative. Obstetrician 34, for example, complained that with referrals from GPs in one hospital in northwestern Ontario that he knew,

> many people are doing things, but nobody's taking responsibility...What they do is they...see a patient who they refer to someone, but they don't index things very well as to who they refer to and what to do.
> (Int. #1, pp. 1-2)

Balint (1957) first documented this process for cases in which the GP was unable or unwilling to "negotiate" an appropriate diagnosis with the patient, and he or she passed through multiple referrals with no resolution of the complaint. Obstetrician 34 identified the problem as abdication of responsibility by the GPs, who did not work to attract good visiting specialists to their town and who continued to refer to specialists some distance away whom this man suspected were not the best available. When they did refer, he suspected, it was as an "afterthought" (p. 7), rather

than as an organized approach to care. Because the GPs were "afraid" to perform certain procedures on their own, Obstetrician 34 believed that they were "clued out" and incompetent: "They can't even handle low-risk normal obstetrics", he complained. "[T]hey don't want to do it. They're not interested, they just refer 'em all out" (p. 8). When he has had to handle their cases, he sneered, "you hold their hand all the time" (p. 10).

Although Obstetrician 34 saw the crucial aspect of a "collusion of anonmymity" as the abdication of responsibility by the GP, the other contributing factor identified in this study was "abdication" by the specialists involved, often due to the "streamlining" of specialty practices described in the previous chapter. While specialists occasionally "steal" cases of interest to them, referring doctors more often complained that they refused to take responsibility for cases that did not interest them. Alternatively, both doctors might incorrectly assume that the other was taking responsibility. Although Balint believes that the GP, by becoming a psychiatrist, can deal with many of the complex problems that end "collusively", it is argued here that this solution is unlikely, since the "treatment" given by specialists is often beyond the competencies of the GP to coordinate. Further, the

patient, after numerous negative experiences, does not trust his or her doctors, and may not be willing to allow such co-ordination.

1. An Example of "Collusion"

The case of Patient 28 illustrates how a team of doctors can appear to be addressing a problem when no one is really assuming responsibility for the case. A long, frustrating sequence of unhelpful referrals and investigations left this man confused and angry. After he suffered a 20-year history of headaches, beginning with a 1958 accident, his wife finally complained to their GP, who referred him to an ENT specialist. This specialist sent him on to an internist, who gave him a nasal spray. In 1984, the patient saw another ENT man who encouraged him to see an ophthalmologist who gave him glasses. At the end of 1984, he went to a neurosurgeon who produced a normal CT scan. The neurosurgeon recalled that the man was rather passive, and certainly not pressuring to be seen, but that he was fearful about the cause of his headaches. "Something is going on and somebody has to tell [him], point blank, look, this is what it is", he remarked, "[and then he can] compensate and be happy" (p. 3). The

neurosurgeon thought that he had been helpful in ruling out a brain tumour, but the patient denies that anyone he has seen has been able to help him and he is no longer willing to bother with them. His final contact involved a trip to a pain clinic, where he was given pills that he threw away. The doctor at the pain clinic described himself as the "last resort" for patients who have previously seen a whole gamut of specialists, since he can at least take care of the pain by nerve blocks, epidurals, steroids and acupucture (Anesthesiologist 28, Int. #1, p. 3). He thought that there might be a chance of helping this man if he could be "worked on" by a multidisciplinary team of psychologists, anesthetists and rehabilitation specialists as an inpatient, but no such facility exists in Canada (Int. #1, pp. 6-7).

The GP, on the other hand, believes that no multidisciplinary assault will solve this man's problems, which are due to family stress and shiftwork, that have left him tense "for long periods of time", thus leading to the headaches (Int. #2, p. 2). The GP has backed off, because he fears that a more active intervention on his part would provoke antisocial behaviour - "I know my limits", he concludes.

Meanwhile, the patient is in limbo, unaware of his doctors' conclusions about his situation.

2. The Dynamics of Collusion

a. Specialist "Abdication"

The failure of the specialist to address the problem for which the patient was referred was often noted by GPs in this study. In fact, as many GPs pointed out, for certain long-term problems such as chronic back pain and psychiatric difficulties, one never "loses" cases (e.g. GP 10, Int. #1, p. 9; GP 32, Int. #1, p. 4) and is more likely to have a referral handed back that hasn't been worked up properly:

> You may make referrals but they always end up coming back to you. Without being any further ahead really. With those kinds of problems...I think some of them there's no solution for.
> (GP 10, Int. #1, p. 10)

Not only did specialists tend not to take over outpatient referrals, but in a few of the urban cases and fully half of the rural referrals in this study, the patient was seen only once by the specialist. For example, Specialist 3 explained that he didn't make any follow-up appointment to check the ears of Patient 3 because "a year or so may not show that much difference

with her". Patients can't be forced to get a hearing aid, he added, and you have to wait for them to request it themselves (p. 14). Internist 4 similarly emphasized that he doesn't hang onto patients. "I may follow them up once or twice in the office, if they have a complex problem. Otherwise, I'd send them straight back to the GP", he says (p. 6). In the past, he admitted, he used to be more aggressive in his interventions, but has learned a more conservative route by experience.

In the south, the rare one-shot referral, in which you can "get it over with and get the patient back to the GP" was spoken of enthusiastically by a number of specialists, including Internist 12 and Gynecologist 19. Gynecologist 19, whose "streamlining" of her practice was described in Chapter 7, claims that most of her referrals outside of pregnancy are "one shot" (p. 5). If there's something she can do, she'll give another appointment (p. 1). But otherwise, for example, if Patient 19 had decided not to have a D. and C., she would have just told her to call her if she ever changed her mind and decided she was ready (p. 4). Orthopod 18, another specialist who is streamlining his practice, emphasized that even during the time when he took all referrals without preference, he never "hung onto" patients. Holding onto patients hurts

economically, he explained, because an orthopod gets $90 for seeing a new patient but only $20 for followups. Thus, in an unlimited market, such as orthopedics, the game should be to get rid of as many patients as possible on the first go (p. 8). The effect of this process has been that the GP has increasingly taken more responsibility for problems such as back pain - as GP 24 explains, "that's better than trying to get them to see a specialist" (Int. #1).

Conveniently, there is a theoretical justification for sending the patient back to the GP as soon as possible. Such a practice is compatible with seeing the GP as the source of all responsibility and information on the patient - whom Orthopod 18 called, the "clearinghouse" (p. 9). This surgeon argues that even when the specialist has the responsibility for a patient who's going to have surgery, it is wise to have the GP involved by inviting them to surgery and asking them to fill out forms on their patients, so that nothing is forgotten (pp. 4,9). His general rule is "I try not to continue seeing patients" (p. 8). Internist 12 also emphasizes the theoretical "continuity of care" argument for getting patients back to the GP quickly, but admits that it really only makes sense to get a case back as quickly as possible if you have plenty of

business, as he does. "There is not that pressure on me to start collecting patients", he says (p. 9). And he generalizes this to all specialists when he says, "I don't know many specialists that are so lacking in business as to follow a patient for longer than they need to". Thus the theoretical argument about respecting the GP's rights is supported by economic self-interest.

These trends are more evident in northwestern than southern Ontario. Internist 40, for example, emphasized that "[specialists] are just supposed to be interventionists and get out, unless there is an immediate need for something I should manage" (p. 2). He felt that the local situation was good because "there is always a primary physician that you can depend on" (p. 3). However, not all northern GPs were happy with this situation. While in southern Ontario, there was an undercurrent of disappointment that not only do specialists not grab cases anymore but they seem not to help you all that much, in northwestern Ontario, there were outright complaints that specialists were obstructive. GP 25, for example, described referrals in which the "consultant is rather cool about the referral and doesn't feel that it is necessary" (GP 25, Int. #2, p. 7).

Specialist 26, in fact, complained about this GP's referral of a patient with ear pain. Following a 15-minute monologue about how he is a highly-trained surgeon and does not want to waste his talents on "reassurance" cases, he commented that whatever was wrong with this patient, it didn't lie in his specialty of surgery (p. 4). Since, he said, "it turns out objectively we can't find anything"...[the only approach is] just to follow her and reassure her that there doesn't seem to be anything major" (p. 4). After her visit with him, the patient expressed frustration. She had waited three months to see him, had driven over 100 miles and had waited for two hours in his office, only to leave "empty handed" and "back at the beginning" (Int. #3, p. 1). She wished that there was some way to short-circuit the interminable waiting for something to be done, but the ENT specialist, who had suggested an oral surgeon, refused to refer her on. In his words, "if you've got nothing that will really help, I would leave it up to [the GP]" (p. 7).

This same ENT specialist repeated the philosophy that it is unfair to the GP not to get such cases back right away. Although he admitted that he sees some friends as patients "off the street", as do other specialists, he added that he tries to emphasize

to the patients that they have to go back to their GPs, because the GP "has to live too" (p. 8). He remarked, "you can see their point of view" when GPs complain about specialists who steal patients. He says that he has been made aware socially of an anti-clinic feeling which has grown up because the large clinic with which he is associated has a reputation for "swallowing up patients" and he does not want to be embarrassed by these criticisms. However, in view of the complaints about specialist service in this area, it appears that "stealing" is a problem of the past. Many specialists emphasized that they did not have time to do "well-baby", "well-woman" or any other kind of primary care, even though they may have done so in the past (e.g. Obstetrician 34, p. 10).

b. Failure of GP or Specialist as "Coordinator"

Obstetrician 34, like many specialists, emphasized that although he lets "the GP do everything, including the delivery", he plays a "supervisory role" by "watching from a distance" (pp. 10-11). He said that he does not "steal" cases by saying "it's time for you to refer to me and I'm going to do the delivery and you just hide", nor does he abandon them. However, even

when there is a great deal of "involvement" by both GP and specialist, paradoxically, the patient can "fall through the cracks" if the specialist assumes that the GP has control and the GP assumes that the specialist has control.

For example, during a period of several months for Patient 14, when she was in outpatient care, both GP and specialist saw the patient regularly. A formal "shared care" arrangement had been worked out, in which the GP did not hand over complete control of the case to the obstetrician, as often happens when an obstetrician handles a delivery in a tertiary care centre. The GP in this arrangement was still able to follow her patients' pregnancies although the specialist took over the major time commitment and risk associated with the delivery of the babies (GP 19, Int. #1, pp. 2-3). Involvement of both doctors seemed to work fairly well, but ambiguity over just what the specialist was responsible for beyond the actual delivery confused the patient and her husband. The obstetrician told the couple that it was not his responsibility, but the pediatrician's, to explain the fact that their previous two babies went into distress after birth (Obstetrician 14, p. 1). He also argued that it was not up to him to identify any problems

with the patient's pregnancy, but that this was up to the GP in their "shared care" arrangement. But the GP in this case was unsure of herself and willing to let the specialist take responsibility. When invited, she didn't want to come to the hospital to observe and assist the obstetrician in deliveries. The result was a gap in responsibility.

The most dangerous situation of this kind occurs when an outpatient is on a very complex drug regimen where it is not clear who is the overall co-ordinator of care. The case of Patient 4 illustrates this problem. In this case, there were a number of specialists prescribing drugs and no one appeared to know the overall effect of the patient's medications. His wife alleged that two incompatible medications were given to the patient by two different specialists and that this landed the patient in the hospital, where he missed some work that he could not afford to miss. The woman told of a medication mixup in her family that had upset everyone (Int. #3, p. 5) and so she checked with the druggist and the hospital resident, as well as medical books, about her husband's medications.

The family physician of Patient 4 reported that the drug prescribed by the neurologist was not supposed to interact with the drug prescribed by the

cardiovascular surgeon. However, it was impossible to reconstruct what actually happened in this case. As the cardiovascular surgeon commented, the drugs may or may not have interacted and the patient may or may not have been having chest pain as a reaction to one or both of the drugs. But he admitted that at least the potential for problems was present. He said that he did not notify the first specialist that he was prescribing the second drug, and remarked that GPs often don't do this. But this specialist's view is that the "family physician is the guy who is responsible for the patient. Full stop" (p. 4) and he added that all the GP has to do is "look up in C.P.S." to see if there might be an adverse reaction. There might be a problem if the GP didn't get his note about what medication the patient was on before an adverse reaction (pp. 5-6), he says, but he usually gets around this by having the GP write the prescription, although he didn't do this here.

Big-city general internists occasionally insisted that they liked to take a coordinating role in this area to avoid just the problem that Patient 4 encountered. Internist 12, for example, said that he doesn't entrust the full responsibility for medication to the GP as most specialists do, but has the patient

bring in all medications, even if s/he needs a garbage bag for them, just to see what is going on. Unlike Surgeon 4, he insists, "If I prescribe, I am responsible" (p. 7). Further, he insists on following patients who are on certain types of medications, like the one prescribed for Patient 12, which is important, he emphasizes, if the GP doesn't have experience with the medication. General Internist 16 also said that he assumed a coordinating role because he doubted that even most tertiary consultants were able to "carry the ball" in complex cases, while a general internist may be able to do so (p. 7). The only subspecialists who may be able to play this "big role", according to Specialist 16, are oncologists and renal specialists. Where so much technology is used, if there is no one to "pull it all together", this specialist argues, cases "get lost" (p. 9). If subspecialists just refer to subspecialists, care is fragmented. Although his arguments about using general internists are based on an obvious self interest, his proposals would probably be welcomed by GPs trying to deal with outpatients on very complex treatment regimens. However, such an attitude on the part of specialists, most of whom are too specialized in one area to be able to perform such a function, was rarely expressed.

Another area in which the GP may not be able to play a co-ordinating role, despite Balint's arguments to the contrary, is in psychiatry. GP 24 pointed out that the patient who used to be "put in a mental institution" is now typically managed by the GP because of the availability of mood-altering drugs (Int. #1). As a result, he said, "you get to be a pretty good psychiatrist" - and the patients want to stay with you rather than going to a specialist (Int. #1). GP 30 agreed that GPs have to "be far more versatile and do psychiatry" because psychiatrists are unreliable (Int. #1, p. 13). "You could only give them referrals if you were prepared to do the acute care yourself", he commented. For example, "schizophrenic patients will be handled inpatient until they're stablilized, and then a note'll come back to the general practitioner as to the medication he's on and you keep following him" (p. 14). As a result, in his practice, "three of the five that I can think of have committed suicide". Although he feels this may have happened even if responsibility for them had been assumed by a psychiatrist, "it's a big burden to a [GP's] practice to have that going on". A number of GPs agreed with his statement that "a shambles occurred when they threw all the psychiatric patients

out of institutions and didn't provide the network to carry on for them" (p. 14).[10]

c. The "Participating" Patient

It was argued in Chapter 6 that the patient exerts considerable influence both on the the decision to refer and on the choice of consultant in referral. How much influence does the patient have over the actual process of care?[11] As the above example suggests, the patient is typically not a passive spectator when he or she detects a lapse in responsibility-taking.

Referred patients in this study often recalled negative experiences which led them to distrust their doctors and to assume responsibility for their care. Patient 27, for example, described an aggressive stance in relating to her doctors:

> If you rely on someone else to do it, it may not be done the way you want it done and as fast. So I think it's up to me to get the best care that's possible...and I will hound those doctors unless they help me get what I want...I go in there like a shark. I go in there nose-first. You can't be shy.
>
> (Int. #1, p. 17)

She attributed her aggressive attitude partly to coaching by her GP who has taught her "how to deal with

specialists" (p. 18) and partly to a learning process. She had suffered a drug reaction to medication prescribed by a specialist, and the GP could not help her because he had not been informed by the specialist. Subsequent to this bad experience, the patient made a point of asking the specialist to write a letter to her GP after each appointment. She also relays the information back to her GP personally. When medication is involved, she decides whether she should take it and has discontinued and modified dosages on her own (pp. 12-13). "They're following me, I'm not following them", she emphasizes.

Patient 31, with a similar suspicion about doctors, also traced her attitude to a bad experience when she was hospitalized for a gynecological problem. She believes that she suffered a severe drug reaction that brought her near death. She had telephoned a girlfriend who'd had a similar problem, who recommended that she ask for a catheter to be put in, because she could not urinate. When, after several days, the catheter was inserted and the drug was discontinued, she recovered. However, later, her suspicion led her to seek a second opinion on an operation proposed by an orthopedic surgeon (Int. #1, p. 19). Regarding a serious skin problem, she has also

decided to discontinue cortisone injections partly because she feels the treatment may cause the problem to spread (p. 10).

Other patients who learned to be suspicious said that they only attempted to "participate" in their care at a much later date. Patient 36, for example, who reported a degrading experience at a hospital where she was having a GI investigation, reacted by avoiding doctors for several years afterwards. However, she had recently observed how her mother and sister, both nurses, handled her father's last illness. Specifically, they were "not afraid to go up to any doctor or any nurse and say, look, what is going on here? Why is it going on?" And now, she says, "I will no longer stand back either" (p. 16). When her son had an operation, she nursed him personally in the hospital, even to the point of changing his sheets. She says,

> In the past, I might have been too backward and shy to ask, but at this point in my life, no. If he's not going to give it to me, then I'm going to take the bull by the horns. And start asking questions and getting to the bottom of it. Because this is my health.
>
> (Int. #1, p. 11)

Patient 19 learned to make decisions about what drugs she would take in what dosages after realizing

that her doctors were not monitoring her thyroid condition closely enough. Her GP and her specialist did not talk to one another, and it was up to the patient to take the initiative. When she realized that she was in difficulty, she ordered her own bloodwork, and interpreted the tests, based on prior experience, as indicating that the drug she was taking was making her condition worse, and then stopped taking it (Int. #1, p. 15). Patient 30 also read her own mammogram, as she had learned to do as a radiology technician, and decided that her local surgeon, who tried to reassure her (without having seen the radiograph) that everything was all right, could not be trusted. She demanded and got a referral to another surgeon who took the X-rays with more modern equipment and read them while she watched.

Patients, who have considerable input in the decision to refer as well as in the choice of consultant, may thus also attempt to salvage the process of care when it appears to be going off track. Like their militant GPs, they learned through experience that they must step in and attempt to take the responsibility themselves if their doctors would not do so.

d. "Collusion of Anonymity" with Non-Physicians

In areas where there are no local specialists and local GPs are not competent to deal with particular problems, non-physicians often become involved in referrals.[12] For example, while the business of optometrists in southern Ontario consists mainly of optical work and referral, in northern Ontario, optometrists treat patients for various eye disorders and do follow-up on patients, who have had cataract extractions (Optometrist #38, p. 7). As Optometrist 33 explained, "whereas a lot of people directly refer themselves to ophthalmologists" in the city, in the north, they go to the optometrist (p. 3). Further, ophthalmologists are surgeons, and many patients prefer optometrists because they have rejected surgical solutions to their problems (p. 12). Optometrist 33 explained that there "used to be a lot of animosity" between opthalmologists and optometrists, and there "still is in a lot of places" because the two compete for the same patients (p. 9). Where both are involved with a case, then, the likelihood of discontinuities increase.

Patient 38, a nine-year old boy, for example, was referred to the travelling CNIB eye van basically

to have an ophthalmologist look at his "wandering eye" and determine whether the ongoing care provided by the local optometrist was appropriate. The optometrist himself did not make the referral, although most opthalmologists now accept referrals from optometrists[13] - it went through the family doctor, who passed the optometrist's referral note on to him, and received a copy of the ophthalmologist's report. The problem with this division of responsibility was that the optometrist did not receive a copy of the ophthalmologist's report and the GP did not understand the opthalmological instructions in the consultant's letter. He interpreted the consultant's letter as "basically saying that the treatment is appropriate and just continue on" (Int. #2, p. 15), but he did not pass the information on. Further, although the patient's mother reported that the ophthalmologist was "happy with what [the optometrist] was doing" (Int. #1, p. 3), she did not inform the optometrist of these results.[14] Ironically, the opthalmologist reported that he had told the mother that the boy's problem was not serious enough to warrant surgery, and that it should be corrected "medically" with glasses (p. 5). He pointed out that ophthalmologists "aren't firm believers in orthoptic training exercises" and that in this

particular case "the [child's] esotropia...would not respond to orthoptic training with these types of peculiar things on television sets" (p. 6). He didn't say anything about it to either GP or patient because he felt "they aren't going to harm the child" and added, "I don't tell anybody, no, you shouldn't be doing these things. Because I don't think it's appropriate for me to do that" (p. 6). In this case, then, the "collusion of anonymity" occurred because neither opthalmologist nor GP could pass judgement on the paraprofessional's treatment. Neither were there any formal channels of communication to negotiate care.

In the case of Patient 33, an optometrist was asked to be involved by the GP because he had a machine through which he could examine her eye injury which the GP did not have. Although the optometrist and the patient in this case believed that the optometrist had performed a useful diagnostic function, the GP remarked that the optometrist's diagnosis had been incorrect. As with Case 38, the optometrist was not informed by the ophthalmologist nor the GP about the final diagnosis, and was not given credit for his assistance. Ironically, the optometrist said that because he'd been around for such a long time, he believed that he had earned their respect. For example,

he thought that local doctors would trust him that a case was an emergency if he referred it as an emergency (p. 6). In this particular case, he saw himself as "letting [the GP] manage" the case (p. 7).

A similar situation may be developing in obstetrics, where, like ophthalmology, the GP has "abdicated" and consultants have become superspecialized. As a result, there is a vacuum left, as pointed out by Specialist 29:

> The GPs don't want to do obstetrics in southern Ontario and gynecologist/ obstetricians don't...The nurse-midwives [will] have no problems moving into that area...[I]t's a lost leader economically.
>
> (Int. #1, p. 12)

Based on the situation in optometry, it might also be predicted that this will mean more discontinuity of communication and confusion about who has responsibility for what.

Although no native healers were interviewed in this study, comments indicated that a similar breakdown of responsibility-sharing takes place when patients receive, for example, continuing psychiatric care from these non-physicians while retaining a traditional doctor. Pediatrician 34 refused to consider the possibility that native healers could be involved at a tertiary care level (p. 10). GP 37 recounted the

unsuccessful attempts of a local hospital to retain such a man (Int. #2, pp. 17-8). Radiologist 36, who had more direct experience on native reserves, insisted that it was possible to split responsibility between traditional doctors and native healers for psychiatric cases (pp. 18 ff.). However, as with eye problems, there is no forum for the negotiation of responsibility-sharing in purely medical areas.

VI. SUMMARY

The silent negotiation of responsibility in referral is a social-psychological process whereby the doctors and patient define the boundaries of their competence relative to one another. It is really the continuation of the process of deciding to refer and choosing a consultant, in terms of assessment of self-competence and the competence of others. It is problematic because each party must make assessments with little direct knowledge of others' competence. The specialist, for example, who cannot observe the GP in his or her office, makes assumptions about the referring doctor's competence based on how well the referred cases are investigated, how adequate are the referral materials, the outcome of previous cases, the

feedback of patients and even "visibility" at the hospital. S/he may then "take over" a case if the GP is considered to have "abdicated" his or her responsibility, although the assessment may be unjustified, and it may anger the GP.

The process of mutual assessment of competence in referral takes place in a variety of settings where the referring doctor has more or less control over how much responsibility must be surrendered. In big city hospitals in Ontario, GPs typically do not participate in inpatient treatment due to a combination of psychological and practical considerations. They are restricted in caring for inpatients by the limits of their licences and hospital privileges, by competition with medical residents, and the vagaries of operating room schedules. In outpatient care, specialists may "steal" cases of academic interest or may refer them on to subspecialist colleagues within multispecialty clinics without consulting the referring doctor. By way of contrast, in smaller hospitals, GPs perform minor surgery and anesthetic procedures and assume more responsibility than their urban colleagues for outpatient care during referral. Their visibility and demonstration of competence through these experiences means that they earn more "respect" from their

patients and their consultants than their urban colleagues can command. Thus specialists are more likely to see "reassurance" cases in the city and to assume that the GP is not competent to receive a case back immediately. Not all urban GPs accept this "squeezing out" passively, particularly those with enough experience to be critical of specialized medicine. Their militant reactions include chastising consultants, boycotting offending specialists, and even attempting to block the hiring of local sub-specialists.

A more serious problem than the "shrinking boundaries of general medicine" is the situation in which both GP and consultant appear to be doing something, but neither takes the main responsibility for the referral. This "collusion of anonymity" (Balint, 1957) was particularly likely to occur in areas of little interest to specialists, such as psychiatry; among specialists with high-volume lucrative "streamlined" practices where specialists prefer to see themselves as interventionists only; and in cases where non-professionals such as optometrists have "taken up the slack" that GPs and consultants have left behind in their retreat from assuming responsibility in the area. Patients, who often

initiate referrals because they distrust their GPs, may attempt to participate in their care when they detect a lapse on the part of their physicians. Like their GPs, who are often assessed as not competent enough to participate in the referral, they may become militant, demanding to know what is going on and taking a hand in modifying their prescribed treatment. The analogy between patient and referring doctor is particularly striking on this point, since both are often unjustifiably dismissed as inexperienced and uninterested.

NOTES

1. Freidson's (1975) study of an American health maintenance organization suggests that continuity of care may be better in these arrangements, but less than five percent of the American population is enrolled in HMOs. Further, there has been criticism of the quality of care provided in these organizations, particularly those with corporate sponsors (Bodenheimer, 1972; Mechanic, 1975; Starr, 1982).

2. This topic will be dealt with in the next chapter.

3. The problem with Gastroenterologist 12's way of assessing competence is that he leaves no room for the GP who decides not to follow his orders. His interpretation of a situation in which the GP does not take his advice is that s/he is "playing the odds" that the patient will get better, as he says they do in "90 percent of the cases". However, it might be argued that this more conservative approach is exactly what he pursued with Patient 12, for which the patient praised him. Again, there is a parallel between the inability of the doctor to understand a patient's decision not to comply with his advice and the inability of the specialist to understand GP non-compliance. This topic will be discussed in Chapter 10.

4. It can get "maddening" running around to various hospitals when your opinion is not valued, this GP complained. However, in this case, his efforts appeared to fill a vacuum, because the specialist would probably not have looked up old records to find out that the patient had had a previous melanoma. This is an older GP who was willing to take more responsibility and succeeded, since there was no resistence, although he failed to be "visible" to the specialist.

5. A medical student who had been placed in a rural northwestern Ontario practice reported a feeling of "belonging" up there, and of feeling welcome in the doctor's lounge, which he did not feel at his own medical school. He said that he might even be "thanked" after a delivery in the north, while in contrast, he was not even allowed in ER or OR in the south, and not allowed to do obstetrics (Education Rounds, McMaster University, April, 1986).

6. This surgeon believed that European specialty training was superior in preparing surgeons for rural practice because it begins with a "very general fellowship", whereas in Canada, you "opt to train in one of 13 specialties", so that training is narrowed from the beginning (p. 2).

