

**COMMUNICATION BETWEEN FAMILY PHYSICIANS
AND INDIVIDUALS WITH DEMENTIA AT THE TIME OF DIAGNOSIS**

COMMUNICATION BETWEEN FAMILY PHYSICIANS
AND INDIVIDUALS WITH DEMENTIA AT THE TIME OF DIAGNOSIS

By

HENDRIKA SPYKERMAN, B.A.

A Thesis

Submitted to the School of Graduate Studies

in Partial Fulfillment of the Requirements

for the Degree

Master of Arts

MASTER OF ARTS (2005)
(Sociology)

McMASTER UNIVERSITY
Hamilton, Ontario

TITLE: Communications between Family Physicians and Individuals with
 Dementia at the Time of Diagnosis

AUTHOR: Hendrika Spykerman

SUPERVISORS: Professor M. Denton
 Professor E.B.Ryan
 Professor I. Bourgeault

NUMBER OF PAGES: vii, 151

ABSTRACT

Physicians are usually the first contact in the health care system for persons with dementia and their family caregivers. Although specialists typically make the diagnosis, it is the family physician who is key to confirming the diagnosis for dementia, explaining what it means physically, emotionally, and describing what to expect as the disease progresses. Our knowledge about interaction between persons with dementia and their physicians is based largely on the caregiver's view while few studies have investigated the physician's perspective. Persons with dementia have been underrepresented in research pertaining to the issue of diagnosis disclosure. The aim of this exploratory study was to examine the attitudes of family physicians and individuals with early stage dementia about the diagnostic process. The effects of a companion on a medical encounter were also investigated. Data were compiled from responses of 14 family physicians to a structured questionnaire containing highly selective questions, as well as in-depth interviews with 9 individuals with dementia. Using a conflict theoretical framework, the results show that family physicians do inform patients of a diagnosis for dementia. Although the majority of individuals with dementia are satisfied with their family physicians' communication, they were dissatisfied in terms of referral to community resources. Persons with dementia also felt that they received less than ideal care, particularly from specialists, in terms of how the diagnosis was disclosed. Overall, physicians and persons with dementia rated the influence of a third person in the medical encounter as positive. Physicians in this study continued to use an illness-centered approach rather than a patient-centered approach that acknowledges the patient as a person with unique needs and a life-story. Future research thus needs to address the development of a patient-centered model in which the understanding of the subjective experience of the person with dementia is essential.

ACKNOWLEDGEMENT

First and foremost I would like to thank and acknowledge Dr. Margaret Denton, Dr. Ellen Ryan, and Dr. Ivy Bouregeault for agreeing to work with me and sharing their wealth of academic knowledge and their experience in the thesis process. All of your insight and expertise has made my thesis project a wonderful learning experience while at the same time has made me a better writer and sociologist. I would also like to thank Ann Anas for providing additional comments and for taking the time out of your busy schedule in order to guide me. In addition, I would like to thank all the family physicians and individuals with dementia who agreed to participate in my research. Without you, this project would not have been possible. Finally, I would like to thank my family for all their support and patience during my time of study.

In Memory of My Friend Jane

One Day We Will Meet Again

TABLE OF CONTENTS

Title Page	i
Descriptive Note	ii
Abstract	iii
Acknowledgements	iv
Dedication	v
Table of Contents	vi
Chapter I: Introduction.....	1
Chapter II: Theory	8
Theoretical Perspectives on Physician-Patient Encounter	8
Functionalist Perspective on Medical Encounters	9
Conflict Perspective on Medical Encounters	12
Sociology of Triads and Its Impact on Medical Encounters	17
Healthcare Triads and Dementia	18
Conclusion	19
Chapter III: Physician-Older Patient Relations.....	23
Communication Issues with Geriatric Patients	23
Companions in Physician-Geriatric Patient Interactions	28
Roles of Companions in Older Patient-Physician Encounters.. ..	30
Typologies of Roles	30
Impact of Third Person	32
Communication Issues between Physicians, Individuals with Dementia and Companions	35
Marginalization of Individual with Dementia... ..	35
Changing Relationship Back from Triad to Dyad.....	37
Disclosing the Diagnosis of Dementia.. ..	38
Reasons Why Physicians Do not Disclose Diagnosis... ..	39
How Do Physicians Actually Practice?.. ..	42
What Do Caregivers Want to Know?	47
What Do Persons with Dementia Want to Know?.....	50
Summary	56
Chapter IV: Study Methods	59
Objectives.....	60
Choice of Methodological Approaches	60
Study Participants and Recruitment.....	61
Data Collection	63
Ethical Considerations	63
Data Analysis	64