7. GP 30 argued that even in northwestern Ontario, "I don't think my time is well-used in the operating room, because there's some other skills that I can use more effectively than that, so that I don't want to literally waste them there" (Int. #1, p. 18) GP 29 agreed that assisting in surgery in a city hospital, even in the north, is disruptive to office practice. GP 30 added that there are three or four local GPs who have made a career of surgical assisting, even though almost all city GPs could have any operating privileges they wanted. This GP instead allows the specialist to assume responsibility for inpatients to give him the autonomy to allocate his office time in the most efficient way (Int. #2, p. 19). He insists that his reason for organizing his time in this way is not economic - "I do not <u>care</u> if I earn more money", he says. What he does care about is "if I'm able to live up to the demands and the number of commitments that I've made" (p. 19). Like many specialists, he is at a point of "streamlining" his practice by about "half". Integral to the streamlining process is asking "what could I refer that would save me time?" and doing fewer house calls and home care visits (p. 19).

8. The patients' views of this situation are described in Chapter 7, pp. 348-354.

9. The "militant" reaction to being "squeezed out" is not confined to the GP. Obstetrician 34 complained that exotic subspecialists in his city are now trying to squeeze out primary specialists: "When you get [gyn-oncologists] and you get perinatologists, they need to have jobs, and if they keep training themselves, then you give the obstetrician less and less to do. And so the philosophy is now coming that the obstetrician can't do high-risk obstetrics because he's not a perinatologist, and you can't do [gyn-oncology] because you need [gyn-oncologists] to do that. So he must just be a glorified GP doing obstetrics. Which is all he can do." (p. 12) The young obstetician's response to the situation is militant: "Crazy bullshit! You're trained to do high risk obstetrics...and I refuse to be pushed in that direction" (p. 12) (6). This is not the only process by which specialists feel a "squeeze". In Chapter 5 (p. 51), the "forcing" of referrals to specialists by government agencies, for example, for licensing purposes and for validation of WCB and DVA claims, was described. Most of the discussion in this section has focussed on the limitations on responsibility-taking faced by GPs. However, it is worth drawing attention to the fact that the relationship between the specialist and these outside agencies seems similar to the relationship between some GPs and some specialists in its ambiguity. As Cardiologist 8 admitted, for example, he really didn't even know "what the Ministry [of Transport] wants" in connection with the "data" to be collected on Patient 8 for his licence upgrade (Int. #1, p. 9). Further, he isn't sure who is supposed to write the letter to them (p. 10). He knows that, as with the WCB, you can't make recommendations to them, because they have their own experts. He emphasizes that he's never sure what they'll come up with - almost describing their decisions as "arbitrary" (p. 7).

10. But northern GPs expressed the view that they did less "psycho-social medicine" than their southern counterparts both because they had other things to do, and because their patients did not have as many psychiatric problems (e.g.

GP 32, Int. #2, p. 8). Specialist 29 thought that southern GPs did more counselling because "there's nothing better to do with their time" (p. 13).

11. Early studies of patient-doctor interaction emphasized that the patient has very little control over the course of treatment in hospitals (e.g. Goffman, 1969; Davis, 1963; Roth, 1963; Glaser & Strauss, 1965; Duff & Hollingshead, 1965; de Beauvoir, 1969). On the other hand, Freidson (1960; 1961) and Stimson & Webb (1978) have suggested that patients can influence at least their GPs by various direct and indirect methods and other studies suggest that they can even "negotiate" outpatient care with specialists such as psychiatrists (e.g. Lazare et al., 1978).

12. "Referral arrangements" between non-physicians and surgeons were occasionally questioned in this study. GP 38, for example, alleged that a travelling orthopedic surgeon in his region used to receive "referrals" from a local chiropractor, "but the other doctors didn't like it. We didn't feel this was above board" (Int. #2, p. 12).

13. Travel grants will not be given unless the GP refers the patient, and so patients who are travelling to an opthalmologist still go through the GP. This particular patient's treatment was "free", i.e. absorbed by the optometrist's office, because OHIP does not cover it, and the optometrist did not want to charge the patient (p. 18).

14. The optometrist complained that this was often the case with his referrals to specialists: "By the time they get through with all their checkups there, or whatever, some of them don't come back to see you for years. Or don't come back at all" (p. 7). He speculated that the situation in the north was better for the patient, who could at least identify the optometrist as the only place to go back to, whereas in the south, "you tend to be sent back and forth without getting any satisfaction for your problem" (p. 10). That is, he believes that there tends to be a "collusion of

anonymity" where there is no non-physician to pick up the responsibility that the opthalmologist does not want and the GP cannot take.

CHAPTER NINE

COMMUNICATION IN REFERRAL

I. INTRODUCTION

This chapter examines communication between doctors and between doctors and patients as part of the dynamic process of getting things done in the context of the referral situtation. Communication between doctors flows more smoothly when they personally interact with one another and is more often disrupted when referrer and consultant are isolated from one another, as is increasingly the case in urban centres. Although economic incentives encourage communication, practical opportunities to interact and mutual respect may be missing. Similarly, breakdowns of communication with the patient may occur as part of the physician's lack of respect for the patient's knowledge and opportunities to interact may be limited by how the physician has structured his or her practice. As part of everyday medical practice, doctors "manage" what they tell patients, but in the referral situation,

there is a tendency for two or more doctors to give the patient contradictory information, which may undermine the patient's trust.

1. Communication in Referral: Issues in the Literature

a. Communication Between Patients and Doctors

Although there is a large clinical literature on medical communication, much of it is narrowly empiricist. Medical talk is analyzed under a microscope without considering the wider context of the process. For example, in the classic American studies by the clinician Korsch and associates, which have appeared in the The New England Journal of Medicine, as well as in Scientific American, minute aspects of more than 800 patient-doctor consultations were analyzed, but nearly half of what doctors said was put under the category "gives information", without specifying what this information was or how it was being given (1968; 1971; 1972; M. Davis & van der Lippe, 1968; Francis et al., 1969; Freemon et al., 1971).

There was an attempt in the Korsch work to give a processual account of communication breakdown: it was noted that physicians did not seem to listen to patients, since the patient was virtually silent in

many encounters. Alternatively, patients would try several times to have their statements acknowledged by their physicians, but then fall silent. Later, they were unable to recall any details of the encounter beyond this "shutoff" point. The significance of this processual explanation of communication breakdown between patient and doctor, however, has not been acknowledged in subsequent clinical studies showing that patients recall very little of what they are told by physicians (Ley et al., 1967; 1976; Tugwell et al., 1983). This research, in fact, has been interpreted by some physicians as suggesting that since patients forget most things anyways, it is a waste of physician time to inform them.

The sociological literature on problems of communication in medical encounters, in contrast, has treated medical talk as part of the dynamic process of getting medical work done. For example, classic sociological works by F. Davis (1960), Glaser & Strauss (1965a) and Freidson (1970; 1986) have explained "communication breakdown" as part of the process used by the physician to control the patient. Unfortunately, this sociological work is not cited by the clinical researchers and there has been little attempt to use the processual interactionist methods of

Strauss and Davis to broaden the significance of the Korsch findings.[1] Further, a shortcoming of the sociological studies is that they do not attempt to analyze the process from the doctor's, as well as the patient's point of view, which would yield a more complete explanation of the process and outcome of medical encounters.

b. Communication Between Doctors

The most popular aspect of referral in volume of articles published in the clinical literature is "breakdowns of communication" that occur when one physician consults another for advice (Kunkle, 1964; Cummins et al., 1980; Clarfield, 1980; Long & Atkins, 1974; McPhee et al., 1984). Unfortunately, this literature has the same empiricist bias of clinical doctor-patient communication studies and there are no sociological studies of this topic (aside from Freidson's comments - 1975). Typically, quantitative studies just "count" the number of times that a referring doctor fails to send the consultant any background information about the patient and the number of times the consultant fails to reply, without exploring the dynamics of the breakdown. Alternatively,

they offer unelaborated economic and psychological explanations for the failure of communication.

Even in the Rockefeller studies, when referring doctors were interviewed, the fact that in 49 of 85 referrals studied, no written or telephone-transmitted medical information was sent to the university medical centre with or about the patient, was not investigated (Williams et al., 1960). In most subsequent studies, researchers have also failed to speculate on why referral notes are not sent or why they are incomplete when sent.[2] Alternatively, articles on communication are prescriptive, giving advice on what should be done rather than analyzing what is done and why (e.g. Alarçon et al., 1960; Alarçon & Hodson, 1964; Barnett & Collins, 1977; Beidleman et al., 1971).

The consultant's failure to communicate to the referring doctor has also been quantified: follow-up information is received in 23 to 89 percent of referrals (Cummins et al., 1980; Hansen et al., 1982; Hines & Curry, 1978; Holmes et al, 1982; Williams et al., 1960). One often-replicated finding is that consultants are more eager to communicate with referring doctors when referrals are their major source of income (e.g. Hines & Curry, 1978; Cummins et al., 1980).[3] The fact that academic specialists and

residents are the worst communicators is linked to the observation that they "have no perceived financial stake in ensuring a continuing flow of patients by referral and in building a practice as private consultants do" (Cummins et al., 1980, p. 1651).

Hansen and colleagues (1982) argue that there is also a social-psychological explanation for the failure of residents to communicate with referring doctors. Specifically, residents show a "lack of appreciation for physician-patient relationships outside their own hospital" (p. 656). Hines and Curry (1978), in a Canadian study, echoed these comments. The Cummins group goes farther to note that communication back to the GP is worst after discharge from the emergency room by house staff and residents because they have a "subtle disdain" of the referring doctors: "The referring physician is often ridiculed for his management and is believed to be disinterested in the university's opinion" (p. 1652). This disdain, they believe, is learned when the specialists-in-training deal with the "rare failures of local physicians".

2. A More Comprehensive View of Communication in Referral

This thesis offers a more comprehensive view of the communication process in referral than appears in the literature, building on the observations made in the last chapter concerning the context and dynamics of the sharing of responsibility in referral. Specifically, it is argued here that communication is less problematic in settings where consulting physicians personally negotiate their responsibilities and where they have developed mutual respect for each others' abilities. A similar process can be seen to operate at the level of patient and doctor, where mutual respect underlies successful consultation, while conversely, lack of respect, social distance, and information control underlie breakdowns in communication. A third point made here is that the referral situation invites difficulties because two physicians often give the patient different perspectives. This may lead to a suspicion of one or both doctors on the part of the patient and may have negative effects on compliance with treatment and on the ongoing relationship between the two doctors.

a. Communication Among Doctors and the Context of Care

Suggestions in the literature that doctors are more communicative when their livelihood depends upon it were confirmed and broadened in this study. Specifically, it was found that in contexts where there was competition for referrals, consultants were more attentive and personal in their feedback to referring doctors. Adequacy of communication between doctors around referral was also traced to the mutual respect that doctors have for one another when they work side-by-side in rural hospitals, as opposed to the mutual distrust that tends to develop when the two are isolated from one another.[4]

Only one other study in the literature links communication breakdown to the context of care in this way. Long and Atkins (1974) argue that communication breakdown is inherent in the British health care delivery system, in which the GP, "though accepted as the key figure in the Health Service, is isolated both administratively and clinically from the hospital" (p. 456). They suggest that it is unrealistic to expect that communication can take place in the form of referral and consult letters when GPs and consultants

seldom see each other.[5] Although a few doctors participating in this Canadian study suggested, like Long and Atkins, that the remedy lay in more opportunities for personal contact, it was generally acknowledged that, with the current "abdication/ squeezing-out" process occurring in their cities, the possibility for improved communication was bleak. The situation has progressed to the point where these physicians find personal contact and even telephone calls to be disruptive to the everyday practical activity of conducting their practices, such that they are unable to contemplate structuring their activities in any other way.

b. Communication and Respect Between Doctor and Patient

When the analogy of the consulting doctor and consulting patient is pursued around issues of communication, a striking similarity can be seen between the isolation of the patient and the isolation of the GP from the medical community, concentrated in the hospital. Just as the specialist has little respect for a GP whom he judges as having limited competence and interest in referred cases, so it has been

documented that physicians have little respect for patients with limited knowledge of medicine who are also afraid to ask questions (e.g. Pratt, 1957; Bain, 1977). In each case, the physician involved may feel that it is not worth the time and effort to "educate" the consultee. A few patients, like their GPs, react militantly to "information control" by trying to force their physicians to inform them fully, but most appear to withdraw, as Korsch's patients. Further, as sociologists have documented, informing the patient involves "managing" the patient, as when a negative prognosis is withheld for the patient's own good.

c. The Cumulative Effect of Communication Breakdown

Because the referral situation involves two levels of consultation, chances are higher that the process will be disrupted as compared to the simple situation of patient consulting GP. Further, the context of referral itself, where referring doctor and consultant do not co-ordinate what they tell the patient, invites the patient to compare discrepant information from the two sources and to question the course of care. Specifically, although both GPs and

specialists withhold information from patients, specialists in particular feel pressure towards disclosure for medico-legal reasons. In this and the following chapter, the argument will be developed that the contradictions that the patient sometimes hears from doctors underlie some of the patient mistrust of their doctors that has been described in Chapter 5. In Chapter 10, a link is made between this phenomenon and non-compliance with treatment, both intentional and unintentional. There has been little appreciation of this fact in the literature, although scattered references suggest that breakdowns of communication are important in the seeking of multiple referrals by patients and "collusion of anonymity" described in the last chapter.

II. COMMUNICATION BETWEEN DOCTORS AND THE CONTEXT OF CARE

1. Communication to the Consultant

In southern Ontario cities, participants estimated that for about 90 percent of referrals, which are considered "routine", there is no direct communication between doctors. Instead, the GP's nurse, secretary or receptionist contacts the secretary of the

specialist, negotiates an appointment and transfers information over the phone. This information may be limited if the referring secretary does not have the chart in front of her and the GP neglects to tell her the reason for referral (Secretary, Orthopedic Surgeon 18, pp. 2-3). Referring receptionists emphasize that in order to get an appropriate appointment for the urgency of the case, you have to be pleasant with an underlying tone of "if you don't give us satisfaction, we'll go elsewhere" (Receptionist 2, p. 12). Most specialists' secretaries have a system to sort out urgent problems from those they put on a longer waiting list, so that physicians rarely became involved in negotiating appointment dates.[6] For the 10 percent or less of referrals that are emergencies, where an appropriate date cannot be arranged, the referring doctor "circumvent[s] that by talking directly to the doctor and saying it's a little more urgent than that" (Surgeon 30, p. 11).

When a date is agreed upon, a referral note or other information might be mailed to the consultant, particularly if the referring doctor is in a teaching unit, but rarely otherwise. Although there were exceptions,[7] most specialists estimated that they received formal communication from urban referring

doctors for ten percent or less of their referrals (Allega, 1986). Consultant secretaries thus take the responsibility for gathering information on the patient.[8] Personal communication between the two doctors would only take place if an urgent or complex request was being made.

In northern Ontario cities and Winnipeg, where group practice clinics predominate, the chances of personal communication around referral are somewhat higher, but there is a similar general failure to send referral information to the consultant. Specialist 31 estimated that in the two weeks he'd been in practice, only 10 percent of referrals were accompanied by a note, which made it difficult to learn anything about where his referrals were coming from. GP 29, of a group practice clinic, described sending a note even when referring within the clinic, but in the case of Patient 29, he reported that he merely made a note in the patient's chart to see the specialist (Int. #1, p. 3). Here, the consultant had access to the patient's chart, but for referrals outside the clinic where charts are not available to the specialist, communication is rare.

Communication around referrals that originate from some rural areas is strikingly different than this

big-city model. Rural GPs typically send excellent documentation on patients, and do not hesitate to make referrals by telephone. As Radiologist 36 pointed out, "the North is actually very small and lots of people know each other very well...Long distance phoning is used very freely" (p. 3). In addition, GPs 32 and 40 emphasized that they <u>always</u> write a letter to the consultant, even in an emergency situation in which they have phoned to transmit the details of the case personally (GP 32, Int. #1, p. 3). This was the procedure followed with the long-distance referral of Patient 33. When specialists come to small towns, as in the case of Cardiologist 35's visit to see Patient 35, communication around the case is face-to-face, with the GP asking specific questions of the consultant and the visitor writing a consultation note directly into the patient's chart. In his city practice, this cardiologist, like those in southern Ontario, has his secretary hunt down referral information for most cases and does not interact directly with the referring doctor (p. 3). In contrast, resident specialists in small towns rub shoulders with their GPs daily in the hospitals, and communication even around routine referrals is comprehensive and direct. As small-town Surgeon 36 observed, rural physicians send "good

referral notes" and "[i]t's only occasionally that you don't get a referral letter" (p. 4). When he refers patients to the visiting radiologist, the two will typically meet face-to-face for a discussion either before or after the referral visit (Radiologist 36, p. 3).

2. Communication From the Consultant

Specialists, whereever their practice in Ontario, typically send at least one formal letter to the referring doctor after seeing the patient, since this letter serves not only as feedback, but as evidence for claiming one's fee from the Provincial insurance plan and as a legal "account", in the sense used by Scott and Lyman (1968) and Garfinkel (1967).[9] On only three occasions in this study was a note not sent, and the GP was still anticipating some response, however late it might arrive. In terms of quality, however, as previous studies have found, referring doctors often complained that letters from specialists were too few, too sketchy or too late to be useful to them, particularly for emergency visits.

GPs in this study were constantly "losing track" of the cases they referred, but this was a

particular problem in northwestern Ontario for referrals to urban centres where residents or very busy specialists were less attentive to providing feedback than their southern colleagues. GP 38, for example, reported one case of not receiving feedback on the medication given a patient referred from another hospital, which resulted in that patient suffering a drug reaction (Int. #2, pp. 2-3). Although he argued that this was an exceptional case, he later talked of routinely questioning his patients to find out whether surgery had been done without his knowledge (p. 5). He pinpointed the "dictation" and "mailing" system as the problem, and said that delays didn't matter for minor problems (p. 6). Other doctors were not so long-suffering. Surgeon 36, for example, complained that feedback from hospital residents in Winnipeg was poor (pp. 7-8). Further, investigations that were received would be filed locally in the patients' records, without notifying him (p. 8).[10]

On the other hand, the feedback from most visiting specialists and local surgeons to northwestern GPs was excellent, as in the case of Specialist 34, who goes so far as to hold rounds at the local hospitals that he visits, "reviewing the interesting patients they've referred to me" (p. 2). He says that he has

such "intimate involvement with [his] referring physicians that [he] knows the state of their house" (p. 11). Similarly, Internist 40 was prepared to give GP 40 face-to-face feedback on Patient 40 later in the day that he was seen (p. 4) and the GP also expected a letter to be written that night (Int. #2, p. 3). Surgeon 32 reported that the harmony between himself and local GPs was promoted through monthly medical meetings held at one of the doctors' houses (p. 5).

3. Economic Considerations and Communication

As with other issues concerning the division of responsibility in referral, participating physicians linked communication to economic considerations. For example, GP 5 argued that GPs can't afford to send referral letters as consultants do - "[i]t would cost them $10,000 a year...[You'd] have to have personnel here waiting just for your letters. And I don't think that's very efficient" (p. 21). Orthopod 18 agreed that GPs would write more referral letters if they could charge for this (p. 2). But GP 8 made no apologies for not writing letters, arguing that the specialist should work for his money:

> The man gets 80 bucks for what he does! I'm supposed to see the patient, make

> the diagnosis, write a letter and send it to the guy too? What the hell do you want me to do - go down to his office and see the patient?
> (Int. #1, p. 16)

Further, GPs may just be seeing too many patients in a day to have the time to write letters. As Specialist 3 pointed out, "while I'm busy seeing, on an afternoon, 20 to 22 patients, the average family doctor may be seeing 50 and perhaps they just don't feel they want to take the time to write something" (p. 3).

Feedback from specialists was also linked to economic considerations. For example, all GPs agreed that feedback was faster and better from FFS consultants, particularly those with private secretaries (GP 19, Int. #1, p. 7).[11] Among FFS consultants, where there was competition for patients, consultants were more willing to please referring doctors than when there was "plenty of business". GP 1, for example, said that he chose consultants "whom I've had good correspondence with", such as Gastroenterologist 1, who had "been extremely helpful with the notes he's written back" (Int. #1, p. 1). In this city, since there was competition for cases, the newest gastroenterologist in practice was acutely aware that he must perform well in this area: "it's a competitive business. So if you don't keep the lines

open, there's going to be somebody who does" (Internist #4, p. 8). But even an established man in this network said that he spent "a lot of time with his letters", taking care to make them easy to read (Gastro-enterologist #12, p. 12). Gastroenterologist 1 took the rare step of adding personal response to his feedback to the GP, phoning in about 30 to 40 percent of cases before his letter arrived. If he determines that the case is not straightforward, as in the case of Patient 1, he notifies the GP immediately of his plans for treatment.

By way of contrast, representatives of other specialties in this city who had a great deal of business, said that they were less concerned with personal communication with the referring doctor or the completeness of their notes. Orthopod 17, for example, showed disdain about calling GPs to ask questions around referral, since this might imply that he was "grovelling" for referrals (p. 5). Specialist 2 claimed that his clinic is no longer totally dependent upon referring doctors for business because it has such a good reputation that patients demand to be referred there. He has even been able to risk "losing" a few by criticizing GPs "in black and white" for inappropriate behaviour around referral. Specialist 3, with more

patients than he wished to have, remarked that he would only telephone the GP "if there's something desperately wrong that requires immediate surgery or hospitalization...Otherwise, there'd be little gain in spending time on the telephone. I'd be spending as much time again on the telephone unnecessarily" (p. 13). GP 14 tried to excuse her very busy obstetrical consultant for his poor record of communication with her (Int. #2, p. 1), but her records on Patient 15 were so confused that she could not reconstruct what happened. She finally admitted that the specialist "should've written" her something beyond a first consult note on this case, if only to answer a query she had about an abnormality turned up in ultrasound.

Similarly, many specialists in northwestern Ontario who see very large numbers of patients are unconcerned or haphazard about their feedback to the referring doctor. GP 27 described one man who was the only representative of his specialty in the region who avoided writing letters because "there was no money in that" (Int. #1, p. 2). Another northern GP singled out very busy othopods as poor communicators (GP 32, Int. #1, p. 1). GP 24 remarked that one specialist "doesn't send me reports on my patients but he gives me them on somebody I don't even know!", referring to a consult

letter meant for another GP that had been mailed to him by mistake. Although he had written a letter to the large city clinic in which this specialist works, explaining that he'd "been referring patients to them for many long years" and that he was "entitled" to specialist feedback, "it didn't make any difference" (Int. #1). GP 29 had become similarly indignant about specialist failures to give feedback, arguing that "if you're that busy, you've got to control your practice" (Int. #2, p. 5), although he later admitted that there is no way beyond a boycott to enforce this policy. In their attempts to boycott non-communicating specialists, these doctors often refer long distances to medical centres where feedback will be better than that from specialists in local cities (e.g. GP 27, Int. #2, p. 6; GP 40, Int. #1, p. 8). However, even from faraway cities, letters may take a long time in arriving (GP 32, Int. #1, p. 3).[12] Another successful strategy has been to woo visiting specialists with generous funding (GP 34, Int. #1, p. 3).

As in previous studies, virtually every GP in this study complained about poor feedback from hospitals regarding admission, progress and discharge of patients, and there were several examples of such communication lapses in this study. Patients 12, 14 and

17 all found it necessary to visit the ER on their own, but their GPs were not sent reports or notifications about these incidents. As GP 5 pointed out, not knowing a patient is in hospital means that you do not visit and "the people get mad at you and say, what a doctor! You didn't come and see me" (p. 20). In the case of Patient 7, the GP had accompanied her to hospital, attended her biopsy and visited her regularly, but was not notified when she died unexpectedly. Being notified by the family of a patient that you didn't even know was in the hospital is "one of life's embarrassing moments" (Int. #1, p. 11), but being informed of her death in this way is "what I hate most!" (Int. #2, p. 1), he said. The head nurse or "somebody" finally notified him about the death, but his only feedback about the case was an exchange of small talk with the neurosurgical resident at a conference about a week afterwards. The neurosurgical resident, who had done the biopsy, said that it wasn't his responsibility to inform the GP while his supervisor was out of the country. He recognized that "patients won't be referred to you anymore [unless] you communicate what's happening with those patients" (p. 17), and said he'd be more careful about it if he was setting up his own practice. However, since he would soon be leaving this

hospital, his only concern was that his staff man might find out and be upset.[13]

4. Communication and Respect

A few referrals in this study were made to consultants with whom the referring doctor had a longstanding relationship, marked by mutual respect by the doctors for each others' abilities. Specialist 16, for example, described GP 16 as an "excellent contact doctor" who keeps him informed by frequent and informal communication. The GP argued that mutual respect led to ease of communication in this type of relationship. For example, of one of his preferred consultants, he remarked,

> [H]e's a very good doctor. A very fine person and a gentleman. He's from the old school. When we talk, we communicate. Not only about cases, but about everything. About life, about philosophy.
>
> (Int. #2, p. 6)

This dimension was missing in referral situations where the doctors had a low opinion of the competence or experience of one another. GP 16, for example, found "greedy" young orthopods "fresh" and "arrogant", emphasizing thet they "don't know how to talk to their patients and they don't know how to talk to their colleagues...[They are] unprofessional" (Int.

#2, p. 9). Specialist 16 shared his criticism of the younger generation by indicating disrespect for GP 19, whose additional training in family medicine, he felt, didn't make up for her lack of experience in the field. While the specialist had no hesitation about calling GP 16 on the telephone, he had never called GP 19, despite several irregularities in a longstanding referral of her patient. Neither would she call him directly, leaving the secretary and the patient to make appointments. Because they had no direct communication, the GP had to rely on the consultant's notes for her feedback from him, which she found unsatisfactory, commenting that they were "anecdotal, they're three pages long, they ramble [and] they very infrequently make a whole lot of sense" (Int. #1, p. 6).

Specialists attributed not receiving referral information from urban GPs to a lack of respect for the consultant or indicated that this type of GP did not deserve the consultant's respect. Orthopedic Surgeon 17, for example, said that 90 percent of his referrals come with no documentation because of the "idleness" and thoughtlessness of referring doctors. Internist 4 generalized that it was "interesting that the people that I consider the better GPs invariably send a note" (p. 8). He was offended that GPs typically did not send

referral notes, although it would only take "three minutes" to "scratch me a few lines", adding,

> There are a few GPs who don't give a shit. So they don't care if you call them and they really don't want to know...[E]verybody knows who they are. I may just wait until the end of the patient's admission to call because I know they don't care about the patient being in the hospital. They won't visit the patient when the patient's in the hospital.
>
> (Int. #1, p. 10)

Thus the GP is typified as an incompetent and the process of feedback is disrupted. Ultimately the consultant replies, but he is bitter that he has to "go along" with the disrespect because he needs their business.

Other specialists expressed skepticism that a consultant's letters would even be read by a GP who would not bother to communicate in the first place:

> [T]here's no point in writing an exhaustive four-page letter to the family doctor. They will not read them. I try to keep mine to one page or a page and a half. Where I feel they will read them.
>
> (Specialist 3, p. 19)

GP 2 expressed amazement to her patient when she received a three-page letter from the respirologist, since such lengthy notes are unusual. Ironically, offending GPs are aware that they anger some specialists by not sending a note, shrugging this off

by suggesting that the specialists would be "much better to give [the GP] a call than to scream at the patient for an hour" (GP 5, p. 11). They thus fail to appreciate that the specialist has interpreted their lack of communication as disrespect, and that to "grovel" for the information is below the dignity of the specialist.

On the other hand, as found in Dowie's study (1983a), GPs were sensitive to the possibility that the specialist would place little value on any information they might send and that letters might reveal their ignorance. GP 14, for example, thought that she was only able to write intelligent referral notes for her gastroenterology referrals, since this is an area in which she has additional training. GP 7 felt strongly that a consultant was not interested in "his impressions" but put a high value on lab reports, so that he tried to send these on a "silver platter". As he explained, "letters are only <u>words</u>. But with a test, you can <u>see</u>" (Int. #1, p. 7). Further, GPs often remarked that they didn't want to "second guess" a specialist or presume to tell <u>him</u> a diagnosis. As GP 30 expressed it, he tries "not to overguide the hand of the consultant...[because] with some consultants, if you ask them too pointed a direction, the answer might

be if you know what you want, why don't you do it?" (Int. #2, p. 14). This belief appeared to be well-founded, since Neurologist 4, Obstetrician 14 and ENT Specialist 26 all emphasized that they didn't read "long-winded letters" from the GP. Neurologist 4 found the two-page referral letter detailing what the GP thinks "irritating" (p. 12). Like most specialists, he "meets the chart when he meets the patient" (p. 1), and feels that he only needs the GP's guidance when a problem doesn't "jump out" when he sees the patient. Specialist 31 similarly believes that if the GP attaches a wrong diagnosis to a patient, you may be "swayed" towards that diagnosis, although it may be wrong. Further, when the GP doesn't send a note, you "don't feel so obliged to send them such a long letter back" (p. 8).

Part of the satisfaction of longstanding personal communication has to do with a mutual respect "earned" by two doctors observing one another and there was some nostalgia expressed about the days when GPs routinely made personal contact with consultants around referrals. Schaffer and Holloway (1985), describe traditional consultation in which,

> a specialist was selected from a close circle of colleagues with whom the physician felt comfortable and was a respected peer. The physician and

> specialist shared similar backgrounds, interests and perhaps education or post-doctoral training. (p. 601)

In this vein, retired GP 23 deplored the impersonality between GP and consultant of the contemporary urban scene, and recalled a time when there was a personal relationship between the two, that was "much more satisfactory than now when you call up three or so and you don't know them" (p. 6). GPs sometimes would personally deliver records, as did GP 7 in this study. This "very unusual" behaviour, as he described it, would not have been so unusual when he began practising in the 30s and 40s. These doctors sometimes now fill out referral forms for complex referrals, although they still prefer personal contact with the specialist (e.g. GP 7, Int. #1, p. 5).

In spite of a general recognition that these days were gone, a few specialists at one small urban hospital thought that GPs should be encouraged to meet informally and regularly with their consultants over coffee in a central area of the hospital such as the surgeons' lounge.[14] Specialist 5 emphasized that when you talk to the referring doctor face to face, "you develop certain patterns of understanding" and "you get to know each other" (p. 2). "[I]t's an exchange", he says, in which one doctor learns to respect the other

doctor's problems, which leads to empathy between the two. These specialists believed that there was more mutual respect and "community" at their hospital than at larger, core-city institutions.[15] Telephone contact is not enough to establish these relationships:

> [M]ost doctors are afraid of phones-because you don't know if you'll get greeted like a long-lost friend, [get] your ear chewed off or told to go to hell!...Some guys I can phone up, I'm never afraid of calling them...anytime and they always treat me the same way...but some guys, you can't always phone them.
>
> (GP 5, Int. #1, p. 27)

The feeling that personal contact around referral was more satisfactory than formal contact was more prevalent in northwestern Ontario. One urban GP there felt that it was more common in his city for surgeons to call a referring doctor about surgery than it was in the south, where he estimated that "80 percent of the time", surgeons would "[g]o in and operate and tell you later". He links his personal communication with consultants to mutual respect, commenting that it "gives you a good feeling that we know we can trust each other in how we're handling it". This mutual respect is so important that he tries to discourage patients from choosing their own specialists. In his words, "I try to discourage it, because I'd rather have good communication.

Communication is one of my criteria for referral. If they communicate, they'll get my referral" (GP 30, Int. #1, p. 19).

5. Communication and "Practical Activity"

Unlike their urban colleagues, rural GPs with local surgeons and visiting specialists saw their major consultants regularly, which allowed them to relate personally around their referrals. For example, GP 35 reported that her feedback from Cardiologist 35 regarding Patient 35's treatment "went quite well"- "he answered all my questions because he was right here" (Int. #2, p. 4). There is a free flow of information to the specialist as well, because typically the chart is available to be scanned.

Urban GPs occasionally argued that if more personal contact were possible, this would "smooth out" the process of referral. For example, GP 5, after observing that "[t]he biggest problem with me and the rest of the world is communications", suggests that "it would be much better if I could spend one minute with every man I refer to because I could tell him what I think" (p. 11). Like Specialist 5, he felt that written material was "no use to the doctor really" (p. 14)- even for legal purposes, chart notes would be "hard to

follow". For his own needs, he felt that "most of the stuff that you write down is not that important". Specialist 5 agreed that "you cannot be too rigid about a letter" and that notes were of limited utility around a case. Even telephone contact is not very helpful, since a doctor's memory for phone contacts is limited and usually lost after a short time. As GP 14 observed, she seldom writes down what transpires over the telephone in her notes, and so it is usually lost. Specialist 8 emphasized that "the written is better, because it's all there" (Int. #1, p. 3).

In general, few urban physicians in this study advocated a more personal contact with each other around routine cases for practical reasons, in Garfinkel's (1967) sense of the phrase.[16] Even telephone communication on everyday practice was seen to be inefficient and disruptive. As Specialist 8 remarked, "if you start to establish a verbal communication with every consultation, then you spend all your day on the phone, and I think you end up wasting your time" (p. 3). Specialist 3 agreed:

> [I]t's only dragging me away from, usually...a moment of rapport with a patient. That's why we took the phone out of [the examining room]...Because I

> know I will phone somebody and the nurse will say, hang on. And I'm hanging on and hanging on, whereas I've got the patient sitting here waiting for me and the doctor finally comes on the phone and says, I'm sorry, I was busy with a patient...So no, I don't think it's feasible...Does it really matter that I have to get on the phone right away and get back, or is a letter, where I can commit myself and there's no room for doubt about what my opinion or conclusions are, is that not better to get back to the referring doctor within a week rather than a phone call that might annoy him and annoys me having to make? And could possibly be misinterpreted over the phone?
>
> (Int. #1, p. 13)

On the other hand, all physicians agreed that the telephone is a necessity for urgent or complex referrals. The telephone call in the urban setting is a signal that a referral is unusual in some way and deserves special attention. For example, GP 5 telephoned the specialist when he referred Patient 5 for investigation of a breast lump (p. 25). As GP 1 pointed out, it "takes a week for a letter to get out there...[and] if you've got someone being seen in a week, sometimes you're obliged to phone them" (Int. #1, p. 6). Specialist 1 has given his private number to all his referring physicians so that the phone lines are open for these contingencies (p. 10).

III. COMMUNICATION BETWEEN DOCTOR AND PATIENT

1. Dependence on the Patient for Information

In the absence of referral information, specialists have to rely on the patient, supplemented by calls to the GP or chance encounters with them in the halls. Specialists 2, 18 and 19 got around not having referral information by asking patients to fill out questionnaires, which they discussed with them, encouraging them to ask questions and correct errors (e.g. Gynecologist 19, p. 1). Neurosurgeon 28 added that he prefers to collect a history from a patient on his own rather than using the GP's information (p. 2). Surgeon 30 agreed that,

> as long as the patient can speak reasonable English, they know what their problem is. They've discussed it with the doctor. They know why they're going to the specialist. It's a question of do I or do I not have a hernia?....In some cases, a letter from a family physician is worthwhile. For the majority it is unimportant.
>
> (Int. #1, p. 8)

Since he typically repeats tests, such as the X-rays done for Patient 30, he feels that even test results need not be sent with a referral. Specialist 31 also insisted that he has little need for notes because in his specialty, the disorder is obvious, whereas in

cardiology, it would be necessary to know what tests have been done (p. 7).

However, it is difficult to rely on patients to relay details of history and reasons for referral where technical or complex histories, non-English-speaking or confused patients are involved. ENT Specialist 3, for example, commented, "I come in and some patients will say, I'm not sure why I'm here - if they're elderly and a little confused, then it's very difficult sometimes" (p. 2). They may not know what X-rays or lab tests have been done or what medication has been prescribed. In such cases, says the specialist,

> we have to get back to the doctor's office and if they're not there then I simply have to say to the patient, well, you know, let's proceed this way now, I will in the meantime get the information that I need.
>
> (Int. #1, p. 2)

He is irritated about the time wasted, as is Internist 12, who described how he can spend "a frustrating afternoon" trying to interview a non-English, multi-problem patient with no referral information.[17] Pediatrican 34 said that when faced with "an uncle who's a native and doesn't communicate very much to you and the child doesn't say a thing to you, you [have to] rely on the referral letter" (pp. 7-8). When short notes are sent with the patient, "at least you can get

an idea why he wants you to see the patient. I mean, obviously, the process of consultation fails if you as the consultant don't address the question posed to you" (p. 7). Anesthesiologist 28 was similarly concerned about the poor documentation of complex histories of patients who were being treated in his clinic for pain (p. 3). He deplored the fact that clinic secretaries have to spend so much time collecting this information and emphasized that background documentation on patients must be improved if the clinic specialists were to be in a position to decide responsibly on appropriate treatment (p. 9).

In situations where patients typically return to the GP for information about the referral, as in northwestern Ontario, any delays or lapses in communication from the consultant can also result in breakdowns of communication. This occurred in the case of Patient 30, who had a disagreement with the consultant to whom she was referred. The consultant failed to contact the GP and the patient returned to inform the GP about the problem. The GP felt that "I know my patients well enough that they'll tell me the whole story and not be surprised that I don't know" (Int. #2, p. 6). Optometrist 38 similarly depended upon her patients to give him feedback on a referral because

letters from consultants "are a long time in coming back" (p. 14). But this situation is disruptive. As GP 24 comments, if a northern surgeon is not courteous enough to send a consultation letter to the rural GP, "the patient comes back and I don't know what he did. I'm in the dark" (Int. #1). In southern Ontario, where consultation notes are more reliable, a similar situation may result when non-English-speaking patients return to the GP for information on the referral before the GP has received feedback from the consultant, which may take two weeks. For example, Patient 6, who spoke little English, but was anxious to find out what Neurologist 6 had found, went to his GP's office the same day, assuming that the two doctors would be in immediate contact around his case. His GP complained, "I get that often...And sometimes I'll bluff, oh yeah, the doctor says everything's fine, you gotta take this medicine. But you know, we shouldn't be doing that. We get them confused" (p. 27). In such a situation, the breakdown of communication between the physicians is compounded by a breakdown in communication with the patient.

2. The Importance of Speaking English

Specialists who received referrals from ethnic practices reported significant difficulties in dealing with these patients. Practical problems of communication between doctor and patient must be widespread in many North American cities, although the literature on communication does not address this problem directly, mainly attributing the communication problems to "cultural" differences (e.g. Zola, 1966; Jaco, Part III, 1958; Harwood, 1981). GP 5, one of the ethnic family physicians in the study, is able to send his patients to a cardiologist, gastroenterologist and psychiatrist who speak their language, but has no such choices in other specialties (p. 5). An interpreter does not entirely solve the problems of communication, because "[b]etween the interpreter and the patient and the doctor, there's something missing. It doesn't all come out" (p. 12). Patient 7 could not speak the language of her specialist, and so had to have her son "get the story" from the neurologist after she saw him. Her GP was aware that "with a second person, it's never so good", but saw no alternative. Often there is no interpreter, as in the case of native patients in northwestern Ontario. For example, the native Patient

35 said that she'd been "trying to tell the doctor" about her heart problem, but that she didn't "know how to describe it" (Int. #1, p. 2).

The two specialists who were most aware of language problems, 5 and 26, themselves spoke broken English. Specialist 5 pointed out that the family physician has to play a larger role in communicating to the patient in such cases and that the specialist may be handicapped in getting at the problem or informing the patient. "[U]nless you speak their language and understand their feelings, they don't come out and talk to you fluently and express their feelings and symptoms", he says (p. 6). On the issue of informing these patients, Specialist 26 suggested that "[i]f it's said to them in their own language, somehow it's more convincing to them. And maybe they want to ask questions and they don't seem to be able or don't want to rephrase them in English" (p. 7). The fact that this specialist was having communication problems even with English-speaking patients was revealed in his failure to understand what Patient 26, a fluent, middle-class woman, had to tell him about her ear pain. This patient reported that when this specialist had seen her several years ago, he had told her that her ear problems were due to inattentiveness. When she reminded him of this

at her current appointment, he seemed surprised that she remembered this from so long ago. However, when he was interviewed, he reported that it was the patient who believes that she is inattentive, obviously having failed to understand what she said.

Pediatrician 34 felt that the communication problems that he had experienced with native patients in northwestern Ontario were more serious than those he had encountered with European patients in southern Ontario. He found native patients "relatively passive, relatively accepting people" who are unlikely to ask questions or make complaints (pp. 8-9). Surgeon 36 agreed that native patients were "very reluctant to open up". In such cases, he emphasized, referral information is absolutely essential because "you're not going to get the information from the patient" (p. 4). GP 37's problems of communication with natives were more practical: he sometimes could not reach them on the reserves to tell them the date, time and reason for appointments (Int. #2, p. 11).

Internist 12 refused to see non-English-speaking patients unless they arranged to bring an interpreter prior to the appointment, but Internist 16, like GP 24, was proud of his ability to "muddle through". This man said that such patients "come with

the turf" and that he will try to do the "best he can" with them (p. 10). He finds "offensive" the suggestions that secretaries should have the responsibility for screening them out or that cleaning staff should translate for them, as Surgeon 20 had suggested often happens. Neither does Specialist 16 call the GP for help with these patients, because he assumes the GP is no more able to communicate with them than he is, if he sent them (p. 10). In fact, because of a dialect problem, he points out that Italian doctors, for example, may not be able to talk to most Italian patients. In such cases, he quips, medicine approaches "veterinary medicine".

Most specialists in northwestern Ontario said, similarly, that they were content to "muddle through" with native and French-speaking patients. Specialist 25, for example, said that he only encountered real problems with "the odd person that's really out in the sticks" who may not only not speak English but who is native and not Westernized (p. 4). But he dismissed even these situations as "not too bad". Neither does Neurosurgeon 28 feel he has much trouble in this area. He needs a French interpreter for a minority of patients referred from north-central Ontario and he arranges this with no difficulty. Native peoples

usually speak English, particularly in the city, he explains, and only three to four percent of the 10 percent out-of-town referrals that he sees require an interpreter. He insists, "I never really had a patient I couldn't communicate with in some way" (p. 2). GP 24 said that he only brings in an interpreter for his many French patients if he feels that he is not getting "the fine shades of meaning" by muddling through in broken French and English. However, it is likely that these three doctors have underestimated how well they have communicated with their non-English-speaking patients, just as they underestimated the "gap" in communication between themselves and their English-speaking patients.

The most serious communication problems in this study were encountered by Patient 6, who complained that it was difficult for him to understand what the English doctors said. He thought he had been told by one to "leave" when he insisted on getting some explanation for the buzzing in his head. At times, he believed that all the doctors he has seen know what his problem is but will not tell him. None of the specialists whom he has seen at three hospitals has been able to get his story straight despite looking in his ears and putting electrodes on his head. They don't even ask him, he says, because they assume that he

can't tell them. After they examine him, they tell him to go to his family doctor, because they can't help him. Specialist 6, for example, spent half an hour examining him and told him nothing. The patient has concluded that all this is happening to him because he can't speak English and that his problem cannot be solved in this country.

3. Social Distance

The problems encountered by patients whose first language is not English may differ in intensity rather than in kind from the problems that English-speaking patients face in communicating with their doctors. The experience of novice language-speakers that the language they are learning is being spoken too rapidly is the type of phenomenon that patients report when they talk about doctors speaking too quickly. There is also a tendency for the physician to spend even less time talking with lower-class patients (Bain, 1976; McKinlay, 1975), with these patients reluctant to question their doctors (Bain, 1977; 1979).

"Social distance" between doctor and patient (Skipper & Leonard, 1965; Korsch et al., 1969) and its consequences in lack of patient recall of the interaction, were familiar concepts to the physician-

participants in this study. ENT Specialist 3, for example, knows that the patient has to be relaxed or what the doctor says "won't register" and that he has to "reinforce" it (p. 16). In Patient 3's account of their encounter, this man clearly made attempts and was successful in establishing rapport with her. Internist 12 similarly recognized the difficulty that patients have in recalling what is told to them by a doctor and spoke of being sensitive to the patient's concerns and giving the patient plenty of time to ask questions on more than one occasion during the interview (pp. 8-9). Rheumatologist 13 was felt to be very approachable by Patient 13, and she said that she had found helpful the written brochure on her condition that he had given her (Int. #2, p. 1).[18]

However, just as some physicians who could not communicate in the same language as their patients failed to appreciate how serious a communication breakdown this posed, so were most doctors generally unaware of the extent of the social distance between them and their patients. A few appeared not to realize that by rushing patients out of the office, they had upset them and failed to address all of their concerns. Others were aware that this had happened, but were unable or unwilling to change the way they practiced.

This happened, to some extent, even with patients who described their specialists as polite and approachable. Patient 13, for example, had a question about whether a program of exercise would help her arthritic condition, but she had forgotten to ask the specialist and felt that it wasn't an important enough question to bother him with outside of a scheduled appointment. Most specialists admitted that they did not have a very good idea of what concerned particular patients and their guesses were often wrong. Specialist 16, for example, had no idea about the turmoil of Patient 16 over his health problem or the skepticism of the patient towards his advice, and Specialist 31 and GP 31 had no idea that Patient 31 had completely rejected their advice based on prior experience with her condition (Specialist 31, p. 13).

The young neurosurgical resident that looked after Patient 7 was aware that patients and their families often do not understand what they are being told the first time. He recalled, regarding the family of Patient 7, that "the first time I told them [about her fatal prognosis], there hadn't really been understanding, whether it was their fault or my fault, I'm not really sure" (p. 5). He admitted that he does tend to use "a lot of big terminology" but blamed the

family's failure to grasp the situation, not to defects in his explanation, but to their fear. The GP reported that the son had informed him that the specialist indeed "was very short spoken" and said things "too much in a scientific line", so that the GP had found it necessary to explain things again for a half hour over the phone, to make clear to him that his mother was fatally ill.

The cardiac surgeon of Patient 4 also explained that patients often do not remember what doctors tell them, and he suggested that patients should bring a "witness" or even a "tape recorder" when the doctor is informing them (p. 6). However, despite the fact that Patient 4 has a failing memory (e.g. he often cannot remember his street address), there is no evidence that the surgeon arranged to have his wife or some other witness attend his appointments. Another of Patient 4's specialists, Neurologist 4, was able to describe how the doctor needs to spend time with patients to make them feel comfortable and allow them to ask questions, but he, too, was unaware that this patient was unhappy that he had not addressed his concerns in their brief first appointment. The patient believed that this specialist was a "nice person" (Int. #2, p.3), but that he had prematurely "cut off" their

meeting when he rushed away in the middle of an examination. This patient complained that,"[t]hey can't take the time to sit 15 minutes with you" (p. 15). Because the specialist did not have time to answer their questions, the patient and his wife went to their pharmacist about the drugs he had prescribed (pp. 5-6) and became upset about the drug side effects. A month after their appointment with the neurologist, they were still bothered by how the specialist had treated them, saying "we'd been left up in the air with a lot of questions and no answers" (Int. #3, p. 7).

4. Communication and Respect

a. Failure to Inform and the Perception of Patient Incompetence

If there is a single theme running through interactionist studies of patient-physician communication, it is that of "communication breakdown" and its dynamics. The evidence that physicians do not inform patients to their satisfaction is overwhelming (Pratt et al., 1957; Roth, 1963; McIntosh, 1974; Cartwright, 1981). Consistent with these findings, most patients in this study would have preferred more feedback from their doctors, and a few were bitter

about how little they had been told. Patient 4, for example, who'd had a bypass operation, complained,

> We are absolutely ignorant of what things have happened to us. Nobody explains anything and afterwards, you say, gee, if I'd known that then, I would've done this and that, but you don't! But nobody tells ya. And sometimes it's only after you've done it that you find out what's what...Doctors should let people know more, but they're in such a hurry.
> (Int. #2, p. 15)

Theorists are split on the question of whether the pervasive problem of not informing the patient is intentional or unintentional, but there was evidence for both processes in this study. Specifically, there was evidence both that it was an unintentional consequence of the doctor underestimating the intelligence of patients as argued by Pratt (1957) and that information was withheld deliberately, as argued by Davis (1963/1972), Waitzkin and Stoeckle (1976) and others.

Pratt's early investigation of the problem of communication breakdown between physicians and their patients suggested that it was less an intentional decision on the part of the physician not to convey information than a consequence of the patient's unwillingness to ask questions, coupled with an underestimation by the physician of the patient's level

of knowledge. Her questionnaire to 214 clinic patients in fact showed that they knew only 55 percent of the answers to 36 questions about common illnesses, although their physicians believed that they they knew 20 percent less than they did. After analyzing 50 taped encounters, Pratt described the dynamics of the situation as follows:

> [W]hen a doctor perceives the patient as rather poorly informed, he considers the tremendous difficulties of translating his knowledge into language the patient can understand, along with the chances of frightening the patient; and therefore avoids involving himself in an elaborate discussion with the patient; the patient, in turn, reacts dully to this limited information, either asking uninspired questions or refraining from questioning the doctor at all; thus reinforcing the doctor's view that the patient is ill-equipped to comprehend his problem, and further reinforcing the doctor's tendency to skirt discussions of the problem. (p. 226)

In this study, physicians sometimes freely admitted that they had a low opinion of the intelligence of patients, and, for their part, patients often reported feeling being held back from asking questions, thus setting Pratt's process in motion. GP 8, for example, argued that it would be a waste of time to discuss the details of Patient 8's illness with him, because of his lack of intelligence:

> [Patient 8's] understanding of anatomy and physiology is for all intents and purposes about the same as this plant...He doesn't have a fundamental tree to hang information on, so you can't give him a lot of information ...And to be perfectly candid, general practitioners don't have the time to educate people.
>
> (Int. #1, p. 4)

Ironically, this patient knew more than his doctor suspected and believed that most doctors withhold information from patients for their own good, to keep them from worrying. He therefore engaged in a "mutual pretence" with these doctors that he did not know how severe were his heart problems (Glaser & Strauss, 1965). Although a few patients who were health professionals felt that their doctors were more informative to them because they might have a "better understanding" than other patients (e.g. Patient 11, Int. #1, p. 6), GP 8 argues that what little understanding they might have would not justify spending the additional time on explanations (Int. #1, p. 4).

Other doctors revealed a disrespect for patients who are unable to convey information accurately and quickly when it is demanded. Specialist 26 appeared angry that Patient 26 didn't remember right away that a local GP had prescribed antihistamine for her earache, thinking it was a sinus condition (p. 3).

Specialist 26 finds that, "it's amazing how what the doctor sends them for doesn't correspond to what the patient's talking about" (p. 1), implying that this is the patient's fault.

Still others, while not complaining about the ignorance of patients, provoked a communication breakdown when they gave a clear message to the patient that time for questioning was limited. The husband of Patient 14, for example, who went to the obstetrician with his wife because of their joint concerns, reported feeling very uncomfortable (Int. #2, p. 2). He said that the specialist challenged him immediately on why he was there and stressed that he should state his concerns "briefly", which made the husband then feel that his worries about his wife's previous deliveries were "stupid". The specialist told him that the question of why the babies were born unhealthy was not one that he could answer. The husband had accompanied his wife because he didn't think she would be aggressive enough in asking about all the concerns they had, but he fared no better. For example, they did not ask whether an epesiotomy could be avoided (p. 3). This couple recognized the phenomenon of rehearsing what you are going to say before you go to the doctor and then forgetting what you want to say, and they joke that a

patient should be able to take a tape recorder (Int. #1, pp. 19-20). The wife felt so distant from the specialist that it wasn't until her second pregnancy that she told him that her first epesiotomy stitches had been too tightly done (p. 10).

Patient 36 also speculated about taking "a tape recorder or my notepad" to see her surgeon, but finally decided to bring her husband to an appointment with her surgeon as a "backup", despite her feeling that this made her "look like a big baby" (Int. #1, p. 5). In this case, the husband was successful in explaining the seriousness of the woman's gastric problems in a way that the patient had been unable to do (p. 6). Later, however, the surgeon called her when she was still groggy after a gastroscopy, and she didn't remember what he said. When she did not receive the results of lab investigations for a few weeks, and attempted to get this information from another doctor, he lost his temper with her, complaining, "what are you doing getting results for your stomach from a gynecologist!?" (p. 9). She excused his behaviour by insisting that he "doesn't beat around the bush about what the problem is" (Int. #3, p. 2) and rationalized the surgeon's failure to inform her by saying, "I guess if there was something wrong...he'd call me" (Int. #3,

p. 5). Since she was afraid to confront him, she finally decided that she'd have to go back to her family doctor for the feedback (p. 6).

Patient 31 reports that the message not to ask questions can be more subtle, but no less effective. She found the "tone" of her interaction with Specialist 31 discouraging: "I felt like, I don't have time for you. There's nothing we can do. There's people out there that could use my help" (Int. #2, p. 2). She added, "if I'd been 75 years old and he had acted like that to me, I would have broke down and cried...You have to be compassionate. It's very important" (p. 6). Patient 33, also a young woman, failed to ask questions when she first injured her eye because, she said, "I was kind of scared and...shook up, and I would cry every time I went to talk because it hurt so much" (Int. #1, p. 3). Later, the GP told her parents rather than her that he was referring her to a specialist, which made her feel like a child. When she saw the specialist, she didn't feel that she could ask questions of him either, because he "didn't smile and didn't say hi to me when he walked in the office" (p. 8), and she felt that she was being treated with less respect because of her youth.