Chapter V: Results ..	67
Family Physician	68
Initial Assessment	68
Disclosure of Diagnosis	71
Terminology Used to Inform Patient and Family	72
Benefits of Obtaining a Diagnosis of Dementia	73
Barriers to Obtaining a Diagnosis of Dementia	73
Provisions of Information and Services	74
Suggestions to Improve the Process of Disclosure	74
Individuals with Dementia	75
Awareness	76
Suspecting	77
‘Crisis’	79
Receiving Diagnosis for Dementia	79
Confirming	80
Reactions to Diagnosis	81
Manner of Giving Diagnosis	82
Advantages of Receiving a Diagnosis for Dementia ...	87
Disadvantages of Receiving a Diagnosis for Dementia	89
Provision of Information and Services	89
Lack of Sufficient Information	89
Lack of Referral to Community Services	91
Lack of Follow-up Medical Visit	92
Suggestions for Improving the Diagnostic Process	93
Companions in Physician-Dementia Patient Interaction	95
Physicians’ Perspectives	95
The Perspective of the Person with Dementia	97
 Chapter VI: Discussion	 96
Contribution of the Study of Physician-Patient Relations and Triads	96
Contributions of the Study to the Practice Related to Dementia	106
Limitations	116
Future Implications	118
Future Research	122
Conclusion	123
The Bridge between Paternalism and Autonomy	123
From Patient to Person	124
 Bibliography ..	 127
 Appendix I: Physician’s Questionnaire	 132
Appendix II: Interview Tool for Individuals with Dementia	143
Appendix III: Ethics Approval	151

Chapter I

INTRODUCTION

“In healthcare the words a physician uses have a profound effect on the well being of the patient... the right words can potentiate a patient. Mobilize the will to live, and set the stage for heroic response. The wrong words can produce despair and defeat or impair the usefulness of whatever treatment is prescribed”
(Cousins, quoted in Coe & Miller, 2000, p. 109).

Older people represent the fastest growing population segment of North America, and their demand for health care services is increasingly exponentially (Roter, 2000). As summarized by Beisecker (1996), the number of physician visits for people 65 to 74 years of age is expected to double in the coming decades and the number of visits by those 75 years of age and older is expected to quadruple. The physician-elderly patient relationship thus will grow in relevance and importance (Adelman et al., 2000). Little, however, is known about the effect of increasing longevity on physician-patient relationships (Haug, 1994).

With age, the incidence of dementia increases, and one would expect that sharing information about dementia issues would occur routinely between physicians and older patients. Adelman and colleagues (2004), however, report that physicians not only under-diagnose dementia but when dementia is detected some physicians do not disclose the diagnosis to the patient. Non-disclosure of information about diagnosis and prognosis can be detrimental to the person with dementia and their family (Pratt et al., 2003).

It can be argued that effective communication among the person with dementia, the caregiver and the physician, particularly during the time of diagnosis, is crucial. The present study was designed to help fill the communication gap by examining attitudes of persons with dementia and family physicians toward assessing and diagnosing dementia, with a particular focus on how a diagnosis is disclosed. This research further addressed a triadic relationship, using the clinical problem of dementia to illustrate how a companion can either facilitate or hinder communications.

There is a great deal of debate around the practice of disclosing the diagnosis of dementia to people with the illness, particularly the question of “to tell or not to tell” (Pratt et al., 2003). Arguments against diagnosis disclosure include that it will be too distressing for people with dementia to know their diagnosis (Dickamer et al., 1992). Although physicians are frequently the first medical contact for the person with dementia, discussions between the physician and older and mentally “healthy” person about cognitive impairment are limited. In a recent study by Adelman and others (2004) they found that memory was only discussed in 62% of medical visits about possible dementia. Physicians, nevertheless, are key to confirming a diagnosis of dementia, explaining what it means physically and emotionally, and describing what to expect as the disease progresses.

The current state of knowledge about interaction between the persons with dementia, family caregivers, and physicians is based largely on interviews with family caregivers, supplemented with a smaller body of survey research literature on family physicians (Maguire et al., 1996; Rice et al., 1994). The benefits of obtaining a specific

diagnosis of dementia from the perspective of family caregivers and primary physicians have been documented (Connell et al., 2004; Maguire et al., 1996). For family caregivers, benefits include knowing what is wrong with their loved one, promoting adaptation and coping, and enhancing communication during medical visits (Connell et al., 2004). For physicians, a specific diagnosis can facilitate ascertaining treatment options, future planning, and need for community services (Foster, 2001). People with dementia have, however, been under-represented in research, particularly in relation to the issue of diagnosis disclosure (Marzanski, 2000).

The views of older people without the illness have been sought on this issue (Holroyd et al., 2002), but the perspectives of persons with dementia who have experienced diagnosis disclosure remain largely absent from the literature. Within the last few years there has been an increased understanding of the subjective experience of people with dementia (Pratt et al., 2003). These researchers postulate that the diagnostic process is one of the most fundamental elements in the experience of dementia. Relatively few studies, however, have focused on the process of disclosing a dementia diagnosis to persons with the illness (Downs, 1997; Marzanski, 2000; Pratt et al., 2003).