But perhaps the best illustration of Pratt's cycle of physician lack of respect for the patient and patient hesitation in questioning the doctor was that of Patient 19's dealings with Specialist 16, which must be a classic of poor physician-patient interaction. What was most distressing to the patient about seeing this specialist was that, in her words,

> it could take you an hour waiting to see him. And literally, two seconds and you were out his door...I could wait an hour, because there would sometimes be 20 people, all within that time, and he wouldn't be there. And...he would race in, coattails flying and zap, zap, zap, zap and it was over. And he'd speedtalk and he'd speedread and he'd talk into a microphone recording your session while you were there.
> (Int. # 1, p.12)

The specialist's view of this situation, on the other hand, was that the patient's illness involved an "organic brain syndrome" or "cognitive deficit" (pp. 3-4). Although he believes that, in general, patients make poor decisions about their health based on a lack of information (p. 10), he thought that the "charming" Patient 19 was even more likely than other patients to misinterpret any information he might give her because of her illness. Because he has run into medico-legal problems with thyroid patients, he says he tries to have them bring a member of their family with them to

"cover himself" (p. 11). However, there is no evidence that this suggestion was made to Patient 19.

b. Informing the Questioning Patient

Just as it was argued in the first section of this chapter that feedback to a GP on a referral can be stimulated in a relationship where the specialist respects the GP's competence, so it appears that sometimes where the patient is experienced with an illness and demonstrates an intelligent interest in his or her treatment by asking appropriate questions, the patient may stimulate better feedback.[19]

The wife of Patient 18, who is a nurse, remarked that she has often observed doctors who "resent the fact that people should ask a question" (p. 23) and that she had taken it upon herself to encourage, particularly ethnic patients, to insist that doctors take a moment to answer their questions and not be "afraid" (p. 23). Her husband believes that his aggressive approach to his physicians has led to his doctors being fairly straightforward in dealing with him about his conditions. For example, he felt that if he had not been aggressive in asking questions, he would not have been told by the surgeon to weigh the

danger that his heart might stop during his bypass operation against the eventuality that he might die of his condition (p. 13). The patient emphasized, "I asked him" because "I want to know" and "I've got to weigh the chances" (p. 8). When the patient specifically asked about the prognosis of his hip condition, his orthopod made the specific prediction that his second hip would last "15 years" (p. 8). Only where the patient has not had the information to ask does he feel that his physicians have not informed him. For example, he read in a magazine about the use of arteries rather than veins in bypass operations, and he had to raise this point with his GP and demand an explanation after the fact (p. 14). But where he has known enough to ask the physicians directly before a decision is made, as in the danger of an angiogram, he feels he has been able to get good answers (p. 10). Patient 29 similarly feels that although he doesn't "have that many doctors volunteering too much information...I usually get a few questions in to satisfy what I want to know" (Int. #2, p. 4).

The experience of Patient 28, who was disappointed in his latest referral for migraine headache, and who could describe very little of what his doctors were trying to do, contrasts sharply with

that of Patient 18. Patient 28 admitted that he never asks about his medications. "I wouldn't know the difference anyways and I don't want him to think I'm questioning [the doctor]", says this patient. The native Patient 35 similarly reported that she "didn't want to ask [the specialist] any questions ...because...I would rather not know" (Int. #1, p. 3). The more aggressive Patient 27 explained that at one time she had taken a passive approach in the "bad old days...when I first got into it. It's a learning process. One learns to deal with doctors as one goes along" (p. 14). Now, she will pry and ask questions, like, "why are my knees sore?", even when she knows why (p. 14). As a novice patient, she says, "you go in innocently" but experience and her GP have taught her that you must ask why and "narrow things down for them" (p. 14). She has learned, like Korsch's patients, that she has trouble hearing a message. "You have to catch on fast because you've only got 15 or 20 minutes", she says (p. 18). Her strategy now is to stall in order to have "time to to deal with the information. A couple of seconds, at least, so that I can ask a question relating to this information". Her doctor "has to answer that question so that I can understand it. If it's beyond me, then I will tell him, you know, I'm not

sure what you mean, you know, explain yourself" (p. 18). Patient 31 emphasizes that she goes "in there and tell[s] them eveything" because "they're not going to ask me these questions. Because they don't really know" (Int. #1, p. 13). She also uses a more covert approach, reading her chart when the doctor is out of the room (Int. #1, p. 22).

Even with her aggressive approach to her physicians, Patient 27 still believes that they have not told her all that they could. "All they do is prescribe you pills. And give you a pat on the shoulder", she comments (p. 11). Although she is not sure that she believes them, they insist that they "can't tell [her] anything because they don't know". She protests that a book on arthritis "will tell me as much as they've just told me" (p. 11). However, she goes along with their treatment of her as a "guinea pig" by recording "every little thing" (p. 12). The fact that she is just a participant in their account construction doesn't bother her most of the time. As she says, "[w]hen I feel good, it's OK. But when I'm sick, it really bothers me" (p. 12). She has learned to "ask or they will just take your statement as a statement" (p. 14), that is, as part of account-construction.

On a more practical level, Patient 27 feels that she was not given important information about drug reactions that she should have been told. "There were certain reactions that were going to occur and I think I was told some of them. And the others I had to pry out of them", she says (p. 12). However, like Patient 18, after she learned to pry, she feels that they were good about telling her about side effects (p. 13). She has learned by experience that one does not go back to the GP to ask about medication because he won't know, but you ask the specialist right away. "I usually nail them right there in the office. What does it do for me, what will it not do, and what are the side effects. Before I even put the stuff in my mouth", she explains (p. 13). Patient 27 emphasizes that she is not aggressive by nature but it is something you learn to do with doctors. She feels that assuming a "detached concern" with regard to her own case helps. In her words,

> [y]ou have to do this and not get involved. Emotionally involved...I detach myself and I say OK, we're not discussing me, we're discussing a case...I treat myself as a clinical case.
>
> (Int. #1, p. 19).

Doctors differed in their personal attitudes towards questioning patients. The specialist of Patient

27 was outspoken in his support of the patient striving for the best care that is available. All other doctors also supported the right of the patient to question, but a few expressed reservations about whether they could help patients who had no trust in them at all. Several, such as Internist 12, observed that the passive patient who "just accepts your word and goes along with what you say because you're a doctor" (p. 13) is easier to treat, although being able to reassure a questioning patient was, in his words, "an essential part of being a physician" (p. 13).

5. Communication and Practical Activity: Information Control

In addition to unintentional communication breakdown, it is well-known that doctors intentionally withold information from patients, a strategy called "information control" by Davis (1960/1972). Based on his study of polio patients, Davis argued that the withholding of certain information could be useful in managing patients and their families. Beyond the third month after the onset of polio, spontaneous recovery of damaged spinal cells has occurred and the physician is able to give an accurate prognosis, but it was never

conveyed to the parents in Davis' study, nor were their falsely optimistic expectations corrected: "parents were kept in the dark" (p. 97). Davis believes that physicians withheld this information to avoid expending the time and effort such a revelation would take and to avoid "unmanageable" emotional reactions from the parents, including their turning to alternate practitioners. Glaser and Strauss (1965b, p. 54) also found doctors reticent to predict a time of death, lest it fail to occur and the family lose confidence in the doctor's expertise. Waitzkin and Stoeckle (1976) similarly argue that physicians avoid any indication that they cannot "cure" a patient, to protect their power and their expertise.

Davis predicted that "dissimulation", or giving an unsubstantiated positive prognosis, might be more common among primary care practitioners, especially in view of the tendency of symptoms to resolve themselves. However, "evasion", or failure to communicate a substantiated negative prognosis might be more likely to occur in large impersonal hospital settings where the GP is not present and the specialist can easily find other things to do than talk to the patient. In this study, the strategy preferred by both types of doctors was neither outright dissimulation nor

avoidance, but instead the giving of "partial truth", bit by bit, as symptoms of the illness developed. It was seldom clear to the doctor what the patient knew, and there was no direct way to find out, given the concern about alarming the patient.[20]

Among primary care physicians, for example, GP 1 suspected that Patient 1 had ulcers and possibly cancer, but he did not tell the patient right off that he might have a malignancy (Int. #1, p. 2). The GP said that he just took one step at a time, advising the patient to get the tests done, since it looked as if he was bleeding from somewhere (p. 3). The GP felt that, "if you just lay it on people and you're not sure, the labelling effect of telling someone they have a potential malignancy can really put you in the stew" (p. 4). He was in a "mutual pretence" situation about which he had no choice because the patient,

> didn't seem to be particularly concerned that it was cancer...I don't think I mentioned cancer...He didn't mention it. But I usually leave it for people to pick up on it unless I'm pretty sure that it is, because I just don't believe in laying it on them ...[and] I think old people, when they get any sort of serious symptom, think of cancer. And if he was going to bring that up or show some concern about that I would address that...[but] I don't think I did.
>
> (Int. #1, p. 4)

GP 38 similarly avoided telling Patient 38 that as a result of her bowel surgery, there would be changes in her bowel habits. His reason for not informing the patient was that he wanted her to "go back to a normal life" without always "looking for things" (Int. #2, p. 11). GP 3 also left out the details of the prognosis of Parkinson's disease in informing Patient 4. Her rationale for holding this information back until the symptoms developed, she insisted, was not subversive, but only an attempt not to worry him needlessly (Int. #2, pp. 10-11).

GP 21 pointed to the considerable difficulties for the GP in actually diagnosing Parkinson's disease. If he became suspicious, he says that he would refer the patient to a neurologist, but would not say "too much". His reasoning is as follows:

> [I])t's always a more elderly person ...Why should I unnecessarily tell him too much about the prognosis?...I don't do this...Would you like to hear, you have this...dreadful disease and in 10 years you [will] probably end up in a wheelchair? You don't want to hear that.
>
> (Int. #1, p. 5)

About cancer, this GP admits that he engages in a "mutual pretence" with the patient rather than disclosing all, since "truth" destroys "hope":

> I think they find out...when they have an incurable disease, and both sides

> are not talking...We speak in general terms, not in particulars...I will tell them certain things, if there are symptoms coming up for instance, a lot of fluid, if they have an ovarian tumour. You have to tell them what is going on...You don't have to lie, just give them a little hope...[I]f you keep on telling them, oh, we cannot do anything about it, they wonder why are you doing anything?
> (Int. #1, p. 7)

This is the course that he pursued with Patient 21, who had a melanoma, a potentially fatal form of skin cancer. When he referred her to a dermatologist, the GP said, "I feel that I should not frighten her more than necessary because either way, you cannot change the outcome", adding,

> I just keep quiet. And say this is a malignancy that had to be removed and if [the specialist has] more to say, he probably will tell the patient the prognosis and so on. If I would try and go ahead now and start to frighten her, it would make it worse.
> (Int. #1, p. 4)

However, he feels that when the condition is labelled, the patient should have the sense to look it up without the doctor having to go into details. "Any intelligent person is going to read about that, I'm quite sure of it", he says (p. 5). GP 32 appeared to be following the same course when he took some fluid from his patient's breast cyst. Although she "could see by the expression on his face...[that it wasn't] good this time", he

suggested reassuringly that "we better find out if it's another one of those benign cysts that you have a history of...We're never sure until we send it out" (Pat. 32, p. 3).

GP 16 argues that, in deciding what to hold back, the doctor has to have a "sixth sense" to evaluate the patient's personality. With totally debilitating disease, such as Alzheimer's syndrome, he says he would never lie but that it would be "impossible" to tell all (pp. 5-6). He would tell the patient's family the truth, but would maintain the patient's hope by not telling the worst. GP 16 asks "[w]hat do I gain if I tell a man who has incurable disease that he'll lose his mind?" (p. 6). Such information is "cruel and useless", and he says, "I gain nothing by it, it just destroys somebody's relative enjoyment while he still has a full life" (p. 6). Echoing the Hippocratic oath, he asks, why harm someone if you cannot help?

How did consultants deal with these issues? Surgeons were aware that it was in their best interests to inform the patient before undertaking a procedure. Specialist 16 suggested that the "pre-op" consult, in which an internist is asked to do a patient assessment before surgery, is not so much a true

assessment as an exercise in "informed consent" (p. 9). The immediate reason for this emphasis on informed consent, as Orthopedic Surgeon 18 explained, is a 1980 Supreme Court of Canada ruling that the doctor has the legal obligation to advise the patient of all material risks attached to medical treatment or intervention.[21]

The willingness of non-surgical consultants to fully inform the patient, however, should not be overstated. Although Specialist 8, for example, insisted that he tells the patient "everything" (Int. #1, p. 6), he admitted that he did not tell Patient 8 about his suspicions that the Ministry of Transport would not give the man a licence upgrade based on his cardiac tests. "I didn't want to second-guess the Ministry", he said, adding, "I did tell him things seemed to be quite stable. They don't seem to be worsening" (Int. #1, p. 8). While technically this may be true, he didn't tell the patient how bad things were in the first place. The same specialist told Patient 9 right away that the cardiac stress test that he had taken was positive, because, in his words, "people usually want to know rather than waiting for a few days" (p. 1). However, in this case, the patient had initiated the referral, "he knew something was wrong" and was so concerned that he went back to see his GP

the next day (p. 2). As the specialist commented, "there are certain things that are just obvious to the patient" (Int. #1, p. 7). In other words, sometimes the doctor is forced to inform the patient about what he already suspects or else risk looking stupid. Specialist 13 similarly insists that he tells the patient "straight out" about an illness, mainly because he doesn't want to be seen as "flubbing around" (p. 5). Specialist 11 cites the literature of probability when "forced to the wall" by patient questions, but he fears being criticized if his prognosis is wrong (p. 10).

Patient 27's potentially lethal problem, connective tissue disease, which may evolve into lupus, was also revealed bit-by-bit by her consultant. He felt that there was such clinical uncertainty that "it would be wrong to go into explicit detail" about prognosis. All that is necessary, is to explain about some of the symptoms that are encountered, such as Raynaud's phenomenon, since if the patient is not careful about keeping her hands warm, she may lose a fingertip. But, says Specialist 27, "I don't have to say she might one day develop systemic lupus...and go on dialysis" (p. 5).

Gastroenterologist 12 is similarly conservative in what he decides to tell the patient. Even

when he finds out that the patient has a degenerative disease like colitis, he says, "I don't always hit them with the fact that this is chronic and forever, which it isn't" (p. 13). In the case of Patient 12, who has a tentative diagnosis of colitis, he says, "[y]ou have to be careful about what you say on the first trip. Then you're eating crow the next time. And then you've upset him". Like GP 21, he believes that a doctor must be very careful not to alarm the patient (p. 16) and instead must emphasize what can be done (e.g. diet control in the case of colitis). Colitis is a pre-malignant condition, but this specialist says that he would only warn the patient about this "if he asks me" (p. 17). To the extent that healing depends upon a social-psychological process, such as acceptance of the doctor's definition of reality, these doctors worry that they may condemn a patient to suffering and death if s/he believes him. And, as Gastroenterologist 12 points out, this is never really justified in view of remarkable recoveries (p. 17). Holding back carries a risk that you may look stupid if the patient relapses, but this is justified in that it is done "for [the patient's] benefit" (p. 19).

The cautious approach was defended best by Specialist 16, who argued that patients who are told in

error that they have heart problems may become what he calls "cardiac cripples", who are afraid to come out of the house (p. 13). For example, in the case of Patient 16, the specialist could not decide whether the problem was cardiac or not, and he was aware that it is dangerous to err on the other side of "overdiagnosing" and producing a "cardiac cripple". Since this specialist felt caught on the horns of a dilemma, he reverted to a "drill" or algorithm that he has developed to lead himself through his dealings with such a patient (p. 13). Because there was so much uncertainty here, he had to "play it in between", leaving a "light open" that the problem was not cardiac. His general rule is that if the patient gets too upset, for example, by not going to work because of his fear of his condition, then the specialist can't leave the diagnosis as open-ended as long as he did with this patient. The internist recalled that "we must have felt very secure with [Patient 16]" because the diagnosis was left open so long. If the patient in question turns out not have a cardiac problem, the next step in the drill is to deal with the "pain" by reassuring the patient that its causes are unknown, but that it is not cardiac (p. 14). The specialist says

that about half of such patients "get better" with such reassurance.

How do patients feel about the bit-by-bit strategy? Although most rejected it theoretically, in practice a few did not mind a careful unfolding of the truth. There was also some evidence that patients in this study whose doctors would not discuss "the worst" with them, in fact suspected it. Patient 4, for example, whose doctors did not give him the prognostic details of Parkinson's disease, said that his father probably had died with it, so that he was aware of the prognosis. Similarly, Patient 12, who was treated very gently by the GI specialist, said, "if it gets real bad, I'll have to go to the hospital and get [my bowel] all snipped out" (Int. #2, p. 1), a possibility he knew about through a friend. However, the patient liked the specialist's bit-by-bit approach, happy that he didn't "rush you into the hospital and get you all tore apart and find it's nothing". He explained approvingly that the specialist "said he'd give me more of an explanation the next time I come in. They'll know more because he'll be able to look at the results from the lab" (p. 12). Unlike the majority of other patients, he insisted that he didn't get any feeling of things being held back.

Patient 7 also appeared comfortable with the "bit by bit" approach after having shown a great deal of initial concern about her dizziness. She dwelled on a vitamin deficiency that was identified in the blood tests and finally admitted that the CT scan revealed some "fluid" on her brain. At least until the diagnosis of brain tumour was verified for certain, she appeared to take comfort in the family doctor's instruction "not to think of anything [and] just wait until you get the answer" (p. 2).

IV. COORDINATION OF COMMUNICATION IN REFERRAL

1. What the Specialist Tells the Patient

Internist 12 explained that there have been dramatic changes in the approach to informing the patient over the past few years, in that the specialist is now "in charge". As Specialist 3 recalled,

> the original idea of the consultant was that he would...examine [the] patient and say absolutely nothing to him, but send him back and say, I will send my opinion to your family physician...It still happens with some...[but] over a period of time, we have learned that <u>that</u> is not what our patients...[or] family physicians want...They want us to tell the patient what's wrong with them and what we're going to do with them...[W]hat's the point of sending the patient back to the family

> physician and saying that they need this or that done...?
>
> (Int. #1, pp. 18-19)

Although this specialist had been following the "old model" when he came to the city to practice, a colleague alerted him that it was now appropriate to simply "go ahead and do what you're going to do, just let the other doctor know what you're going to do" (p. 19). And now, he says,

> I'm conditioned to have a patient leave the office and know what's wrong with them...and I'm not even sure...whether the family physician really wants to take my words and use his judgment. Because if there are questions to be asked or something is to be elaborated on, you see, I'm the best person to answer those questions.
>
> (Int. #1, p. 19)

All doctors agree that the specialist is in the best position to inform the patient. Specialist 8 assumes this responsibility for courtesy and in order that there will be no misunderstanding of the "flavour" of the advice, since nuances may not get communicated in a letter. After the consultation has been initiated, this specialist says that he maintains an "open door" policy - the patient is told "please don't hesitate to call" when medications are prescribed. And even after a patient is referred back to the GP, he remains available (Int. #1, p. 15).

Not all specialists are comfortable with this role and a few GPs are critical of how they handle it. GP 16 summarizes the situation when he argues that many specialists in general are good technicians but that they lack the empathy for patients that "can't be taught" (Int. #1, p. 7). "I wish they would leave the talking up to me", he complains, because he feels that many of them do not share his respect for the patient that demands withholding cruel information. GP 10 also believes that patients probably find it easier to talk to him than a specialist, so he tries to give them "as much information as possible". He also admits that he tends to hold back "where the diagnosis is uncertain" because of his concern lest a fatal diagnosis or a time frame that is not optimistic may kill a patient's morale. Like GP 16, he reported being upset with a specialist who joked with one of his patients about her being "still alive". GP 29 had similar complaints about surgeons in his city whom he described as "pretty aggressive in their conversation", which reflected "a lack of awareness and to some extent a lack of maturity" (Int. #2, pp. 6-7).

GP 21 denies that he has encountered serious problems with specialists alarming patients, pointing out that this may be because his specialists are "in

the middle age group" who are more cautious, while while younger specialists might be "a little bit rough" (Int. #1, p. 6). When "you are young, you are ambitious, you are one hundred percent right and you throw all the facts in their faces", he says (pp. 6-7). Young doctors fail to see how full of anxiety the patient is, he says, and the GP sometimes has to smooth things out. "Are they trying to play God?" he asks, adding,

> I think experience and years will tell you. I was the same...I was criticizing quietly on some things and not so quietly on others...[H]ow could you, I said, not tell anybody! But later on, you learn, you have to be a little bit patient.
>
> (Int. #1, p. 7)

Gastroenterologist 12 has the opposite problem of difficulty in facing the patient with fatal or debilitating chronic illness. He recognized that he can't delegate this task to the GP although he would prefer this. This means that the GP whom the patient has grown to feel comfortable with is out of the picture, so that a patient, in his or her last illness, is often left with a doctor who doesn't know him and who feels uncomfortable with informing him.

The responsibility for informing Patient 7, for example, fell on the staff neurosurgeon, and by default, to a young resident. As has been mentioned

above, the patient's family found this man "abrupt", but his own view was that his attitude of "detached concern" had evolved through his numerous experiences of death-telling. In his words,

> [y]ou have to compare what the experience is like if you've never done it before vs. if you've done it for the past number of years (p. 15).

Like other surgeons and GPs, he doesn't tell a patient about prognosis: "unless they specifically go out of their way to ask me on more that one occasion...I'll just sort of skirt the issue". He prefers to be quiet unless he's 100 percent certain. And even when he is certain, as he was of the diagnosis of cancer with Patient 7, he says that the patient "knew that she had a tumour [and]...I didn't think she needed to know anything more than that".

On the other hand, there are pressures on the specialist to give the "complete picture" to surgical candidates. As GP 21 says, "anyone that is performing the procedure has to inform the person what he is doing" (p. 6). Surgeon 36, for example, said that he would sit down with Patient 36 before surgery "and explain it in detail because [I believe in] this informed consent business" (p. 3). Thus while there might be delays while a chronic disease is unfolding, or while "tests" are being done, ultimately, for

medico-legal reasons, the consultant must obtain "informed consent". Even where surgery is not involved, GP 7 argues, it is wise to prepare a patient or his or her family for impending death. For example, if the doctor protests that the patient will be alright, and then the patient dies, they may think that the doctor didn't know what was going on or did something wrong. Regarding Patient 7, he says, "it would be foolish not to tell her [that she had a tumour]", but the details can be omitted (Int.#2, p. 5).

2. What the GP Tells the Patient

With most referrals, GPs do not have enough information from the specialist to fully inform the patient, a point made by GP 2 concerning the case of Patient 2, who was undergoing complex respiratory therapy. This is partly due to their decreasing presence in the hospital, since, as GP 30 puts it, "the only way you know how to tell Mrs. Murphy's family where the tumour was is to go in there and see it" (Int. #1, p. 17). Consequently, the urban GP's role has become mainly supportive:

> I am like a good friend or family member and I come in and I comfort him as much as possible. Try to take away the fear as much as possible....[And]

> in a very smooth way, direct him in the way he has to go.
> (GP 21, Int. #1, p. 6)

Following this line of reasoning, the GP did not say anything to Patient 21 about her potentially fatal melanoma because, in his words, "she is at the moment under [the specialist's] care. He is preparing her, or has told her of her malignancy" (Int. #1, p. 4). He had merely explained when he referred her that the mole was suspicious, and that she needed to go to the specialist to have his opinion on it. This GP felt that even if he was almost certain that this was a malignancy, he would still wait for a biopsy (p. 4). In his experience, melanomas may clear up, so that he feels no necessity to alarm the patient. As he says, "my duty is to tell them a little bit [and] make them aware of the disease. And there are certain ways it can be done. I never frighten them." (p. 6). GP 29 agreed that terminally ill patients want "something to hang on to". He says he always tells them if they have cancer, but never sets a time limit on their lives, instead emphasizing that "treatment options are very limited. And that we'll give it our best shot" (Int. #2, pp. 6-7).

GP 24 admitted that "mutual pretence" between patient and GP, in which "the patient knows and you know and they'll ask and you don't tell them" is also a

common response from the GP. However, he felt that the "fact that [the GP is] concerned and sympathetic...is good enough". Like other GPs, he thought that certain specialists were very good at this type of communication - for example, "people in the cancer clinic are real experts on how to handle things like that" (GP 24, Int. #1).

The urban GP is expected to play a more active role only if s/he has a long-standing relationship with a particular patient. For example, Specialist 11 says that although he won't send a patient back to the GP for information, he will withhold information at the GP's request (p. 10). GP 1 recalled such a case in which he thought a patient had an esophageal malignancy and said to the specialist, "this lady will take it very badly if she has cancer", adding, "I had good rapport with her, and I thought it was better that I speak to her". On the question of how often this happens, he remarked that, "it varies. I like telling them myself if possible" (Int. #1, p. 4). Since this GP has only seen Patient 1 once, he said that he would leave the responsibility for advising this particular patient about cancer to the specialist, since he is under his care. However, the GP argues that where the necessity for intervention is critical for life, as

with a cardiac bypass, the GP might have to spend a great deal of time reassuring the patient that this treatment was better than medical management. While it would be redundant to have the GP and specialist informing the patient in all referrals, he feels this is a necessity in cases where the patient will soon die without the intervention (p. 16). After an experience with a patient who avoided such an operation because of his fear of a naso-gastric tube, this GP says he realizes that "you've really got to tap into what people believe about it because you may have some expectations about that but you might be quite wrong" (p. 16).

Specialist 16 also points out that it is useful to refer patients who balk at what they may consider to be a dangerous treatment, back to the GP to discuss the options. The GP has a strong role to play as an advocate of the patient, he says, and should be able to inform the patient as a result of getting letters of explanation from the specialist (p. 5). In urban areas, however, this option was seldom pursued. For example, when Patient 29 was booked for a lung biopsy by a respirologist, the patient had misgivings, but was unable to discuss these with his GP, who was unavailable.

In rural areas, the GP is sometimes the major informant because the "person's often back home by the time [the consultant] gets the results of a lot of his investigations" (GP 24, Int. #1). Since patients do not want to travel long-distance back to the specialist to be informed of the results, the GP may inherit the major responsibility for informing them. However, GP 32 points out that since consult letters do not arrive quickly, the patient may have to return to the specialist for explanations, and his role, like that of his urban colleagues, becomes "backup and supportive" (Int. #1, p. 3). In the case of his Patient 33, the patient had not yet been back to the GP more than a month after her long-distance visit to a specialist, and so she was left with only the abrupt comments of the ophthalmologist that nothing could be done. As she explained, the specialist "was in such a hurry that he didn't say, are there any questions? It was just bang, bang, bang and he was out". Therefore she would have liked "to talk to [the GP] because [the specialist] told [her] next to nothing" (Int. #1, p. 6).

The rural GP may also be in a position to influence how the local specialist informs the patient. Internist 40, for example, reports that he respects the

GP's request to "be careful" how a patient is told about a diagnosis (p. 3).

3. Contradictory Information in Referral

Given that direct communication between doctors is rare, there is a potential that information will be omitted by one or the other doctor if neither takes full responsibility for talking to the patient. Further, since specialists have greater pressures to disclose bad news to patients, while GPs tend to be reassuring, there is also a potential that the patient will receive contradictory information from these two sources.[22] Froom et al. (1984) argue that "the major risk to the patient from consultation is confusion that can result from disagreement between the referring physician and the consultant" (p. 623).

Possibly because GP 16 is forced to shop for young consultants in some specialties, he claims that he increasingly faces the problem of the specialist being overzealous in informing the patient. He comments that it happens "more and more so! I'm very upset about it" (pp. 6-7). He describes a case of a man with prostate cancer to whom a specialist gave an incorrect fatal prognosis, and where he was later unable to

convince the patient that he was not going to die. The GP added, "this is not an isolated case". Bard (1970), in a paper describing other such patients, also makes the point that such damage can often never be reversed. GP 16 believes that the problem arises not because the patient trusts the specialist any more than the GP who is reassuring him, but he suspects that the GP is a "nice guy" who would hold back the truth to protect him.

A few specialists also report being unhappy with contradictory information given to the patient by the GP. One young specialist, for example, comments,

> If it's a GP who is going to talk to the patient and has the skills to understand what it's about, then I would prefer that the GP do it. And what I do in that situation is I call the GP and...he and I decide who's going to talk to the patient. But if the GP's not involved at the hospital, then it's my problem and I talk to the patient...I have occasionally had the GP tell something to the patient which was incorrect. Because they didn't comprehend the situation...Sometimes it's because communication is poor, but usually it's a misinterpretation of the situation.
>
> (Internist 4, Int. #1, p. 14)

Internist 12 feels strongly that the GP should avoid giving information to the patient that might contradict what the specialist says, emphasizing that it's not a question of asking the GPs <u>permission</u> to tell the

patient something but to "make sure we've got our stories straight" (p. 14).

Specialist 27 doesn't see any way to coordinate what the two tell the patient:

> I don't think until we're totally computerized and everybody understands the same thing by [a particular] disease will we be able to fix that. And even then it may be the same discussion but two people can come across differently. (p. 6)

He notes that in communicating with the GP, there are breakdowns even,

> when the doctor works next door...[Y]ou try to be on their wavelength if you can...[but you] obviously can't give a full textbook description in every referring letter. You just hope that you're talking the same language. (p. 6)

The case of Patient 16 illustrates how much contradictory information can be given to a patient in a referral situation and how difficult it becomes for the patient to know what or who to believe. After going to the ER, the man was whisked in to be seen in five minutes, a reaction that "shocked" him, such that he began "wondering what the hell was going on". A specialist in the ER traumatized him by saying, "we have reason to believe you have had a heart attack" (p. 2). Then, he quietly sat in ICU for five days until they had to discharge him when he spent 18 minutes on

the exercise treadmill, an impossible task for someone with cardiac problems. The patient was originally not alarmed and ultimately got the news that he didn't have a heart attack. Subsequently, all his tests have come back normal (p. 4) except that he believes that his chest the pain responds to nitroglycerin, which is used for cardiac pain. All three of his doctors called to reassure him within an hour of hearing of his normal angiogram (p. 5). Specialist 16 told him that the heart attack was something "someone has implanted in your head" (p. 5). They are right, they implanted it, and it is difficult for the patient not to continue to be concerned about his condition. Four months after the event, the patient was still not sure of his diagnosis (p. 11).

Patient 31 said that doctors she had seen in Toronto had told her that her skin disease might be related to her diabetes, but that doctors at the Mayo Clinic told her that "anyone can get these" (Int. #1, p. 4). When she repeated this to Specialist 31, he thought that <u>she</u> was confused about the etiology of the disease. He commented that "[s]he went to all these places, but ...she doesn't quite know what she has" (p. 13). He said that he usually puts some explanation in the consult letter so that the GP can inform the

patient, but no explanation appeared in the consult letter that GP 31 received from him.

Patient 19 also found herself faced with a contradictory situation when she was asked to drink a radioactive substance, but saw "people working with it use protective gloves and steel bibs and you have to drink the bloody thing!" (Int. #1, p. 9). Unfortunately, the technicians neglected to tell her not to hug her baby for three days until after she had swallowed it and she remembered thinking "what the hell am I going to do?"(p. 9). She went through a bad time with the baby and she still has concerns in spite of physician reassurances. "I may die of cancer of the throat in 10 years", she remarks (p. 9). In this case, she blames the technicians for not informing her properly, not the specialist. She say she knows the specialist would not have been able to help because he spends so little time talking to patients. In her words, "[y]ou blink and you miss him...You don't speak for more than three minutes" (p. 10). "It wouldn't have made any difference if he had been involved", she declared. When he did talk to you, "he'd just very quickly tell you and it's so quick that you can hardly grasp what he's saying" because he talks a "mile a minute" (p. 11). The specialist had the feeling that

this patient already had been informed before she came in, but since he didn't talk to the GP, he doesn't know it was her who filled in for him. On the issue of informing the patient about her treatment, he questioned why the radiology staff makes such a "big deal" about this particular radioactive treatment, even though the danger, in his word, is "zilch". He faults the patient for getting upset about the radioactivity, because, he suspects, "some people have a pathological fear of radioactivity" (p. 5). He has difficulty seeing that if someone is given a "song and dance" about radioactivity that this might be causally related to their fear of it. He also mentions that this particular radioactive treatment has been associated with cancer in the past, implying that the fears of such patients may not be so irrational.

As this case illustrates, the potential for contradictory advice is not restricted to the patient's doctors. Many patients in this study also sought information from elsewhere that turned out to be different than what they received from their doctors. For example, the specialist gave Patient 9 some information about his medications, but the patient sought more information from his druggist, which prompted him to call his doctor in alarm (Int. #2, p.

2). The patient admitted that the specialist had tried to explain but, in his words, "I don't know whether they have a tendency to talk too fast or talk too much in medical terms that I don't understand" (p. 3). Patient 33, who saw an optometrist and then an ophthalmologist, also got two different versions of what was wrong with her eye: "one tells me it's a cut on the cornea and the other tells me it's a cyst", she complained (Int. #1, p. 12). But what concerned her most was the discrepant prognoses of GP and specialist, the former reassuring her that "it's getting better", at the same time that the latter was telling her that her sight would never improve (p. 10).

How do patients deal with contradictory information? Occasionally, they reported forcing physicians to talk to one another to sort out their stories. Patient 27, for example, explained, "if I have any questions that [my GP] can't answer, he'll call and talk to the specialists" (p. 4). Neither does she hesitate to call specialists on the phone, although she is careful to keep her GP informed. More common responses, however, are confusion about who to believe and tendencies to withdraw from treatment; to passively or uncritically submit; or to seek further opinions. These outcomes will be discussed in Chapter 10.

V. SUMMARY

As described in the previous chapter, the GP is increasingly isolated from specialist-dominated hospitals in urban settings, and this has important consequences for the process of referral. Communication between referrer and consultant in such settings is typically indirect, except in the case of emergencies, in contrast to the personal communication that takes place in rural settings among GPs and local or visiting consultants. The urban GP usually fails to send referral information to the consultant because this does not fit into his or her everyday activities or because s/he feels that it is not necessary. However, this failure to communicate may be interpreted by the consultant as a lack of interest, competence or respect, which may further provoke delayed or incomplete feedback. In northwestern Ontario, personal contact was part of everyday practice, and referral information was sent routinely. Urban consultants did not single out rural referrers for better feedback, however, and the rural GPs often complained about the responses of city consultants to their referrals. To some extent this can be traced to a lack of economic

incentives for better communication when there is a surfeit of patients.

In the absence of referral information, the patient is the consultant's informant, a situation which is problematic when the patient cannot speak English or is otherwise unable to communicate. Even where there are no language barriers, specialist-patient communication may be disrupted by the social distance felt by the patient and subtly or not-so-subtly imposed by their busy doctors. Just as the specialist may lose respect for the competence of a referring doctor who does not attempt to communicate with him, the doctor may assume that the timid patient is unable to grasp what s/he might be told by the doctor. Patients almost universally deplore the partly-unintentional, partly-intentional withholding of information from them by doctors, and experienced patients in this study reported aggressive techniques for stimulating better feedback.

Although both referring doctor and consultant tend to prefer a gradual disclosure of important diagnostic and prognostic information to the patient, the major responsibility for informing the patient falls to the consultant, and consultants have a number of reasons for informing the patient more fully than

the GP. First, they tend not to know the patient as the GP does, and so perhaps are more successful in assuming an attitude of "detached concern". Second, there is a tendency for younger consultants to be in favour of full disclosure. But more important than these are medico-legal considerations that pressure the specialist into closer observance of informed consent. Except in rural or ethnic practices, the GP has been largely relegated to a supportive role in informing the patient. Where s/he gets more involved, a serious problem sometimes arises: that what the two doctors tell the patient may be contradictory. While patients may react by trying to sort out who is telling the truth, they also may remain confused and unsure about who to believe, with important consequences for their willingness to follow the advice being given.

NOTES

1. An exception is Svarstad's (1974) demonstration that failures to communicate with the patient underlie what she called "unintentional non-compliance" with physician advice. Reviewers of the literature on patient-doctor communication have lauded Svarstad's processual analysis of hundreds of encounters as a "radically new method for exploring the impact of the information that doctors give to patients" (Tuckett & Williams, 1984: 577; see also Garrity, 1981) but there have been no followup studies.

2. One consultant neurologist complained that, of 100 patients referred to him, almost half either brought no information (28 percent) or perfunctory notes "of meagre value" (19 percent). He hinted that this breakdown of communication was associated with unhappy patients who "ricochet among several physicians by chain referral or on their own initiative" (p. 663), but he did not pursue this. Dowie's review of 358 letters sent by referring doctors led her to conclude that even in Britain, where referral letters are mandatory, the letters show substantial deficiencies in the information they contain (1983a, ch. 3). In Canada, where the frequency of sending referral letters in training centres for family medicine is also high, similar deficiencies have been reported. In the Toronto study by Clarfield (1980), for example, consultants felt that in 9 percent of referrals, the referring doctors did not provide enough information, and that 16 percent of referral notes were deficient in information on physical examination, while 20 percent were deficient in information on lab data. However, there is no analysis of what might be going on in these situations.

3. In one study of 200 referrals, there was a 90 percent return rate of feedback from private subspecialists and only 65 percent from

university-based subspecialists (Cummins & Smith, 1975). In a later study, Cummins et al. (1980) found that of 233 referrals made by two National Health Corps physicians, follow-up information was received from 78 percent of private specialists and 59 percent of university specialists, but only 48 percent of emergency room cases. Hanson et al. (1982) similarly found that, of 141 referrals from North Carolina GPs, reports were received from 88 percent of community consultants but only 75 percent of university faculty and 43 percent of university outpatient clinics. The authors explain this effect in terms of university faculty "being less dependent for survival on referrals from primary care physicians than are community consultants" (p. 656).

4. The idea that mutual respect underlies successful communication and that lack of respect is part of unsuccessful communication is not new. The studies of Rosenhan (1973) and Goffman (1959), for example, show that health professionals communicate perfunctorily or not at all with mental patients, whom they do not respect as people like themselves. A similar phenomenon is described in Key's (1975) review of the literature on communication between men and women. More recently, Hite (1987), in an exploration of breakdowns of communication between men and women, presents evidence that men "talk down" to women for whom they have "subtle disdain". Within the referral literature, Grant (1982), in reviewing a study that showed that psychiatrists are uninterested in the diagnostic formulations of referring GPs, recognized that "respect" is missing from interactions of this kind. In his view, these problems can be remedied when the doctors get to know one another, because "[r]elationships over time appear to be the factor in the development of mutual respect" (p. 1281). Saunders' (1978) brief review also concludes that "intraprofessional tensions" underlie communication breakdown in referral and he advocates teaching of residents as a way of preparing them to cope with the problems of referral. Saunders cites Bergen et. al. (1970) as suggesting that "[t]he most critical of these for understanding the consultation

process is how one member of a profession is able to seek help from another about something of which he is ignorant without losing his professional demeanor" (p. 126).

5. In the Long and Atkins study, 85 percent of consultants had either not seen a GP in the past month or had seen one or two in a "domiciliary visit" (a unique feature of British medicine, which is in sharp decline-Dowie, 1983b; Cartwright & Anderson, 1981; Birrell, 1974). They emphasize that shortcomings in referral letters "must have their origin precisely in the general failure of mutual understanding between the parties, indicating the need to build up other possible areas of contact and communication" (p. 459). However, they admit that there is "little impetus in medical circles" to deal with the longstanding problem.

6. Rarely a specialist like Gastroenterologist 12 might insist on making these decisions himself. "[I]f it looks like a very urgent problem, then I'd have to tell [the secretary] to move it up or do something", he commented, although usually the "family doctor will call you himself" if a case is urgent (p. 1). Specialist 2 said that there was a potential that urgent referrals might be delayed if the secretary "just accepts a six-week consult, doesn't give adequate information and somebody that should have been seen earlier waits a long time. That doesn't happen very often though. I have a mechanism with my secretary and our front desk reception area so that they can take calls with a list of standard problems that I would consider urgent even if the referring physician's secretary or whoever, calls...like hemoptysis (coughing up blood)" (p. 2). In this study, the system failed at least once when Patient 19 was given an appointment five weeks hence for a thyroid condition which should have been looked at in a few days rather than a few weeks.

7. A few specialists handpicked their referring doctors such that they more consistently sent referral notes. Gastroenterologist 1, for example, insisted that there was some sort of

communication from his referring doctors in 75 percent of cases. He pointed out that he may miss phone calls since he only has office hours on two half-days per week, and so does not mind phoning the referring doctor for details. Alternatively, he will phone the pharmacy if the patient cannot remember the medication. Others, such as ENT specialist 3, complained that they received letters on "not more than five percent of consultation/referrals" (p. 2). The estimate of 10 percent is also based on the results of a study done by Allega (personal communication, 1986) of a sample of consultants in the first urban hospital, in which he had consultants review and report on the percentage of the last 10 consultations for which they had received documentation. Gastroenterologist 12, who participated in the project, thought before the tabulation that about half of his referrals had backup information, but was surprised to learn that this was a great overestimate. He developed an appreciation for how much work was done by his secretary, such as the tracking down of old X-ray films (pp. 3-4).

8. For example, the secretary of Orthopod 18 has out-of-town patients bring their own X-rays and picks them up herself for city patients. She also has the patients fill out extensive questionnaires, which has resulted in better backup information for the specialist's files (p. 2). Although only two other secretaries in this study were encountered who gathered background information so systematically, most others assumed responsibility for assembling what information was available. Occasionally referring secretaries were encountered who helped make sure referral notes were written and who helped make emergency referrals (Receptionist 2, p. 12).

9. A minority of specialists in this study went beyond the expected single formal consultation letter to send notes after each visit even if this involved a score or more notes over a period of years. One orthopod who practiced in this way cited a court case in which a specialist had been sued for not informing a patient of the possible negative outcomes of a

procedure. This precedent, he emphasized, had made him and many other doctors uncomfortable. He thus spoke highly of writing clear consultation letters with paragraphs and titles to make them easier to read, which he felt was "the smart way to get back to them what they want to know" (Orthopod 18, p. 6). Neither was he averse to phoning the GP, sending letters inviting him or her to attend surgery, sending copies of consult letters to patients (even if they couldn't speak English) and generally encouraging the patient to get the GP involved (p. 5). The more correspondence that was generated around a case, the more comfortable he felt. His secretary, who had developed a comprehensive system for collecting information on referred patients, excused GPs for not sending much background information with referrals. She realized that the hospital or tertiary consultant may not have sent the GP a copy of previous notes in the first place (p. 8) and emphasized that her office did not want to contribute to the problem. To keep the GP up to date, she will even send copies of tertiary information. This specialist became aware of the extent of the breakdown of communication to the GP when he began to deal with medico-legal cases, in which he now prefers to deal with lawyers rather than GPs, since they have more information on the patient (p. 6). His secretary believes that only specialists that are "compulsive" themselves about getting information will be bothered to keep other people up to date in this way (p. 4).

10. A similar problem developed in the case of Patient 29 in a northwestern Ontario city, who was seen by a specialist within the GP's group practice clinic. The consultation note was written into the chart where the GP did not see it until he was questioned about the patient (GP 29, Int. #2, p. 1). Ironically, this GP had emphasized that typed feedback from specialists within his clinic was prompt - within two or three days - while feedback from outside consultants might take weeks (Int. #1, p. 1). Specialist 29 explained that he tries to phone the GP to tell him that he is referring a patient on to a surgeon, but in most cases, as with Patient 29, he merely writes this

information in the chart, where it may be overlooked (p. 11). In more complicated cases, where a specialist refers a patient on to another specialist, the tertiary specialist only reports back to the first specialist, since it a consultant generally only feels obliged to communicate with the doctor who referred the case (Surgeon 30, p. 5).

11. However, feedback from salaried consultants in tertiary care centres on interesting cases was also good. For example, Rheumatologist 27 in Toronto said that he frequently telephoned the referring doctor, wherever in Ontario the referral originated, because about 50 percent of his patients are so ill that this requires direct communication back to the GP (p. 2). The Winnipeg specialist 28 also reported extensive use of the telephone in communicating with the GP. "You can always use the phone. It's on the hospital", he commented (p. 4). The importance of having a secretary to handle correspondence was illustrated by the case of Specialist 31, who had just set up practice, and was staying until 8 or 9 every evening in his office trying to finish his correspondence, and completing much of it in handwriting (p. 8).

12. When there is a delay in receiving the consultant's report, the effect is often the same as if a letter were not received. This was a problem in the Cummins study, where it took an average of 10 to 12 days to receive follow-up information, which was "delayed for weeks on numerous patients" (p. 1651). In the Metcalfe and Sischy study of four family practices in New York state, no report was received within 24 days of referral in over 40 percent of cases. About half of these cases were never reported on, a proportion that the authors felt was "surprisingly and unfortunately large" (1973, p. 1693). In a study by Fraser et al. (1974), a consultant's report was received by the referring doctor in only 60 percent of cases studied two weeks after routine referrals and only 40 percent contained a mention of diagnosis. In both the Cummins and Fraser studies, a particular problem was noted in communication back to the GP after discharge of

emergency admissions from hospital, which often consisted only of hospital discharge summaries "without personal physician to physician communication". The Cummins group complained that telephone feedback was the only communication from the ER in many cases and that lapses were common with patients who needed continuing specialist care, even though the GP is expected to provide the ongoing supervision and counselling for such cases.

13. According to GP 7, chairs of departments of family medicine in this city's hospitals have recommended that there be "a designated person in a ward who is on the permanent staff who takes care of [notifying the GP]" (Int. #2, p. 13). He thinks a ward clerk could look after this, but the hospitals have not yet approved this. The GP defended Resident 7 by suggesting that residents are usually more conscientious than staff in notification of GPs, although technically it is the specialist's responsibility to provide the feedback. No estimate of how often information about emergency referrals is sent to the GP could be made, but a few consultants insisted that they tried conscientiously to make sure that GPs got a copy of the "final summary" or "operating notes", particularly if the GP telephoned to let them know that the patient was coming to the hospital, but also if the patient is self-referred "if I knew who the doctor was" (e.g. Toronto Surgeon 30, p. 6).

14. Gastroenterologist 12 was the strongest advocate of this strategy, arguing that it is necessary to talk face-to-face to the GP before an appropriate way of approaching and treating a patient, such as someone who is being sent for reassurance, can be worked out (p. 4). He believes that some GPs still cling to some mechanism for direct contact by hanging around the surgeons' lounge, which is also a kind of local marketplace. His comment, "[i]f I ever get slow on consultations, I just got there..." (p. 10) suggests one reason why most other specialists avoid it - they may feel that it is undignified to be seen soliciting referral.

15. Specialist 8, who had done his residency at a core-city hospital, commented that "certainly you didn't see as many GPs coming down to see the patients there" (Int. #2, p. 7) as at this particular hospital. He thought that this might be because the core hospital handles more out-of-town cases and also because "there are more full-fledged university people [there] who have on-site offices and they tend to be lower volume" (p. 8). It might be predicted that the more a hospital functions as a tertiary care centre, the less "community" and the greater "communication gap" between GP and consultant.

16. GP 12 commented that the surgeons' lounge was "comforting" - a place to call for an urgent referral (Int. #2, p. 8). But he called this process "serendipitous", since doctors seldom remember who has been referred, let alone the details of cases, after a few days. Orthopod 17 agreed that only a few local GPs used the lounge in his hospital, and since the conversation typically didn't focus on referrals, he thought it was questionable whether it could be used as a forum for communication.

17. Ethnic GPs are not unaware of these problems. As GP 5 commented, "I get complaints from the surgeons and I really think you should do everything you can to help them because otherwise it's ridiculous. It's a real disadvantage...but sometimes I forget - like [one patient I referred] who doesn't speak a damn word of English. Somehow or other, she was supposed to come here and get all the information, and she never came and never picked up any letters and she went to see this doctor and it was <u>terrible</u>!" (p. 12). Of another case, he remarked, "I wanted to talk to him about it...but I didn't have any data to send him. And the next thing you know, I go away on Friday or something and he sees her that day and it ended up as a schmozzle. The patient thought he was crazy and I think the doctor thinks I was a little nuts" (p. 11).

18. Patients 34, 36 and 39 from northwestern Ontario also all spoke warmly of the nursing staff in their small local hospitals, who

offset the social distance with physicians to some extent. Patient 36, for example, explained that it was "really good" to have a friend of hers who is a nurse be with her when she came out of a D. and C. (Int. #1, p. 14). This patient also recalled that when she was being induced in pregnancy, she "drove the nurses nuts...with questions, because [she] was so worried" and that "two of the nurses there spent a lot of time with me and explained a lot of stuff to me about being induced" (Int. #3, p. 13). The "coziness" of the small-town hospital was felt to be particularly important in native hospitals, where native patients are comfortable asking questions in their own language (Surgeon 36, p. 10). Radiologist 36, who visits this hospital, said that it was the type of place where "I'll be in recording and some little kids will come in and sit down and say, what's that? and I'll say, it's a heart, and I'll talk about it" (p. 14). This is in striking contrast to a big-city radiologist that Patient 37 met, who "could care less about the baby - he didn't know if it was a boy or a girl" (p. 6).

19. The interactionist literature provides some evidence that patients are able to ferret out information even under the most difficult situations in hospital and that they may actually "negotiate" with a physician around diagnosis and treatment despite their position of relative powerlessness (Skipper & Leonard, 1965; Glaser & Strauss, 1965; Roth, 1963). Haug (1969; 1981) has more recently detected a "consumer" stance among some patients and she, with Freidson, advocates a more collective movement to challenge the authority of the physician. Roter (1977) and Lazare et al. (1976) have tried to instruct patients to be more aggressive, and have observed that such patients tend to express more anger, anxiety and dissatisfaction during their interviews with the doctor. Lazare views this as a healthy situation which brings the conflict out into the open and allows for negotiation over the definition of the problem and thus potentially promises a better basis for developing trust in the physician . Pratt (1976), on the other hand, while supporting

these developments, fears that an adversary stance may have negative consequences for consumers who do not approach it judiciously.

20. The literature on death-telling illustrates the point that what doctors say they are telling the patient cannot be taken at face value. Glaser and Strauss reported in 1965 that the majority of physicians in their study preferred not to tell a patient of impending death. However, reviews of physicians' attitudes (e.g. Waitzkin & Stoeckle, 1976; McIntosh, 1974) suggest a split among practitioners on this issue. And a more recent survey suggests an abrupt change in professional attitudes towards telling the truth to terminal cancer patients. In 1961, a JAMA survey showed that 90 percent of those surveyed preferred not to confront such patients with the facts, while in 1979, 98 percent said that "it was generally their policy to tell cancer patients the truth about their condition" (p. 208). However, "the truth about their condition" may be considerably less than the whole truth. One of the only studies so far that has attempted to unravel what physicians say they have said to the patient <u>vs</u>. what the patient remembers, was done in 1959 by Aitken-Swan and Easson. They reported that when 231 patients were told that they had curable cancers, the large majority expressed gratitude about having been told. However, 19 percent denied having been told in a later carefully-conducted interview. Thus it is possible that, just as practitioners are more aware of doctor-patient communication issues, they are more aware of patient attitudes towards death-telling although they still do not put this knowledge into practice. The Aitkin-Swan and Easson results suggest that even if the physician <u>thinks</u> he told the patient, the patient may not have gotten the message.

21. Only if the patient is so informed is the signed, formal consent form valid, and, if not fully informed, the patient can sue the doctor for damages for any negative outcomes, including those beyond his control. A recent Saskatchewan Court of Appeal decision expanded the requirements around informed consent to

include the stipulation that the patient must be advised about alternative treatment. This stipulation was based on a case in which a man sued a surgeon successfully for negligence in not informing him of the alternatives after he became paralyzed as a result of an operation on an arthritic knee that was causing him only mild discomfort and which should have been left alone. Surgeon 18, as well as other surgeons, mentioned this case and indicated that proper "informed consent" was necessary in order to protect themselves from lawsuits, in addition to its usual humanitarian and decision-making purposes. This surgeon also uses the protective tactic of sending copies of his consult notes to the patient (p. 5), because this serves to remind the patient what was discussed, including decisions, in view of the research that shows that patients don't remember much of what doctors tell them. It makes sense from this orthopod's perspective to have things on paper - so that if it comes to it, he is protected - whether the patient speaks English or not (p. 2). Specialist 16 also referred to the importance of such "backup letters" in a dispute.

22. There is always a potential for contradictory information when the patient sees more than one doctor for a problem. Patient 32, for example, tells of going to a doctor who was covering for her GP while he was away, who took her blood pressure and instructed her, "you don't need to be on blood pressure pills!" When she checked with her GP, he told her that she would have to stay on them (p. 9). There is also a good chance a single doctor will give contradictory advice at different times. As Patient 31 commented about her orthopod, "I don't like [him because] he changes his story so much. You don't know what to believe. First it was nothing, then it was something" (Int. #1, p. 27). In addition, GP 40 thought that patients who travel across the border to American specialists were in the worst situation, because they see multiple specialists and "no one person tells the patient what's happening" so that "patients can come away with the most appalling muddles" (Int. #1, pp. 4-5).

CHAPTER TEN

COMPLIANCE AND CLOSURE

I. INTRODUCTION

Consistent with the emphasis in this thesis on patient as well as physician participation in referral, this chapter examines the "outcome" of the process from the point of view of the patient as well as the physician. Since virtually all referrals in this study had unclear outcomes, the central issues dealt with here are why referrals tend to have ill-defined closures, why patients and referring doctors fail to follow the advice of their consultants and what consequences may follow when a referral is assessed by the participants as "not useful".

1. Compliance and Closure: The Approach in the Literature

In theoretical or normative clinical discussions about referral, there is typically an assumption that the specialist gives good advice which

is then put into practice by the GP and patient. Barnett and Collins (1977) would take this one step further by suggesting that it is up to the GP to "facilitate the patient's and the patient's family's acceptance of the consultant's recommendations" (p. 666) and to feed back relevant information to the consultant. Such discussions fail to address the evidence that most patients do not return to the GP to report the outcome of the consultation directly.[1] Neither do they question the value of the advice to the GP and patient.

Further, the majority of studies on the outcome of consultations focus on inpatient referrals from internists to other specialists within hospitals, rather than on referral from primary care practitioners. Typically, they examine the patients' charts for evidence, discover that the compliance of the referring doctor with the consultant's recommendations is not high, and then declare that this indicates the ineffectiveness of consultation, probably linked to some characteristic of how the advice is given (e.g. its length, centrality).[2] Among these studies, a thoughtful one by Horowitz et al. (1983), although still relying on simple quantification, suggests that the lack of attention of referring

doctors to recommendations may be largely unintentional, based on their inability to understand the recommendations or implement them in time.[3]

Two more sophisticated investigations have rejected the chart review method used by most studies and have tried to identify the factors that lead to breakdowns in the consultation process by following cases prospectively and interviewing participants. A study by Lee et al. (1983) of 156 referrals at the Brigham and Women's Hospital found that in 20 percent of cases, there was a substantial disagreement between the doctors on the reason for the referral or the diagnosis, and these referrals were rated as less useful than the others. The two parties also disagreed about the usefulness of the consult in two-thirds of cases, with the consultant tending to give higher ratings, while the researcher consistently "underestimate[d] the value of the consultation" (p. 109). In their discussion, the researchers critique studies that assume that "non-compliance" is due to not reading the consultant's note, since they found that "breakdowns can occur much earlier in the process" (p. 111). Specifically, they identify tensions between referring physicians who work up cases on their own, referring only at the last moment, and consultants, who

would like earlier referrals, noting that referring doctors find the latter cases less useful.

A similar study in Britain, in which questionnaires were sent to all three parties in 306 referrals, found agreement on the reason for referral in only one-third of cases (Grace & Armstrong, 1986). Bringing together the observations that GPs do not send referral letters because they don't want to "second-guess" the consultant, and that consultants are not interested in the GP's reasons for referral, they argue that if there is no consensus on the reason for the engagement, it will be limited in usefulness. The researchers are unable to understand why the process of referral does not break down in the face of such misunderstanding.

2. A More Comprehensive View of Compliance and Closure

In this research, there has been an attempt to develop a more comprehensive view of referral by taking the patient's participation into account. In terms of compliance and closure, it does not make sense to focus only on whether the referring doctor "complies" with the consultant's advice if the patient does not return

to him or her. In outpatient referral, the patient is the person who chooses to follow or not to follow the consultant's advice, not the doctor. Thus, in this chapter, the unsatisfactory "open-ended" nature of consultation is viewed from the perspectives of both doctor and patient. In contrast to other studies in the literature, the outcomes of the actual cases and their consequences for future care-seeking are examined.

Typically, participants were not aware of the "open-ended" characteristic of referrals and revealed confusion about how to interpret what happened when they were asked to review and assess the outcome of their case.[4] Many referring GPs, like their patients, simply "lost track" of the referral, passively failing to monitor its course or influence the outcome. Even the substantial minority of patients and referring doctors who attempted to participate more fully in the process by selective or non-compliance appeared to be "carried along" by events, despite and sometimes through their attempts to participate. A third group of patients, with or without the support of their doctors, continued to actively seek treatment after unsuccessful experiences, in the way that Balint (1957) has described.

In the previous chapter, the failure of referring doctors in urban settings to communicate directly with their consultants was set in the context of their isolation from the hospital and linked to a lack of mutual respect and breakdowns in the coordination of the referral. In following up cases of referral in this study, it was found that referring doctors often assumed an "attitude of everyday life" (Berger & Luckmann, 1967), imagining that the referral had proceded smoothly on its own, with the patient as the consultant's informant. Typically, they were not fully aware of its outcome. This happened even when the patient had been back in their office since seeing the specialist and even if a letter from the consultant had been filed in the chart. When this lack of monitoring was combined with a tendency for some patients to passively allow the specialist to define the situation, the result was the scenario of the "powerless" patient, which has been described so vividly by sociologists in hospital settings (F. Davis, 1963; Roth, 1963; Duff & Hollingshead, 1968; de Beauvoir, 1969; Hoffman, 1974).

By way of contrast, a "militant minority" of both experienced reierring doctors[5] and patients[6] knowledgeable about the process of care reported some success in controlling their medical "careers" by

selective or non-compliance with the consultant's recommendations. The important question raised by these findings is, did the participation of these patients in their care make any difference to the eventual outcome of the process? That is, did referrers and patients who participated in their care find treatment that "worked" or were they better able to accept a conclusion that medical science could do little to address their problems? Examination of outcomes, detailed below, suggests that participation usually did not make a difference. In most cases, in spite of participation, there was either dissatisfaction or a tendency towards "serendipity", in which both patient and physician "lost track" of events, and did not really know what had been the outcome of the process.

Further, unhappy patients - about a third of those in this study - appeared unable to accept the evidence that "nothing could be done", and continued to look for additional practitioners or treatments over a number of encounters, which might stretch into years. This process, first described by Balint in England (1957), involves multiple referral or direct contact by the patient with multiple specialists, none of whom give him or her satisfaction. According to Balint, no one involved in these open-ended and unsatisfactory

sequences is willing to take responsibility for treatment, in a "collusion of anonymity". In most cases, no one has gained the trust of the patient to convince him or her that nothing can be done and that the cycles are futile.

II. "LOSING TRACK"

1. The "Open-Ended" Outcome

A number of physicians saw the question of when the consultant should hand the case back to the GP as problematic. GP 8, for example, commenting on the disengagement of referral, admitted that he "never understood how this worked" (Int. #2, p. 3). He thought that more experienced GPs, in keeping with their wish to maintain more responsibility for cases, would like patients to be returned more quickly, although "different consultants do things differently". He rationalized that the length of time that a consultant kept a case was mainly related to the number of tests done, because there is a waiting period for results, and the patient must be called back to be informed about them (p. 3).

Retired GP 23 complained that since the number of tests has been increasing, the "wait" for the GP to

have the patient back has also increased. Further, the multiplication of tests tends to result in less definitive rather than more definitive answers about what is wrong. The specialist may thus keep bringing a patient back because the referral has dissipated into an unsatisfactory, open-ended series of investigations in a completely unnecessary series of visits (p. 16).

Patients also sometimes report confusion about when to go back to the referring doctor. Patient 9, for example, felt that he was "cut off" in the fourth and last session with his cardiologist when he was told to come back in six months (Int. #2, p. 11). GP 7 added that part of the interest in seeing the patient again is curiosity on the part of the consultant to "see how it all turns out". But, he adds, "it [doesn't] hurt to charge either" (Int. #1, p. 4). As pointed out in Chapter 5 (in the section on "Dredging", pp. 204-209), in such situations, it is to everyone's benefit to prolong the series of encounters.

In addition to these practical considerations, open-endedness clearly was a consequence of the "wait-and-see" approach adopted by physicians in this study, described in Chapter 8.[7] For example, Patient 36 had "lived with the pain" of her stomach problem for many years (Int. #1, p. 1) but recently had numerous

investigations of her GI tract. She expressed disappointment that her surgeon kept hesitating to perform surgery during this time (Int. #2, p. 1), by telling her that she was just "going to have to live with it" (p. 7). He explained that he was delaying until it was absolutely necessary, partly because he knew that there was a good chance that surgery would not solve her problems (p. 3). The GP had instructed the patient to pressure the surgeon into a decision because the medications she was on were not controlling the pain (p. 5), but the GP recognized that this "referral" would continue indefinitely, even after surgery, since there would be no "miracle cure" (Int. #2, p. 2).

2. Failure to Monitor the Referral

In the previous chapter, it was reported that most urban GPs in this study thought that there was no need to send a note in routine referrals where a problem should be obvious to the consultant. Even family practice residents, who usually sent referral letters, drew the line at ENT or ophthalmology consults or requests to look at a skin rash (Receptionist 2, pp. 11-12). As GP 12 wondered, "[d]o I need to tell the

orthopod that this man has sore feet?" He argued that the need for communication was less pressing when you could trust the consultant to proceed. This view was also expressed by GP 38, who argued that "even when there is a communication breakdown, it makes no difference in the long run" (Int. #2, p. 5). Furthermore, the practical considerations of everyday medicine just do not allow closer monitoring, and it is inevitable that the GP will lose track of cases when they are referred (GP 12, Int. #2, p. 13).[8]

In keeping with this philosophy, GP 12 had not read the consultation notes from Specialists 12 and 13 a couple of months after their referrals and appeared to have "lost track" of these cases. Neither case was a "dump",[9] in the sense that the GP had worked up both cases for months before referring them. For example, before her referral in January, he had X-rayed Patient 13's arthritic hands, and had given her an arthritic drug in the late Fall and another series at Christmas that did not control the swelling (Pat. 13, Int. #1, p. 1). However, these patients did not return to brief the GP about their referrals, although the specialists had advised them to do so and had indicated that the referrals were at an end (e.g. Pat. 13, Int. #2, pp. 2, 6). When asked to comment on the consult letters, the

GP read them for the first time, since they had been filed in the charts without him seeing them. He judged that the answers from consultants in both cases were inconclusive, and suspected that they were "snowing" him with verbiage. He had developed no plan for proceding beyond this point, shrugging his shoulders that nothing could probably be done anyway.

GP 14 also took this attitude in her referral of Patients 14 and 15 (Int. #1, p. 2) and she periodically lost track of what happened to her patients. Unlike GP 12, she attempted to keep in touch with these patients and they called regularly to check the specialist's advice with her (e.g. Pat. 15, Int. #2, p. 5). However, like the cases of Patients 12 and 13, her referrals also "petered out", with no clear point of disengagement. With Patient 14, the birth of a healthy baby appeared to be an end point, but even then, it was not clear which doctor was supposed to be deciding when the patient could be discharged from hospital.

Even where communication takes place between referring doctor and consultant, often the doctors "lose track" of what each has done or said. For example, when Respirologist 29 referred Patient 29 to a surgeon for a lung biopsy, the surgeon called the

respirologist back to tell him that he had discussed the options with the patient. However, the patient told the respirologist that the surgeon had instructed him to phone the respirologist about what to do (p. 15). In this case, the respirologist felt that the GP should help the patient make the decision about whether to have the biopsy, but the GP was on holidays, and had not yet seen the surgeon's note (p. 9). None of the three doctors involved were fully aware of what was going on, although they assumed that events were proceding smoothly.

Physicians were aware that patients also "lose track" of their medical advice in the same way that they lost track of cases. A few mentioned that return visits should be scheduled to determine whether the patient is taking his medications or other treatment properly (e.g. Cardiologist 8, Int. #2). However, few doctors saw themselves as policing compliance, tending either not to double-check what the patient was doing in terms of treatment or to let their vigilance on these matters slacken. It was also argued that if the pain is severe enough, the patient will comply on his or her own.[10] Conversely, if the condition is trivial, the patient may even fail to show up for the appointment with the consultant, as in the case of

Patient 10, who had a minor skin disorder. Her GP was not aware that the patient had not kept her appointment with the dermatologist (Int. #2, p. 2), but he emphasized that he cannot "babysit" his patients. He regretted the patient's lack of courtesy, but explained that since he "wasn't concerned about it being a serious problem in the first place...it slips your mind" (p. 2). Specialist 31 agreed that compliance with dermatological recommendations was probably very low because these disorders are not life-threatening (p. 16). Occasionally, however, the patient may fail to define the problem as seriously as the physician - as in the case of Patient 35, who had missed appointments with her cardiologist (Cardiologist 35, p. 7).

3. The Contribution of the Patient's Passivity

The completely passive, compliant patient was rare in this study. Patient 8, who, by his report and those of his wife and doctors, follows orders to the letter, may be exceptional in compliance because he was warned by his GP that he would die if he did not. However, a number of other patients embarked on lengthy, invasive and possibly unjustifed courses of treatment that they did not seriously question.

For example, the doctors of Patient 1, in whom a low hemoglobin reading was detected in a routine test, became concerned about the possibility of gastrointestinal cancer, and initiated a series of painful GI investigations. The patient knew that his drinking was implicated in his "stomach problems" and reduced his alcohol consumption voluntarily during "treatment" with a very costly drug. The small stomach ulcers that were detected by a gastroenterologist healed within a few weeks, probably due to the cessation of drinking, rather than "treatment", as his doctors admitted. What are the chances that this man will stay "healed"? His GP admits that "his drinking problem is longstanding" and that his ulcers, therefore, are "likely to wax and wane" (Int. #2, p. 2). The patient, while protesting the "treatment", failed to question whether it was completely necessary, given the link between his drinking and the ulcers. Most other sequences of investigations initiated by doctors in this study did not culminate in even temporary relief of problems for the patients who suffered through them. Patients 12 and 13 let themselves be carried along by events with no changes in their conditions. After two months, five appointments, four different drugs and several invasive

tests, Patient 12's diarrhea (or "flu" as he called it) was no better, and his GP, reading through the correspondence from the specialists the man had seen, pronounced the interventions unhelpful. "I would like to know whether he could be labelled or whether he should be labelled as an ulcerative colitis...if it's possible to say that", the GP complained (Int. #2, p. 6). The man thought that "nobody" really knew what he had and that the effects of his medications were inconsistent (Int. #3, p. 6). He admitted that he couldn't tell if the diarrhea was getting better or worse and suggested that "when I die, and they do an autopsy, maybe they'll find out" (p. 7). His wife thought that all his treatment was a waste of time, but the patient thought that the diet that had been given to him by the specialist, at least, was useful (p. 8). Although a gastroenterologist had spent a great deal of time telling the patient how his GI tract worked, he had no idea that his doctors were worried that he might have the serious debilitating disease, colitis, nor did he realize that the "cause" of this disease is "stress".

Patient 13, whose GP similarly remarked that her trips to the rheumatologist had been largely unnecessary and unhelpful, gave the specialist whom she

had seen the benefit of the doubt, although there was little improvement. She did not even realize that she had been diagnosed as having "fibrositis", which is the rheumatological equivalent of "housewife's syndrome" (or what the GP calls a "garbage can diagnosis" - Int. #2, p. 3), and that she had been put on a sedative. Like Patient 12, she was "drifting away" from medical treatment, hoping that the "nice weather" of spring might improve her condition (Int. #2, p. 2).

For Patient 16, medical investigation not only did not help, but actually magnified the man's complaint out of proportion and left him seriously disturbed about his "problem". This patient was not originally concerned that his chest pain might have anything to do with his heart. In fact, he called his GP and waited a few hours because he did not think that his illness warranted a visit to the Emergency Room. He was shocked at the diagnosis of heart attack that was finally made, and confused by multiple subsequent investigations, which have been contradictory. His doctors now believe that he did not have a heart attack, and that his concern about his heart is something that is "all in his head" (GP 16, Int. #2, p. 1). The heart specialist quickly divested himself of this uninteresting case, and the GP now believes that

the problem is "tension" due to the man's "stormy marriage". As in the case of Patient 28,[11] there is no real closure to the referral. Patient 16 remains confused about his condition and fearful that he may have a psychiatric problem. However, he is not overtly critical of his physicians for their equivocation on his problem and indicates that he would be ready to trust a physician again when the occasion arises.

III. THE FATE OF PARTICIPATING REFERRERS AND PATIENTS

1. The Influence of Referring Doctors on Outcome

As concluded in Chapter 8, referring doctors have more or less control over consultation depending upon the context of care. In the urban situation, except for a "militant minority", referring doctors are excluded from direct participation by practical and other considerations. This context is the setting for the process of "losing track" described above. However, it might be asked how much influence was exerted by referring doctors who are more experienced and more skeptical of the value of the consultant's advice, who claimed that they referred less, were very particular about which consultant they chose, and were selectively

compliant with the advice they received from consultants.[12]

The evidence in this thesis suggests that even "militant-minded" GPs were limited in how much control they could exert if they had inadvertently lost track or were not informed about what the specialist was doing,[13] or if the patient chose to follow the advice of the specialist even if the GP objected. The former tendency has been described above for the case of Patient 12, but there are also elements of the latter. Specifically, this patient showed no inclination to return to the GP, whom he saw as just a referring agent (Int. #2, p. 6). Similarly, GP 19 commented that even when a patient returned, she did not feel free to modify the consultant's orders, even when she disapproved of the treatment. For example, she dislikes a particular aspirin-caffeine-barbituate medication that is prescribed for migraine headaches, but she sometimes cannot convince the patient to discontinue it. "I don't feel I should be prescribing it", she says, "but I feel tied into it" (Int. #1, p. 8). She adds that, "if I feel uncomfortable with them on the drugs, I should take them off completely, although...if they're feeling so much better on it, I am just careful on the amounts" (p. 8).

2. Patients' Claims about Influencing Events

Since the patient appears to "hold more cards" than the referring doctor, what can be said about the patient's influence on the outcome of referral?[14] Few patients in this study returned to "check out" advice with their GP. Instead, many claimed that, on their own, they were able to exert control by selective and non-compliance with specialists' advice.[15] The elderly Patient 29, for example, with a long history of thyroid illness, rejected the suggestion of a specialist that a lung biopsy be done when he became ill thousands of miles from home. Instead he exerted an effort to keep on top of the situation:

> I love that if somebody like that jumps on me. I just reach down and hone my spurs right there. And we had at it. I said, OK, Charlie, you want to be hard-nosed. I can get hard-nosed too... So...all of a sudden, he soft-pedalled it down.
>
> (Int. #1, p. 2)

An elderly native patient indicated that she handles these situations in a more passive-aggressive way. For example, she remarked that if she "had to go for an operation, I don't think I would do it" (p. 8). Patient 37 reported a similar reticence to confront the doctor but commitment to taking responsibility for her own care, commenting that "common sense" is needed in

listening to doctors' advice. For example, when told to "triple-diaper" or to give her baby Tylenol after a vaccination, she reports that she says, "oh, sure, fine", but then does not comply in the better interests of the baby. "I know my baby more than any doctor! They're just technicians as far as I'm concerned", she explains (Int. #1, pp. 4-5). Patient 39 agreed that she would only do "whatever's best for my baby" (Int. #1, p. 8).

Patients often reported that the doctor had been unable to convince them of the usefulness of a particular treatment and that they rejected it for that reason. Both Patients 14 and 15, for example, refused to take iron pills prescribed during pregnancy, because they did not believe that they needed them (Pat. 14, Int. #2, p. 9; Pat. 15, Int. #1, p. 12). When Patient 14's GP suggested that she take Metamucil to counteract the side effect of constipation with the iron pills, she decided it would be more effective to cut down the iron. Neither does she drink four glasses of milk a day as suggested by the GP (p. 10), since she feels that she is getting enough calcium. This woman quips that the GP probably didn't drink milk and take iron pills when she was pregnant either, although she must direct her patients to do so. Further, when different doctors

give contradictory advice on how much weight to gain during pregnancy, patients begin to question which ideas are correct (p. 12). Patient 15, who was bleeding during pregnancy, said that it was unreasonable to instruct her to stay still all the time, and she did not believe that her doctors would be upset to hear that she did not comply with this advice (Int. #2, p. 2).

It has been argued in this thesis that the key component in deciding to follow medical advice is trust of the advisor. It follows that if the patient's distrust is aroused, the advice will be taken "with a grain of salt". One patient who learned to be suspicious during the study was a pregnant woman who almost died as a result of misdiagnosis of ruptured appendix as a bladder infection. Although the GP ultimately called this outcome a "tragic, sort of bad-luck situation" (Int. #2, p. 2), the patient blamed herself for trusting the doctor:

> I know my own body, and most people do except a lot of people don't want to take the responsibility of it. I know what I'm feeling and (lowers voice) really, I think I should kick myself in the ass for what happened...I should have known, I <u>knew</u> - I mean, I felt so lousy that I accepted exactly what he said... (Pat. 39, Int. #3, p. 11)

In this case, the GP thought, incorrectly, that the patient had forgiven him and that "not a lot [had] changed" in their relationship (Int. #2, p. 9). The patient, on the other hand, reported that although she had not confronted the doctor on this point, she would never trust him again.

Other patients who approached doctors with "guarded trust"[16] either did not raise this issue or tried only at a much later date to confront them. Patient 25, for example, had not told her GP of her disappointment in his failure to interpret a pregnancy test, but, urged by her mother, went ahead and took another, which prompted her to pressure for a referral to a specialist.[17] Patient 26 "never doubted" a previous GP who had found a breast lump on his first examination of her. When she was having trouble conceiving, she says that her "brakes" finally went on when he suggested a sex therapist. She claims that she has been more cautious ever since, although she has had a hysterectomy and ovarectomy, and now suspects that there are "growths on [her] bowel". For her current problem, ear pain, she laughs about the fact that a medical student in her GP's practice looked in her ear, and went out to consult with her GP, who then looked in her <u>other</u> ear, and said "I see it". She doubted that

her GP is competent to handle this problem and pressured for a referral to a specialist to check her ear.

Although she did not report the lack of trust described by other patients, Patient 13 took some initiative in her own care by cutting back on the medication that she had been prescribed without informing anyone, because she felt it was too strong (Int. #2, pp. 2-4).[18] Patient 12, similarly adjusted his pills: "I took them for a couple of days. And then I went off them. I've been off them for three days, just checking to see what's going on. I think I'll just stay off them", he said (Int. #3, p. 5). Patient 40 says that this is his general rule of thumb: "I figure if the pills are not doing me no good, or after I'm better, I stop" (Int. #1, p. 14). Patient 9, a man who diagnosed his own heart condition by taking a friend's nitro during an angina attack, also modified his doctor's orders to suit his lifestyle. For example, he doesn't take his medication as prescribed because he experienced some difficulty after taking it at work (Int. #1, pp. 13-14). Further, although he has received no specific instruction from his doctors on diet, he has purchased a cookbook with low-cholesterol recipes, and checks his physicians' orders regularly with his

friends. He attributes his suspicion of physician advice to watching a friend die in cancer treatment under peculiar circumstances (pp. 18-20). Patient 32 showed her swollen breast to a daughter-in-law who'd also had a breast operation when she felt that her doctors were not monitoring her recovery properly. When the daughter looked at the breast and suggested that it was infected, the patient approached her GP and surgeon and demanded that they give it some attention (p. 2).

3. Evidence of Patient Influence on Outcome

In the clinical literature, the patient's participation in medical treatment is termed "compliance", emphasizing submission to the expertise of the doctor. By labelling participation in this way, the assumption is made that deviation from compliance is unjustified, and investigation of the process of the patient's participation in care is cut short. In this research, when the patient's participation in care was traced, it was found that patients' attempts to carry out advice were sometimes compromised by the incomplete or contradictory advice they received. Futher, their selective compliance was often justifiably based on a distrust of the prescribing physician. Finally, where

patients attempted to reject treatment, the rejection appeared reasonable, even when it was considered by their physicians.

Unfortunately, despite the attempts made by patients in this study to participate in their health care, there was little evidence that the outcome of their cases was improved as a result. It might be argued that medicine can do little for patients with serious GI disorders, rheumatological problems, cancer, back problems, irregularities of pregnancy, respiratory deterioration, and numerous other difficulties. However, the "open-endedness" did not appear to relate to the limitations of medicine as much as to a failure to systematically follow and finish the business of the referral. A referral might be considered successful even if the outcome was that the patient was assured that nothing could be done for the condition, but patients seldom reached this point of closure. Whether they reacted passively or aggressively, their treatment tended to "peter out" after a series of unsuccessful interventions. Just like their more passive counterparts, "active" participants, too, were "carried along by events", without really being helped by medical interventions.

a. Unintentional Non-Compliance

In the previous chapter, breakdowns of communication between patient and doctor were traced to both unintentional lapses between the two as well as to intentional information control by the doctor. Whatever the dynamics of the breakdown, as Svarstad (1974) has demonstrated, the patient, based on inadequate information, may inadvertently fail to carry out the doctor's advice, even if willing to do so. Physicians were aware of this problem, although they tended to attribute it to the patient's deliberate decision not to comply rather than a lack of knowledge about, for example, how medications work.[19]

Patients in this study displayed unintentional non-compliance when they received incomplete as well contradictory information from different sources. Patients 8 and 9, for example, complained that their GP had not given them specific instructions on diet for patients with heart problems, although the GP claimed, on the contrary, that he has very strong views about informing the patient. The GP insisted that instruction on diet must be very specific (Int. #2, p. 7) and given forcefully, preferrably in written form (p. 10). A "girl" in his office is a "diet specialist" and

patients are routinely sent for their "lipid profiles". Why, then, do Patients 8 and 9 claim they were not informed? The GP suggested that he gave them minimal instructions, which they can't recall, although there is no record of this in their charts. He believes that he may also have decided that, in the their cases, that the "cure" of diet restrictions was more severe than the "disease". Thus although these patients had obtained written material on diet from the specialists and friends, the GP probably gave them the message that they need not be overly concerned about following advice on diet.

Patients also reported confusion when they were asked to make "judgement calls" in deciding to take medication. Patient 12, for example, was instructed to "go back on [a particular medication] depending on how bad it is". He was given the heavily-qualified instructions that if he felt good to the point where he was "picking up energy", but was not sure about it and was still having diarrhea, but "just a bit", he should avoid the medication (Int. #3, p. 4). He eventually stopped taking the drugs even though he felt bad, without asking for help in making a decision, because he'd "rather not take the pills anyways" in case they make him sleepy at work (p. 5).

Even patients who reported that they trusted their physicians, understood the treatment prescribed, and wished to be compliant, reported occasional lapses. Patient 18, for example, said that he was careful to take the coated aspirin that has been prescribed for his heart condition - "[i]f I'm told to do something, I will", he declared (Int. #1, p. 22). However, he was embarrassed to admit that he had gone up a ladder to clean out the eavestroughs after being told by the orthopod who replaced his hip to restrict his activity (p. 9). Further, he reports some difficulty in complying with diet restrictions for his diabetes (p. 12) as did Patient 35 (Int. #1, p. 6). Patient 18 finally quit smoking, not in compliance with doctors' orders, but out of fear after waking up one morning unable to breathe (p. 16). Patient 2 similarly found it difficult to cut down his smoking, commenting "I was told to stop around [19]45 and I'm slowing down" (Int. #4, p. 2). In addition, he failed to take his respiratory inhalers regularly, even though he reported being willing to comply. Patient 9, who modified the activity, drug and smoking orders that were given to him (Int. #1, pp. 12-13), theorized in this way about his behaviour:

> [I]t's the same thing as you buying something at the store. And looking at

> the directions after you've bought it. And saying, oh, shit, and not following the directions. It's the same thing ...it's human nature...You think you can do these things without somebody telling you what to do. And invariably you screw it up. And then you go back and read the directions and say, I shoulda done that in the first place. (Int. #1, p. 16)

Since there is no "label" to remind patients of instructions given by physicians, they tend to distort or forget it over time. However, even with written instructions, patients made mistakes, as Patient 12 said he had done by failing to read the directions for taking a laxative in preparation for a barium enema (Int. #3, p. 4).

Patients were aware of such lapses, and a few had bought pill dispensers with a number of tracks of different colors to arrange dosages and times for medications (Pat. 35, Int. #1, p. 4; Pat. 41, Int. #1, p. 9). Patient 36 kept her valium and blood pressure medication beside her toothbrush, so that she would be less likely to forget it. However, she expressed concern about her image of herself as a "pill-popper" and about the possibility of getting a "bad pill" that might kill her (Int. #2, p. 9). These attitudes towards taking medications were widely recognized by physicians (e.g. Cardiologist 35, p. 14), but no one mentioned talking to patients about their fears.

b. Selective Compliance and its Consequences

Like patients who unintentionally fail to follow medical advice, patients who pick and choose among the advice offered by their doctors typically end up providing an inconsistent potpourri for themselves in which no one seems really to know what is going on. In the case of Patient 27, for example, who insisted that she takes full responsibility for deciding when and how to take medication for her fatal rheumatological disorder, the doctors involved didn't know just how many pills she was taking. After a drug reaction several years ago, this patient said that she would follow a doctor's advice only "up to a point" (Int. #1, p. 13). When she was prescribed a dangerous medication, Plaquenil, she reports that she discontinued it "when I felt I no longer needed it" (p. 13). She also thought that it was "horrendous" to take six Naproxen per day, another prescribed drug to control swelling, and so "told the doctors" that she "would take one a day". She actually varies her dosage from "less than four" to eight depending on her assessment of the swelling (p. 15). The specialist in Toronto who monitors her condition annually claimed that he directs the amount of medication that she

takes. However, letters in her chart show that a specialist in northwestern Ontario who saw her when she was supposed to be taking five Plaquenil per week, actually found out that she was taking one "every fifth day", which was too low a dosage to have any effect. Further, an ophthalmologist who was supposed to be monitoring any negative effects of the drug had not been notified that it had been discontinued, and was angry that the patient had not kept her appointments with him. The patient believes that her disease is in remission because of her "mind over matter" approach to keeping her illness under control, but neither her GP nor specialist put much stock in her beliefs, calling them part of a "copper bracelet syndrome".

Patient 19's doctors appeared to be similarly in the dark about what she was doing about her "treatment". Although she was given a prescription for iron pills after seeing a gynecologist, she didn't think seriously of filling the prescription until she felt "crummy", and got her husband to purchase the $38 pills (Int. #2, pp. 10-11). However, in the process of taking them, she believes that she had a drug reaction (Int. #3, p. 1). When she discontinued them, she felt better, and then "draggy" and nauseous when she started them again (p. 2). She thought that it was "ludicrous"

to take both ferrous sulphate prescribed by her GP as well as iron pills prescribed by the gynecologist (p. 3), but did not try to sort this problem out with her GP, who was moving that week (p. 5). In the meantime, she experimented by discontinuting the ferrous sulphate and taking the iron pills and an anti-inflammatory drug prescribed by a rheumatologist. Her rationale for the experimenting was that, "I'm not going to know which one it is if I take them together " (p. 4). However, her experimental technique was inconsistent, because she stopped taking the anti-inflammatory drug when her husband discontinued it because he believes he had a drug reaction (p. 7). Finally admitting that she doesn't know whether she feels bad because of drug reactions or her original complaint (whatever it is), she blames the doctors: "They just throw it at you and expect you to take all that garbage!" (p. 10) In her case, as well as that of Patient 27, no one really knows "what is going on".

c. Rejection of Treatment and its Consequences

Patients who decide that they do not want treatment do not fare any better than those who decide that they do. Patient 29, for example, who had tried to

avoid a dangerous lung biopsy by stalling, began to lose control when his GP referred him to a respirologist and then went on holidays. The respirologist referred the man to a surgeon, who booked the biopsy despite the fact that the man had not had a chance to discuss his preferences with his GP. Two months after the original referral, the GP admitted that the biopsy wouldn't necessarily establish diagnosis. Further, he thought it was "one of those Catch-22 situations where you don't have a diagnosis, but it may not change things...It may not be worth going through" (Int. #2, p. 2). He suggested that a trial of steroids might be attempted before the biopsy, but pointed out that in some cases, his knowledge of the situation is not sufficient to give the patient good advice, so that he must leave things up to the surgeon. The respirologist thought that the man's diagnosis was fibrosis and was not likely to be treatable (p. 5), but he'd been booked for the surgery anyhow. The patient declared triumphantly that he was "one step ahead of them" because they hadn't got him "on the operating table" yet (Int. #2, p. 5). He reassured himself with the thought that patients no longer bleed to death with appendectomies or tonsillectomies, but feared that "things are going to

move very quickly" once the results of testing were in (pp. 6-7). Because of the man's hesitation, his doctors offered a less dangerous type of biopsy which does not involve cutting open the lung, but this had been downplayed, since "the gold standard for diagnosis is an open-lung biopsy" (p. 7).

IV. SEEKING FURTHER TREATMENT

So far, examples have been described that illustrate the point that patients who attempt to influence the course of their care fare no better than those who passively submit. After a series of unhelpful interventions, such patients either "drift away" from treatment or actively sabotage or circumvent it.

A third category of patients react by refusing to accept that medical science can do nothing for them, and continue, unhappily, to seek out other doctors and treatments repetitively. The elderly Patient 3, for example, has developed a routine of visiting the GP weekly and requesting referrals at least monthly. Although not serious, she feels that her problems cannot be dealt with by the family medicine residents that she meets in the clinic, and regularly demands to see more experienced doctors. Like Patient 1, she fails

to comply with advice given by the young residents because she doubts the competence of the prescriber (GP 3, Int. #1, p. 2).

Patient 26 also continues to seek treatment, but for a problem about which, despite her pressure on her physicians, they have been unable to advise her. She began to feel pain in her ears on exposure to sound in early June, and waited unhappily for an August referral to an ENT specialist. Because the problem was so severe, in the interim, she tried to get an earlier appointment, checked with another GP and went to the Emergency Department complaining that something had to be done. The result of this activity was no change in her appointment date with the specialist, and a bottle of allergy medicine which the second GP gave her. When Patient 26 finally got to see the specialist, he complained that whatever was wrong, it didn't lie in the area of surgery, which was his specialty (p. 4). After her visit with him, as described in Chapter 8 (pp. 54-5), the patient expressed frustration about being "no further ahead" (Int. #3, p. 1) because she was handed back to her GP. When she finally gave up and failed to contact her GP after the referral, he suspected that she was unhappy, but wasn't sure, noting that "she comes in with different levels of anxiety at

different times" (Int. #2, p. 4). The patient's fear that her GP believes that she is neurotic appears to be well-founded, although he insists that he is willing to offer more referrals if this is what the patient wants (p. 5).[20]

Patient 32, who had breast cysts removed twice, was also unhappy about the outcome of her breast surgery. She had taken the initiative by checking with a relative to determine that it was not healing properly, but both GP and surgeon had dismissed her concerns with the attempted reassurance that it was "alright - don't worry about it" (Int. #1, p. 2). When she expressed further concern about chest pain she was experiencing, the surgeon dismissed it as a "flu bug".

The persistent patient may fail to trust the specialist after a history of contradictory and unhelpful treatments, but rather than withdrawing from care, may continue to seek satisfaction. Patient 31, for example, who had determined that cortisone shots are too painful a treatment for her skin disorder, was disappointed by a referral to a new dermatologist in town, the fourth doctor she had seen for this problem. The patient reported that she'd been given the "revolving door" treatment by the specialist, who'd told her that there was no alternative if she didn't

want cortisone shots. He'd prescribed a creme that she had no intention of using because, as she said, "I've used many cremes before and I think, oh, naw, not one more!" (Int. #2, p. 2). The GP hadn't realized that the consultation was unsuccessful, because the patient had not told him about it even though she had had the opportunity (Int. #2, p. 11). However, after examining the consult note, he agreed that the new specialist's advice wasn't "any more satisfactory than [what] we were working on" (Int. #2, p. 13).[21]

Far from accepting the opinion that nothing beyond cortisone could be offered her, though, the patient was secretly hoping that doctors at the Mayo Clinic, where she was referred for a knee problem, would take an interest in her skin disorder and give her more advice. "[Y]ou never want to hear that there's no hope", she concluded (Int. #2, p. 4). Her lack of faith in her doctors is so profound that she even doubts that she has diabetes as they have diagnosed and she hopes that they are wrong (Int. #1, p. 26). Her GP supports her decision to reject a knee operation from a local orthopod and to have doctors at the Mayo Clinic examine it (Int. #2, p. 9). The patient had opposed the orthopod's advice that she should ski after her knee injury (Int. #1, p. 17) and finally stopped treament

with him because she visited him for months with no improvement (p. 27). Of her general situation, the patient says that,

> for the rest of my life, I'll have to do what I want to do in order to survive...[I]t's always in the back of my mind that I'll have to struggle ...I'm a fighter.
> (Int. #1, pp. 10, 12)

Another patient who "would not give up" was Patient 30, who'd determined that she had a breast lump by reading her own radiograph and then demanded a referral a thousand miles away to a top surgeon. There she was "reassured" for the second time in two years that she had no problem. However, she reported afterwards that she still did not feel well (Int. #2, p. 2), and both GP and surgeon said that they expected to hear from her again.

The beginning of such a cycle can be seen in the case of Patient 33, a 16-year old who'd been told by an ophthalmologist that nothing could be done to improve her sight after an eye injury. She did not accept this prognosis, citing the miracles that medical science could perform. She was unhappy that she'd not had a chance to discuss her discontent with her GP, commenting that her parents were treating the whole problem cavalierly, "just thinking, well, we'll wait three to four months...not even questioning it" (Int.

#1, p. 11). She, on the other hand, hoped for a referral to another ophthalmologist, or a visit to one directly if her GP would not refer her.

V. SUMMARY

In summary, in this study of the referral of patients to specialists, most cases had an unsatisfactory, "open-ended" outcome. Doctors, like their patients, often "lost track" of what was going on by failing to monitor it, regardless of how much "medical science" might be able theoretically to contribute to the "cure" or "reassurance" of the patient. Although consultants were seen as failing to close cases because they were unable to interpret the meaning of their investigations or because of economic considerations or academic curiosity, another reason for consults that dragged on over time was that specialists were hesitant about applying radical treatment until all of the possibilities of conservative treatment had been exhausted. Inevitably, participants tended to lose track of what was going on. This process of serendipity tended to prevail even when GPs and their patients made serious attempts to monitor referrals. A question raised by these findings is

whether the numerous interventions suffered by patients who failed to question their necessity, were really justified.

It has consistently been argued in this thesis that most referring doctors have little opportunity to influence the course of referral, caught as they are between the power of their consultants and the agendas of their patients. Most patients in this study insisted that they actively participated in their care by deciding who they would and would not see and whether they would or would not comply with the treatment offered. Their reports of participation are at odds both with their physicians' accounts, and with much interactionist literature that describes the patient as helplessly caught in the social construction of illness built up by their doctors. Patients traced their "awakening" to negative experiences in which they learned to trust themselves rather than the doctors, and reported that they sometimes later learned to "take on" the doctors by direct confrontation.

A crucial question raised by these findings is whether the "outcome" of care-seeking was any more satisfactory for patients who reported a major role in their care than for patients who more passively allowed themselves to be carried along. Examples were given in

this chapter that show that both active and passive patients tended to get caught up in sequences of unpleasant interventions that gave them no relief from their problems or, occasionally, compounded them. Intentional and unintentional lapses in communication between doctors and patient triggered "unintentional non-compliance" with medical advice (Svarstad, 1974). Further, attempts by patients to pick and choose the advice that made sense to them often resulted in a nonsensical potpourri of treatment, where neither doctor nor patient understood what was going on.

The typical patient response in the face of the disintegration of care was to withdraw, but a number of patients refused to do this. They sought care further afield and resisted giving up hope that someone or something might eventually be able to help them.

NOTES

1. For example, half of the patients in the North Carolina Rockefeller study had not returned to see their referring physician by the time a letter had been sent by the consultant, one to two months after the visit (Williams et al., 1960). About one-quarter of these had only visited the GP once to get a referral, and so it was reasonable that they might not return, but as many physician-referred as patient-initiated cases failed to reach closure in this way (p. 1506).

2. In a study by Perlman et al. (1975), for example, when the records of 75 patients referred to the chest service of the Milwaukee County General Hospital by house staff were examined, it was found that of the 43 that involved therapeutic recommendations, 21 showed no change or a negative outcome a year to 18 months after the initial consultation. Of these, one-third were determined to be a result of disease severity, while errors and non-compliance of patient or doctor were claimed to account for the other two-thirds, although the authors felt that the recommendations were "appropriate" in 95 percent of cases. In a more recent investigation of 202 consultations requested of resident internists by surgeons (Sears & Charlson, 1983), overall compliance of the surgeons was 77 percent, with compliance decreasing markedly for cases with more than five recommendations. Compliance was greatest with medication recommendations but least where physician or nursing actions were required. The authors note that there were no relationships between their rating of the "soundness" of the recommendations, the "cordiality" of the service and compliance, and they leave the impression that referring physicians cannot read beyond five recommendations. A similar American study of 156 consultations by internists (Klein et al., 1983), showed that compliance was very low when advice was "suggested" (15 percent) vs. "definite" (60 percent) and, of the definite recommendations,

when a recommendation was "additional" (25 percent) as opposed to "central" (65 percent). As in the Charlson study, there was greater compliance with medication recommendations than medical management recommendations, but there was no analysis of why this might be so. A fourth quantitative study of 394 cardiology consultations (Mackenzie et al., 1981) also found that drug recommendations were followed more often than other recommendations (82 percent compared to 64 percent). An exception was a 70 percent noncompliance rate for beginning antihypertensive or antianginal drugs. This is consistent with the researchers' earlier finding that psychiatric advice around psychotropic medication was least likely to be followed (Popkin et al., 1980). They argue that the noncompliance is not linked to the status of the consultant, since there was similar compliance whether the consultant was a student, resident or staff member, and conclude that total compliance "would represent docile implementation without the exercise of careful clinical judgement" (p. 20).

3. In a cross-section of 250 referrals within the Yale-New Haven hospital, mostly from surgeons to internists, significance tests showed that recommendations made within a day of the request were more likely to have an effect than those made subsequently; that those eliciting many notes were more effective; and that drug recommendations specifying dose and duration of drug therapy were implemented 100 percent of the time while non-specific recommendations were only implemented 64 percent of the time.

4. This may be related to the fact that there are few opportunities to "talk over" what has transpired between doctors and between patient and doctors. As Berger and Luckman (1967) and Hewitt (1988, pp. 193-200) point out, talking is a "nomic" or "reality-building" activity and events that have not been talked over may take on an air of unreality. Since doctors and patients in this study had often failed to examine the course of events in the referral, they were typically unaware that it had not proceeded the way they had originally imagined. When forced to review the process, they

When forced to review the process, they revealed confusion about how to interpret what had happened.

5. See Chapter 8. In Chapter 5, the related point was made that experienced GPs tend to be more selective in their referral of patients (pp. 147-148).

6. This finding is consistent with the early work of Freidson, on outpatient encounters (1960; 1961), that suggested that patients, backed by friends and relatives, are able to negotiate care, at least from their general practitioners, by various direct and indirect methods. Following Freidson's call for a challenge to physician dominance (1970a), numerous accounts of patients' active participation and negotiation of care appeared in the literature (Hayes-Bautista, 1976; Lazare et al., 1976; Roter, 1977; Stimson & Webb, 1978; Ugalde, 1984; Feierman, 1985). In the last instance, patients can simply fail to comply with treatment (M. Davis & von der Lippe, 1968; Stimson & Webb, 1975; Svarstad, 1976).

7. Conversely, the few successful referrals in the study involved clear-cut, quickly-solved problems. For example, Patient 36 went to an obstetrician for a gynecological problem that was taken care of by an adjustment of her birth control medication (Pat. 36, Int. #1, p. 11). Another example involved the referral of Patient 37 for correction of a "squint" in her baby's eye. As the GP pointed out, this was "a simple, clearly-defined problem where the patient recognizes the diagnosis, I recognize the diagnosis [and] the consultant in Winnipeg recognizes the diagnosis" (Int. #2, p. 10). Therefore, the GP expected an unproblematic outcome.

8. This problem plagued specialists as well. For example, in spite of the most strenuous attempts of Specialist 8 to have everything recorded on "forms" with "reasons for referral" and a rationalization of the process, inconsistencies still emerged. As the specialist explained, "[e]ither people forget

or they put it aside and then by the time they come back, they can't remember why they were referred" (Int. #1, p. 5). Because of this, the reason for referral of his patients often appears differently on different forms in his files. Thus although Garfinkel (1967) has emphasized that records and accounts are constructed as part of the attempt to make interaction look more rational, these attempts were only partly successful in the case of referral. The ambiguity about what is really happening persists despite attempts to iron things out.

9. See Chapter 5, pp. 198-201.

10. Orthopedic Surgeon 18 put forward this theory, explaining that he only makes "friendly", "threatening" comments to patients regarding compliance for less painful conditions. An example of this approach was Obstetrician 34's "friendly threat" to Patient 34 that if she didn't quit work during the latter part of her pregnancy, she would be hospitalized for hypertension several hundred miles away in Winnipeg (Pat. 34, Int. #1, pp. 5-7). Once in hospital, compliance to restricted activity orders would, of course, be enforced by the hospital staff (p. 11). Even with Patient 2's life-threatening respiratory disorder, his GP did not pressure him to see the specialist, leaving the patient to decide whether he would comply (Int. #2, p. 4). Optometrist 38 said that she had no control over whether her patients complied with treatment, arguing that, "[i]t's something they have to do on their own" (p. 12). She recognized that eye-training exercises were difficult for parents to enforce on their children and that many "can't do it", although they are attracted to a conservative, rather than a surgical solution to their child's problems. Others like the easy surgical solution to avoid the trouble of the training exercises (p. 14). Specialist 1 spent little time thinking about patient compliance. Regarding Patient 1, for example, he commented, "I do not usually have a great deal of particular follow-up for compliance on ulcer medication. For a couple of reasons. One is that the medication that we used has very few

side effects, and so there are not many negative reasons why people should not take it...The second thing is...most of the time when we're treating ulcers, we're treating a painful condition and people usually comply...[T]hirdly, especially for gastric ulcers, we invariably do a follow-up examination in four to six weeks which is when 80 to 90 percent of them should have healed" (p. 5).

11. Described in the section on "Collusion of Anonymity", Chapter 8, pp. 466-468.

12. GP 7, for example, who was concerned about the large amounts of heart medications prescribed for his patients, reported that he usually reduced the dosages of medications prescribed by cardiologists, since "if you push [patients], they won't take it anyways" (Int. #1, p. 3). Cardiologist 8, on hearing about this GP's attitude, appeared worried, but agreed that "the family doctor can still make his own decision on whether he wants to do something a different way". Later he added that it was wise to schedule a return visit with the patient to see what the GP was doing about the medications (Int. #2, p. 5).

13. Even when patients took it upon themselves to inform the GP of any salient bits of information that might be relevant to their case, they were unsuccessful in keeping him or her up to date. Patient 14, for example, knew that letters were not as helpful as patient accounts as feedback (Int. #1, p. 13), but was frustrated that the patient's report is often not taken seriously (Int. #2, p. 5). Further, although this patient had resolved to ask her specialist to send her GP a copy of his hospital report on her condition the next time she saw him, she forgot (p. 6). Thus, like their GPs, patients "lose track" of what is going on, even if they resolve to be vigilant.

14. Physicians consistently underestimated patient influence over the course of referral, just as they underestimated the contribution of the patient in initiating referrals. GP 21, for example, argued that his patients "<u>will</u> accept

what you tell them" (Int. #1, p. 10). He predicted that even if a patient failed to trust a specialist's advice, s/he would ultimately "come back to me and show me everything that they don't take" (Int. #1, p. 17).

15. Of the 37 patients in this study, based on the referrals that were studied, 14 could be classified as "passive", 12 as "active" but tending to "drift away" or sabotage their treatment, and the remaining 11 as "seeking further treatment". Although this is not a "random" sample and the numbers do not have any meaning in terms of generalizability, it is interesting that there are so many "active" patients. Referred patients tend to have more experience with the system which may awaken them to participation. Further, the large number of patients who persist is of interest. Do most patients "give up" before getting involved in the frustrating cycles of referral and treatment experienced by these patients? In interactionist terms, it could be argued that experienced patients have more blind "faith" or "trust" compared to their counterparts who may simply boycott medical care altogether after a few negative experiences.

16. See Chapter 6.

17. The mothers of Patients 25 and 34 also advised them as to the appropriateness of their treatments. Patient 25's mother made her daughter consult an obstetrician when she felt that the local GP was not handling her daughter's problems appropriately. Patient 34, a young woman with a baby who lived with her parents, reported that she uses her mother "for a first opinion and [goes] to the doctor for a second" (p. 10).

18. Physicians were not unaware that patients adjust their medications in this way. Cardiologist 8, for example, agreed that this was necessary if the cure turned out to be worse than the disease, referring to the side effects of antihypertensive medication for an asymptomatic disorder (Int. #2, p. 2). He argues that it is impractical to check for

compliance, but that physicians can encourage it by, for example, prescribing "long-acting drugs" that don't have to be taken as often (p. 3).

19. GP 5, for example, complained about a patient who was put on a hypertensive drug three times a day, but who only took it when "her head was hurting a little bit" or "when she feels like it". Other patients do not understand that their blood pressure will only stay down if the medication is taken daily, and they may discontinue it when they believe that they are "cured" (p. 26). Specialist 5 agreed that there was a tendency to discontinue following advice when the patient felt better. Several patients in this study admitted that they had done this in error.

20. Patients 17 and 20, who, like Patient 6, were men involved in trying to obtain compensation for industrial accidents, had similar sequences of care-seeking stretching over decades, but their doctors attributed their persistence to the hope for compensation rather than to psychiatric difficulties.

21. Like other referring doctors, GP 30 realized that the specialist had not really helped the patient, as he had originally assumed when he received the consult letter. "Possibly falsely", he said, "reading between the lines, I thought that he had answered [my request] - I mean, I thought he had offered her injections" (Int. #2, p. 13).

CHAPTER 11

CONTRIBUTIONS OF THE THESIS AND AREAS FOR FUTURE RESEARCH

I. INTRODUCTION

It was suggested at the beginning of this thesis that a study of medical referral would contribute to an understanding of a number of sociological, economic and clinical controversies. In this concluding chapter, there is a summary of the model of referral developed in this research and a discussion of how the work adds to what is known about referral. This is followed by suggestions for future research and speculation about the implications of the findings for health care policy.

II. SOCIOLOGICAL ISSUES

This inquiry into the nature of medical referral has moved far beyond most of the existing literature on the topic to explore the dynamics of how

the system operates within different organizational settings. It answers theoretical questions about referral differently than the models proposed by White et al. (1961) and Shortell (1974), and addresses important points not dealt with in those models.[1] It is compatible with and extends Freidson's "medical dominance" model of referral (Freidson & Rhea, 1963; Freidson, 1975). Further, following the distinction made by Glaser and Strauss (1967) between substantive (topic-oriented) and formal (generic sociological) theory, it also contributes observations on the importance and operation of the social-psychological process of "trust" in medical settings that might be generalized to other settings.

1. The Model of Referral: A Summary

a. Trust as the Basis of the Referral System

The results of this research on medical referral lead to a conception of the process as an inherently problematic activity that would break down completely were it not for the "trust" that patients place in their medical advisors and the "trust" that referring doctors place in consultants. Thus the thesis answers the question posed by Grace and Armstrong

(1986) about how the system is maintained in the face of substantial disagreements among patients, referring doctors and consultants about what is to be accomplished and how. This trust is constantly challenged by the open-ended and unsatisfactory outcomes that result when patients and their doctors seek specialist advice (Balint, 1957; M. Brown, 1979). However, it is held in place by the belief that advisors can be found who are competent in their fields of specialization, and, indeed, direct and indirect assessments of competence guide the choice of advisor (Freidson & Rhea, 1965; Modrow, 1976).

How does trust in the legitimacy of specialist medicine manifest itself in everyday referral? In general, participants in referral avoid making critical assessments of the progress of their advice-seeking. They typically do not consciously monitor and assess what is going on, assuming what Berger and Luckmann (1966/1981) and others have called the the "attitude of everyday life", that "nothing unusual is happening". When their attention is drawn to the situation, they actively "make excuses" for their advisors if all is not going well. For example, they would often declare trust that an advisor was a "good doctor" or a "good consultant" almost in the same breath as they pointed

out some irregularity in the process or apparent failure of the consultant. This behaviour is reminiscent of the "documentary method" exhibited by participants in Garfinkel's "breaching" experiments (1967; McHugh, 1968) and is a rationalizing behaviour that has been observed to occur among patients and doctors alike (Millman, 1977; Bosk, 1979). When a "breach" of trust occurred, most participants in referral did not tend to abandon advice-seeking itself, but merely sought someone whom they felt was a more competent advisor, if one were available, thus reaffirming faith in the system of specialized medicine.

b. Trust and the Patient-Initiated Referral

The process of seeking a "more competent advisor" is clearly illustrated by what was found to be the most common type of referral - the "patient-initiated" variety. This process is seldom mentioned in the literature, although Freidson (1960) has drawn particular attention to the susceptibility of the GP to client pressure, and the original Rockefeller studies of referral estimated that over half of referrals are made by general practitioners in response to client

expectations and requests (Williams et al., 1960). What happens is that there is a breakdown of trust between patient and GP. The patient decides that his or her problem lies outside the areas of competence of the GP, and pressures to be referred to a specialist (Dowie, 1983a; Rovner et al., 1985). The physician responds by sensing the distrust, perhaps also feeling a lack of self-confidence in dealing with the problems presented, a response that has often been noted by psychological researchers (Dowie, 1983a; Pinneault, 1974) and acquiescing to the voiced or unvoiced request.

This familiar process was recognized by every physician in this study, and its ubiquity challenges the views in the literature that patients do not assess the competence of their advisors and that it is really referring doctors who are in control of the referral process. Like the physicians in the Rockefeller studies, doctors in this research consistently underestimated the extent of distrust and influence of patients on the referral system. In economic terms, physicians sometimes saw client pressure as resulting in a "crisis" that should be dealt with by limiting access to care. Occasionally they also sensed that patients had lost their trust in general practice. But

they were seldom able to make the connection between the "crisis" and distrust of general practice.

c. Role of the "Boycott" in Referral

The seeking of more competent advice has been described by Freidson and Rhea (1963), after Carr-Saunders (1933), as a "boycott" of less desirable consultants. In this study, there was evidence of boycotting at both the level of the referring doctor and at the level of patient. That is, referring doctors attempted to avoid consultants whom they distrusted and patients sought new doctors when they distrusted their doctors. Theoretically, since consultants depend directly or indirectly on referrals for their income, it might be expected to operate as a mechanism of social control by which less competent practitioners are excluded from the network. In practice, however, because consultants are often isolated from direct observation of care-seekers and because evidence of incompetence is seldom discussed (Freidson, 1970b), those who seek specialist advice are often not in a position to make informed decisions.

Even if a patient or referring doctor wished to "boycott" a consultant, however, this study revealed

that most medical contexts do not allow alternative choices. In "underdoctored" areas, such as northwestern Ontario, there are virtually no choices unless referral is made to distant cities where the advice-seeker typically does not have first-hand information about the consultant. In urban areas, choices are further restricted by ways in which specialists have structured their practices. Specifically, the most popular consultants are able to make patients wait for their services or may even close their practices to all but cases of their choice, leaving less desirable or interesting referrals as "dirty work" to be "picked up" by their less popular and less experienced colleagues. Further, in highly organized settings, specialists divide areas of specialization among themselves, effectively limiting the choice of consultant for a particular problem to a single individual. Thus while patients and referring doctors may try to "shop around" to find the "best" consultants, in effect, their choices to seek the care of their choice are limited by the ways in which the specialists have organized their careers and practices.

Where the possibilities of "boycott" are limited, what do patients and GPs do? The results of

this research suggest that when there are no available alternatives, patients and their GPs are forced to seek advice from those whom they have not yet evaluated, or worse, from those they do not wholly trust. They make what they perceive to be "tradeoffs" between accessibility and competence. They approach the consultant with the increased vigilance that is termed "guarded trust" here, and this attitude may then contribute to a further deterioration of trust and a lack of acceptance of advice and treatment.

2. Contributions of the Thesis to Understanding the Referral Process

a. The Shrinking Boundaries of General Practice

Freidson (1975) has described the referral system as an ongoing "negotiation" of the lines of responsibility between generalists and their consultants. This model of referral is supported by the results of this study, which showed that the "lines" varied with the setting within which referral took place. Specifically, rural GPs tended to assume more responsibility than their urban colleagues by participating in and monitoring referral more closely.

Urban GPs, on the other hand, have "lost ground" in the "negotiation", squeezed as they are on one side by their powerful consultants and on the other by more experienced, untrusting patients.

To the extent that a GP has trusting clients who do not pressure for referral, s/he might be better able to "hold the line" in the "negotiations". This situation may have existed in the rural North Carolina practices studied in the 1950s (Williams et al., 1960). However, the contemporary GP is pressured by patients who want more sophisticated care, and by lack of direct access to specialized equipment and techniques, and is limited by hospital regulations, licensing restrictions and general isolation from the hospital where specialists practice. S/he has thus relinquished many of the traditional responsibilities of general practice. Babies are no longer delivered, eyes cannot be checked, and even simple casts are no longer applied by the urban GP. GPs no longer conscientiously visit their patients in big-city hospitals. The abandonment of these traditional responsibilities is taken by patients and specialists as a demonstration of lack of competence, and feeds into the distrust that patients and specialists feel for these doctors, thus increasing the pressures to refer.

This "vicious cycle" of ebbing responsibility, distrust and pressures for referral has been addressed by militant family physicians, who are a significant minority in both urban and rural settings. These physicians actively attempt to participate in the care of their referred patients, even to the extent of "boycotting" specialists who do not keep them informed about the progress of a case. Their philosophy is that the family physician must remain actively involved with referred cases in order to ensure "continuity of care" (Barnett & Collins, 1977). However, they fight an uphill battle when patients and specialists fail to keep them informed about the progress of referral.

b. The "Collusion of Anonymity"

Another little-understood aspect of referral that is addressed in this research is the phenomenon of "collusion of anonymity" that was first identified and labelled by Balint (1957). Balint argued that a patient may be referred to a number of specialists by a general practitioner who does not know or does not want to become involved in the patient's psycho-social problems. His view is that the GP has "abdicated responsibility" in such cases, and he advocates that

unsuccessful multiple-referral sequences, that typically end in frustration for patient and doctor, would be avoided if the GP would practice psychiatry as part of general practice, becoming involved in advising the patient on his or her life problems. In this research, in keeping with the observations made above, the "collusion" is not seen as a problem that can be dealt with by the GP alone. As well as happening with respect to the socio-psychological problems identified by Balint, unsatisfactory multiple referral was also found to occur in areas where GPs often do not feel or are not judged to be competent - such as obstetrics, ophthalmology, psychiatry and orthopedic surgery - and where the corresponding specialists in those areas were not willing or able to take the responsibility for the type of case being referred. In each of these areas of medicine, there is a "gap" of responsibility. In such areas, patients would assume more responsibility for their own care and/or withdraw from medical care. Because GPs cannot just "assume responsibility" by fiat, but must depend upon favorable evaluations of their abilities by others, this research suggests that a unilateral solution to this problem is not possible.

A related observation was that patients sometimes sought help from non-physicians in these areas - for eye care, from optometrists and for back pain, from chiropractors. For obstetrical problems, the advice of relatives was sought, and one physician suggested that the "gap" here may soon be filled by midwives. In addition, patients described active seeking of help from non-medical advisors for these problems - including alternative practitioners, spiritualists and fortune-tellers. In fact, the "collusion of anonmymity" concept overlooks the role that the patient and non-physicians might be able to play in cases where physicians are unwilling or unable to help. However, a significant minority of patients in this study were so trusting of the medical hierarchy that they continued to seek multiple referral even after it appeared that physicians could do nothing for them.

c. Communication Breakdown in Context

By volume of articles, the most popular aspect of referral in the clinical literature is the "breakdown of communication" that often takes place during the process of referral. Unfortunately, research

on communication in referral[2] tends towards microscopic, quantitative analysis, without exploration of the dynamics or context of the situation. In this thesis, it was found that communication was less problematic between doctors in settings where physicians personally negotiate their responsibilities and where they have developed mutual respect for each others' abilities. In settings where such interaction is not possible or probable, breakdowns occur.

The observation that, in urban settings, GPs are becoming more and more isolated from their specialist consultants, would suggest that the problem of "communication breakdown" will only assume greater proportions in the future. In this research, it was clear that communication, even via telephone, in the urban setting, was considered disruptive in the everyday practice of medicine, and so any suggestion that there "should be more personal communication between referring doctors and consultants" (e.g. Long & Atkins, 1974; Grant, 1982) does not take into account the realities of everyday practice.

Early in this study, it was recognized that referral contains a "nested" consultation, in which one consultation takes place "inside" another - the patient consults a doctor, who, in turn consults another

doctor. It was a useful intellectual exercise to compare what happened at one level to try and understand what was happening at the other. In the case of communication, the finding that distance and lack of respect underlies "communication breakdown" between doctors at different levels of the medical hierarchy has a parallel between the early finding, often reported in the literature, that unsuccessful doctor-patient communication involves lack of mutual respect, social distance and "information control" (Pratt, 1957; Goffman, 1959; Davis, 1963; Skipper & Leonard, 1965). A general theoretical question that might be posed in viewing these parallel processes in the light of "communication breakdowns" of other types (e.g. Key, 1965; Hite, 1987) is whether satisfactory communication is possible at all in situations where participants judge themselves to be at different levels of competence.

Another, related, "communication" problem that has previously not been reported in the literature occurs when two or more doctors give the patient conflicting information about his or her medical problem. This tendency was found to be "built in" to the situation of referral in that specialists, for a number of reasons, are more likely to give patients

detailed and negative prognoses, for example, than their GPs. Because the doctors tend not to co-ordinate what they tell the patient, discrepancies result which have a far-reaching effect on the patient. Specifically, the patient may lose trust in one or both doctors and may fail to follow their advice.

d. A Fresh Perspective on "Non-Compliance"

As Sackett (1976) points out, the term "non-compliance" "carries with it connotations of sin and serfdom" (p. 1). Patients are described by clinicians as not following the advice of their doctors because they have a "faulty perception" of the physician's advice, which is assumed to be sound; because of their failures of knowledge, attitudes or behaviour (Marshall & Maiman, 1976); or, admitting that physicians can sometimes be cold and harsh to their patients, a kind of "retributive justice" by which the patient "gets back" at a nasty physician by not following his advice (M. Davis, 1967; 1968). Sociologists, on the other hand, have tended to blame the physician for not conveying the message to the patient either "unintentionally" (Svarstad, 1974; Pratt, 1957) or deliberately through "information control" (Hoffman,

1974; F. Davis, 1963). When the "outcomes" of referral were examined in this thesis research, neither perspective appeared to fit the experiences of the participants.

What happened to the cases of referral in this study? Typically, the referring doctor "lost track" of the process when the patient went off to the specialist, and the patient failed to keep the referring doctor informed. Even "militant" GPs who tried to "keep control" of their cases and "militant" patients who insisted that they were in control of their own health care, appeared to suffer this fate. Participants tended to trust that events would eventually resolve themselves without their conscious intervention, acting somewhat like "sleepwalkers". When asked to evaluate the referral, they occasionally went into the confused state described by Garfinkel (1967) that "breaching" of an "attitude of everyday life" provokes. In view of this finding, it is difficult to speak of "non-compliance" with advice, either by referring doctor or patient. If those who seek advice do not consciously evaluate what is happening, but allow themselves to be "carried along" by events, this does not constitute a "rational" decision about whether or not to follow advice. Ironically, participants in

this study appeared to believe that they had more control over events than they actually had, judging by the difficulties they were unable to resolve. Their attempts to "negotiate" treatment sometimes resulted in an irrational potpourri of "treatment". Finally, a substantial minority of patients and referring doctors unhappily sought more care, without critically evaluating the source of their dissatisfaction.

This view of most medical referral as having open-ended, unsatisfactory outcomes is consistent with the model of referral presented here as based on "trust" in the specialized system of medicine, in which participants actively "make excuses" when things do not go well, or "vote with their feet" by seeking another consultant, without questioning the validity of the system itself.

3. Directions for Future Research

a. Recommendations Concerning Method

Chapter 3 of this thesis lays out a critique of previous clinical work on medical referral, describing it as largely atheoretical, preoccupied with calculating referral rates or quantifying microscopic aspects of the process, without any attempt to explain

how referral works. As clinicians themselves have recognized (e.g. Morrell, in Dowie, 1983a), this type of research has failed to throw much light on the complicated process of referral. On the other hand, ethnographic research, such as that undertaken by Dowie (1983a), Freidson (1975), Balint (1957) and in the Rockefeller studies (e.g. Andrews et al., 1959) has yielded most of what is now known of the process. Clearly, more ethnographic research should be undertaken.

A shortcoming of previous ethnographic work on referral has been exclusion of the views of certain participants or limitation of the contexts investigated. For example, Freidson (1975) did not report on the patient's perspective in referral. The Rockefeller researchers, who interviewed both patients and physicians, looked only at rural referrals to a university medical centre (Williams et al., 1960). Dowie's research (1983a) explored how the self-confidence of the referring doctor affects referral, but did not look at the process from the perspective of patient or referring doctor. None examined the process in different settings. This thesis research suggests that referral can only be understood, consistent with the framework of symbolic interactionism, as an

interactive process that occurs among the three or more participants within specific contexts. Future research should therefore attempt to take this into account, and should explore the generalizability of the model presented here to other settings.

b. Referral in Other Settings

In what other settings should referral be studied? Following the suggestion of Glaser and Strauss (1967) that the researcher should construct a theory using the method of "theoretical sampling" of important dimensions identified in research, what important dimensions of referral identified in this thesis should be pursued? First, referral for psychiatric problems would appear to be an important parallel to "medical" referral. Although no psychiatric referrals were examined in this research, indications from participant comments and the literature suggest that psychiatric referral often entails significant problems with establishing mutual trust and communication.

Referral of patients with different ethnic backgrounds is also of interest, given Hall's research that suggested an ethnic segregation in the health care system (1946; 1948). This would be of particular

relevance in Ontario because of the proportion of minority groups in large cities (e.g. over 50 percent in Toronto) and in view of the unusual arrangements for provision of health care to native Canadians, involving two levels of government. Previous sociological research on referral[3] tends towards describing the referral system as rooted in the hierarchy of perceived competence of the practitioners. This conception of referral must be reconciled with Hall's depiction of a hierarchy based on ethnic segregation. This study did not explore fully the dynamics of referral in cities as large as that studied by Hall, and Modrow's suggestion that city size is the key to understanding referral patterns should be explored.

Finally, a third important aspect of referral not examined fully in this work is the influence of the funding and payment of doctors on the process. There are many observations made by participants on this aspect of referral - for example, that "greed" plays a part in how specialists structure their practices and that communication is related to economic considerations - but there is a great deal more to learn. For example, how does the referral process differ when the patient "pays"? How important are "time and money" considerations in the referral process as

compared to the issues identified in this thesis? What are the effects of having a private health care system alongside a public one? An obvious comparison would be between American and Canadian referral. In this thesis, perhaps with certain economic considerations "out of the way", other social-psychological aspects of referral were more predominant than they might be, for example, in the American setting.

c. Research on Patient-Doctor Relationships

When a comparison is made between the experiences of a referring doctor consulting his or her specialist and the patient "consulting" with the doctor, the researcher is liberated momentarily from an assumption that the experiences of doctors are somehow different from those of other human beings because they are experts. The researcher is encouraged to see these two processes as examples of the same generic process and to discount, momentarily, the mysterious aura that surrounds "what experts do". This approach is very much in the tradition of the sociology of science (Mulkay, 1980; Berger & Luckmann, 1966/1981) and allows a "demystification" of the work of experts. It also allows a refreshing look at patient-doctor relation-

ships, where researchers tend to assume that the patient cannot evaluate the doctor and that he or she is generally a passive pawn in his or her own medical care.

A major finding of this thesis research was that the influence of the patient on the referral process is much more substantial than has been generally recognized. This was suggested in the Rockefeller studies of referral (Williams et al., 1960) and in Freidson's argument that the GP refers in response to client pressure (1960), but it had never been investigated empirically. "Utilization" studies that focus on "physician characteristics" such as the experience of the physician and the role of his or her feelings of self-confidence in the making of referrals fail to take into account the fact that in interacting with the patient, the patient evaluates the doctor's competence and that the doctor reacts to this evaluation. When this is put together with the observation that the content of general practice is "shrinking" and that confidence in general practice is questioned by many patients, this suggests that referral is not driven by patients or physicians, but by a complex interaction between them. The "patient-

initiated" referral, although virtually absent in the literature, is the largest category of referral.

Just as patient influence on the decision to refer has been underestimated in the literature, so has patient influence on the choice of consultant. In this study, patients were found to assess the competence of their advisors in the same ways as their GPs, with their preferences typically taken into account by their GPs. Alternatively, as in Hayes-Bautista's study (1975), they were found to "vote with their feet", seeking GPs who would refer them as they wished or seeking consultants, medical and non-medical, directly.

Finally, although doctors generally have low opinions of the competence of patients to participate in their care, there was much evidence in this study that even the most passive patients would adjust prescribed medications, question the value of treatment and withdraw or seek out other opinions in the face of contradictory advice given to them by different doctors. Since typically, patients do not return to the referring doctor, it is the <u>patient</u> and not the GP who decides whether and how to follow the consultant's advice.

III. IMPLICATIONS FOR POLICY

It was suggested in Chapter 2 of this thesis that, in addition to the theoretical value of research on medical referral, it might add to our understanding of the health care crisis in Ontario. The research reported here was not undertaken with these goals in mind. However, it is still interesting to trace the implications of the findings reported here and to speculate about what might be if it were possible to translate what we know into what we do.

1. Trust and the Health Care Crisis in Ontario

Perhaps the most poltically-charged current health care issue in Ontario both as reported in the media and in the minds of the participants of this study was the question of who is "responsible" for rapidly escalating health care costs. It was suggested in the introductory chapters of this thesis that specialist care outstrips the cost of primary care and that rates of referral for specialist care can be observed to be higher in countries, like Canada, where "free" care is provided (Chapter 2, pp. 24 - 25). In Chapter 5, the views of physicians that <u>patients</u> are

responsible for these higher rates - because "if you give the people something for nothing...they are going to work it to death!" (GP 23, Int. #1, p. 3) - were recounted. How fair is this indictment of the consumer of health care?

The results of this study would suggest that debates about who is to blame reveal over-simplistic assumptions about how and why care is sought. Patients may in fact be to "blame" in the literal sense of insisting on seeing the specialist - and it is argued here that sophisticated patients are doing just that - but they do so for understandable reasons. Rather than trying to "get something for nothing", patients want specialist care because they can no longer trust the general practitioner or the local specialist whom they trusted in the past. One observation that clearly illustrates that it is a breakdown of trust that underlies patient-intiated referral and not the seeking of "free care" is that patients in northwestern Ontario were prepared to pay hundreds and even thousands of dollars in their pursuit of care from specialists in the U.S. This is a strong argument against the view that instituting user fees would discourage patients from seeking specialist care. Any government that

institutes a policy like this fails to appreciate how and why patients seek care.

Patient lack of trust is reinforced by many specialists, who describe the GP as "abdicating" responsibilities that were once in the area of general practice and who "keep" patients who might be referred back to GPs if they could be trusted. Are GPs really "abdicating" their responsibilities, then, and are they the culprits in the current health care crisis? The results of this research suggest that, contrary to the clinical model of the GP making a "free choice" to refer a patient, the GP is being "pushed out of the way" by patients as well as "squeezed out" of the hospitals and specialist-dominated areas of ambulatory care by their consultants. Thus the speculation of Somers (1983) and others that GPs might serve as "gatekeepers" to the system of specialist care, is probably futile.

In the complex interactions among participants in referral described in this thesis, it is difficult to distinguish whether a failure of a GP to "work up" a referral adequately involves "dumping" the case or merely responding to irresistable client pressure. Further, when the GP fails to monitor a referral, it is difficult to tell whether this an indication of

"abdication of responsibility" by the GP or "dredging" (i.e. "taking over" the case by the specialist). In fact, none of these emotionally-charged words used by participants in this study - "abuse", "dumping" and "dredging" - really capture what is going on in most situations of referral. This research reveals referral as a complex interpersonal process that involves mutually deciding the extent to which all three parties can trust one another. When there is a breakdown somewhere in this interpersonal process - as there usually is - the other parties react and influence decisions about who to trust.

The current situation in Ontario encourages referral to the extent that no one really "loses" when the GP passes on a case that might have remained at that level - the patient sees someone who perhaps can invoke more trust, the GP passes on a difficult case, and the specialist makes money. There is thus no "internal brake" and no one is directly to blame if "over-referral" is taking place. Legislation to discourage referral may appear to be a solution. However, if the pressure to refer originates in a breakdown of trust in interpersonal relations among patients and doctors, and not directly because of

economic considerations, any legislation that did not address this problem would be doomed to failure.

What, then, could be done to address the problem? Initiatives to recover the "lost respect" of the community physician by certification as a specialist in family medicine looks like a step in the right direction. Although patients in this study were generally unaware of this certification process, their respect for "militant" family physicians who want to stay involved in their patients' care was revealed. As argued at length in this thesis, demonstrations of competence through participation in care invoke respect of patients and consultants alike. Policy should thus be directed towards strengthening this political movement among community physicians if the goal is to reduce the rate of referral and "losing track". Where specialists dominate hospitals, it is unlikely that even "militant" family physicians will be successful in "keeping" their patients - but again, opportunities to <u>demonstrate</u> competence may ultimately win the respect of some of their consultants, and, in urban areas at least, the remaining specialists may be "boycotted", as one GP in this study suggested.

2. Is the Quality of Care Adversely Affected by the Referral System?

A second potential policy issue raised in the introduction to this thesis is the one repeatedly raised by Freidson in his analyses of "professional dominance" (1970a,b; 1986) - can and do professionals insure that patients are cared for according to accepted standards of the profession, given the current referral system? In Freidson's analyses, he placed his emphasis on the observation that some physicians are in a better position than others to know whether a consultant is competent and thus deserves to receive a referral. Where this knowledge cannot be obtained, due to structural features of the organization of medicine - the fact that the referrer is never in a position to observe the consultant and may not hear rumours of incompetence -his answer was that this mechanism of "social control" or way to "insure the quality of care", fails.

The findings in this thesis support Freidson's observations. Some referring physicians in this study were unaware of the suspicions that other referring doctors held about the competence of particular consultants. This limited knowledge of consultants can

be linked directly to the way in which medical practice is organized. That is, as GPs "abdicate" or are being "squeezed out" of urban hospitals, they are less and less in a position to work with and observe consultants first-hand. In their relatively isolated community offices, they may not even hear rumours about their consultants. They may rely on their patients to give them feedback about irregularities. However, the patients are not fully informed either. Therefore, attempts to assess consultant competence by referring doctors may often be a case of "the blind leading the blind".

However, this is not the whole story. In addition to the structural constraints on knowledge of consultant competence, this study revealed that there is significant restriction of <u>choice</u> of consultant. In some settings, even if the referring doctor does not trust the consultant, or does not know the consultant well enough to know whether s/he can be trusted, there may be no available alternative. As described above, in some areas, there are few consultants from which to choose. In areas where there is apparent choice, popular specialists with enough "business" tend to specialize in narrow areas, forcing the referring doctor to seek referrals from less popular consultants.

In some cities, specialists may divide the referrals among themselves by area of interest.

The consultants whom referring doctors are forced to consult may merely be less experienced-doctors who are in the process of "building a practice", who may thus be in a position to take "all comers" until they become established, and who really can be trusted to give the best available care to patients. However, if the model sketched here is pursued, it can be seen that "less popular" practitioners might also be those who are "less popular" for reasons related to suspicion of their competence. In fact, it may be that "dirty work", or medical work that popular practitioners do not like to do, gets done badly by doctors who would rather be doing something else. This is a possibility that is well worth further investigation, in view of its implications for the standard of care that might be provided in "unpopular" areas of medicine.

Is there a role for government intervention in this picture of a health care system unable to monitor its own standards of care? Balint (1957) recommends more active involvement by the general practitioner. Freidson advocates more "patient education" and more participation of patients in the health care system,

including the placement of patients on hospital committees that review the "quality of care". More radical solutions from the political right call for individuals to "recover" the responsibility for their health care (Illich, 1976) and from the political left, for a "refocussing" of priorities (McKinlay, 1979). Support of systematic "peer assessment", as is now being undertaken by the College of Physicians and Surgeons in Ontario, would be the most conservative response. Perhaps hospital boards and tissue committees can be encouraged to include more "patient" members, as suggested by Freidson. But neither approach will address the consequences of "informal" specialization described in this thesis. Perhaps restrictions need to be placed on this process, with greater encouragement of generalist careers in teaching hospitals.

3. Alternative Models of Health Care Delivery

A related issue has to do with what happens in areas of medicine that are so "unpopular" that GPs are not involved in addressing the problems and specialists are not meeting the demand. There were a number of such areas identified in this thesis. For example, GPs are

"getting out of the business" of obstetrics and gynecology and obstetricians and gynecologists appear not to be keeping up with the demand. GPs no longer want to "fool with an eye", but there are no ophthalmologists in large areas of Canada. Orthopedic surgeons are unhappy about and typically not trained to deal with most cases of back pain, but most family doctors do not know how to address the problem either. When patients come to their doctors' offices with these complaints, it was shown in this thesis that an unsatisfactory situation that Balint (1957) has called a "collusion of anonymity" often results. Patients are handed back and forth among physicians who cannot deal with their problems, although some treatment may be attempted. "Quality of care" undoubtedly suffers here.

Is there a role for government in dealing with these serious breakdowns of the referral system? What appears to be happening in Ontario is that the "slack" is being picked up by non-physicians. That is, as one specialist in this study foresaw, midwives would soon be free to move into the "abdicated area" of obstetrics. Optometrists already provide much of the care of the eyes in northwestern Ontario that ophthalmologists provide in the south. And patients in this study with back pain had all visited or seriously

considered visiting a physiotherapist or chiropractor in order to deal with their problem. Perhaps the funding system should be adjusted to take these developments into account.

Following the argument made in this thesis that patients have much more influence on the process of care than they have been generally given credit for, one interesting question is, if confidence in the medical profession hits an all-time low, will they find alternative practitioners any more to their liking? They already do this in areas where doctors are unavailable. Is the neighbourhood health centre, an idea which has not yet had its day in Canada, feasible - since it is cheaper to consult these practitioners? Will patients continue to prefer GPs to other health professionals, as they did in Freidson's study of a PPG in the Bronx several years ago (1971) or are they more receptive now to this concept? Perhaps government policy should be geared to testing out this interesting possibility.

IV. SUMMARY

This investigation of the process of medical referral led to a vision of the health care system as

based on coalitions of "trust" among the patients and physicians involved. When trust in specific advisors fails, participants typically exhibit trust in the system of care by seeking another advisor. This process is particularly clear in the seeking of specialist care by patients who pressure their general practitioners for referral. This "boycott" of certain consultants, however, is limited by availability of consultants, which is controlled by the way specialists structure their careers and practices in various contexts.

This model of referral goes beyond the existing referral literature to suggest that there is a "shrinking content of general practice" which involves a "vicious cycle" in which GPs are increasingly excluded from the hospitals where their specialist consultants practice and thus from much responsibility for patient care. It also identifies areas in which neither specialists nor GPs take responsibility, as a result of the growing specialized structure of medicine. It links "breakdowns" of communication to the structure of these settings as well as the problematic outcomes that referrals typically involve.

Recommendations for future research are that theory-driven approaches must replace the scattered, "empirical" studies that dominate the literature and

that ethnographic methods should be used. Medical referral is a complex interactive process among patient, referring doctor and specialist and research methods must address this. Study of psychiatric referral, referral of non-English speaking patients, and those from minority groups would address certain aspects of the theoretical model. An examination of referral in different systems of funding would be theoretically useful as well. This thesis has shown that ignoring the role of the patient in referral has been a grave error, leading to a failure to appreciate the dynamics of the situation. Perhaps the study of patient-doctor interaction in general, and the study of "compliance" might also benefit from an approach that explores the patient's activities outside the doctor's office over his or her life history.

Finally, the results of the thesis bear on some important policy issues, including the "cause" of the fiscal health care crisis and suspicions that the medical profession is not adequately monitoring standards of care. While research would suggest that recommendations concerning policy are seldom possible to implement, the thesis concludes with speculation about what political responses might be made in view of the material presented in this thesis.

NOTES

1. These models are discussed in Chapter 2. White et al. (1973), who have described the organization of medicine as a pyramid, with medical generalists at the base, making referrals to specialists at the pinnacle are unable to explain why generalists do not refer on all cases that might benefit from tertiary care (Williams et al., 1960; Clute, 1973). This thesis research suggests that the reason for the "under-referral" has to do with the coalitions of "trust" among participants. Shortell's "exchange theory" model of referral (1974) does not address the issues raised in this thesis, concentrating mainly on predicting referral choices based on the "rewards" and "punishments" that these involve for the referring doctor.

2. This literature is reviewed in Chapter 9.

3. This literature is reviewed in Chapter 3.

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INFORMED CONSENT FORM

Consultation
Research Project

(PATIENT)

This is to confirm that I have read the attached study description and that I understand the goals of this study and its method. I agree to being interviewed and to having the interviews tape recorded. I am also agreeable to allowing access to my medical records and to letters that my physicians have exchanged during the consultation process.

The investigators have assured me that the data will be handled confidentially, and that my relationship with my doctors will not be affected to my detriment. They have also assured me that my identity will be protected in the final reports.

I understand that I am free to withdraw from the study if I so wish.

.....

Signature

.....

Witness

Principal Investigator

MRS. LINDA MUZZIN
McMaster Health Sciences Ctr.,
Room 3N51, 1200 Main St. W.,
Hamilton, Ontario.
525-9140 X2112

INFORMED CONSENT FORM

Consultation
Research Project
#84-559

(PHYSICIAN)

This is to confirm that I have read the attached study description and that I understand the goals of this study and its method. I agree to being interviewed and to having the interviews tape-recorded. I am also agreeable to allowing access to the medical records of participating patients and to letters that my colleague and I have exchanged during the consultation process.

The investigators have assured me that the data will be handled confidentially and that doctor-patient and doctor-doctor relationships will not be compromised. They have also assured me that my identity will be protected in the final reports.

I understand that I am free to withdraw from the study if I so wish.

.....

Signature

.....

Witness

Principal Investigator

MRS. LINDA MUZZIN
McMaster Health Sciences Ctr.,
Room 3N51, 1200 Main St. W.,
Hamilton, Ontario.
525-9140 X2112

SUMMARY

STATEMENT REGARDING PROPOSED

CONSULTATION PROJECT

The purpose of this project is to better understand medical consultation. We expect that consultation is most effective when personal communication takes place among the participants at critical decision-making points. Ten patients, their family physicians, and specialists consultants, will be interviewed at those points in the consultation sequence. The focus of the interviews will have to do with the integrity and quality of communication. Confidentiality of health data as well as participant identities will be preserved. The relationships between physicians, and between physicians and patients will be respected during the interviews and in our subsequent report of findings. We expect to be able to make recommendations on how to improve consultation, with the ultimate aim of improving quality of patient care.