To make matters more complex, older patients frequently are accompanied to the physician by companions; estimates of the percentages of all visits that include a companion range from 20% to 57% (Prohaska et al., 1996). Physicians, therefore, increasingly participate in a more complex interaction; the physician-patient-family caregiver relationship (Adelman et al., 1987). The presence of an accompanying person can have significant impact on the interaction between patient and physician. The

companion may inhibit or enhance patient-physician encounter and is likely to play multiple roles during a medical visit (Adelman et al., 1987; Beisecker et al., 1990; Greene et al., 1994). It is important to know, therefore, how a third person can influence the therapeutic relationships between physicians and patients. Fostering the physician-patient-family caregiver relationship can be a complex task because three-person relationships are frequently unstable; that is, they can easily decay into coalitions of two against one (Simmel, in Wolff, 1950).

Communication in a triadic encounter can be considerably more complicated among patients diagnosed with dementia. Here we find that physicians are faced with the daunting task of obtaining information from and sharing material with dementia patients, family members, and significant others who might accompany patients to appointments. Fortinsky (2001), for example, argues that adding a companion to the medical encounter increases the risk of marginalizing the patient with dementia. Patients with dementia, furthermore, progressively lose cognitive functioning as the disease process advances over time, and frequently are portrayed as “incidental objects and passive recipients in the process of their dementia” (Keady et al., 1999, p: 325).

This perception of patients with dementia as non-participants in their own care decisions is rapidly changing, as increased public awareness of dementia leads to medical intervention and diagnostic testing earlier in the disease process. As patients with dementia engage in the care process, it will be increasingly important to understand how they interacted with both family caregiver and physician before their dementia, and how they interact during medical encounters (Fortinsky, 2001). Although there have been a

number of studies examining the influence family member participation in geriatric medical encounters (Adelman et al., 2000; Prohaska et al., 1996; Silliman, 2000), these studies were quite limited and based on small samples.

In an increasingly managed health care environment physicians have less time for older patients and/or patients with dementia, for whom assessment of psychosocial factors is as important as physical diagnosis, who move and respond more slowly than younger patients, and need more time for the physician visit (Waitzkin et al., 2000). The influence of time constraints on the physician style and patient communication may have the unintended effect of reinforcing the physician dominant role that most older patients are accustomed to experiencing, which reinforces the passive or submissive role of the older patient (Tennstedt, 2000). Finally, the communication between physician and dementia patient is difficult because the patient's insight can be impaired at the moment of the diagnosis and thus compromise the communication of disease-related information, and patient autonomy. When diagnosing cognitive impairment, the physician's approach to the older patient thus must be modified.

There are, of course, important ethical principles to consider in disclosure including the individuals "right to know" as well as that of withholding information to prevent harm (Meyers, 1996). Very little research, however, has been done about the preferences of individuals with dementia, the effects of disclosing the diagnosis directly to them, or the ways in which they try to cope. Woods (1999) thus argues that people with dementia are the "hidden victims", not because of the effect of the disease but because their experience of the illness is ignored. Disclosing a diagnosis of dementia to

patients and family members is a complex event that requires the physician to consider the potential for psychosocial harm and the patient's moral and legal rights to receive the diagnosis (Connell et al., 2004). Many physicians tend to inform relatives first of the poor diagnosis and do not share the diagnosis with the person with dementia (Adelman et al., 2004; Drickamer et al., 1992; Erde et al., 1988).

The interaction that takes place between physician and patient is an exercise in communication (Cockerham, 1998). The effectiveness of physician-patient interaction depends upon the ability of the participants to understand each other. Fisher (1984), for example, reports that a failure to explain a patient's condition is a serious problem in medical encounters. The difficulty is that most physicians are not trained to be the bearers of bad news. Physicians often use indirect methods of "telling" that are thought to cushion the blow for the patient. Physicians may use euphemisms, such as 'tumor' instead of 'cancer', 'forgetfulness' instead of 'dementia', or medical jargon so they can reassure themselves that they have fulfilled their responsibility of telling the patient (Foster, 2001). Although families are useful sources of information and need attention, the early stage of dementia is a critical time to elicit patients' values and preferences for treatment and to allow the patient to maximize quality of life and to plan for the future (Silliman, 2000).

To date, some literature is emerging that acknowledges the individual's experience, rights and perspectives (Bahro et al., 1995; Holroyd et al., 1996; Woods, 1999). These authors argue that persons with early stage dementia are valuable sources of information regarding their daily experience with dementia. It is, however, not

commonly accepted in North America that persons with dementia have a viewpoint, nor is it commonly accepted that if they do communicate a viewpoint then this should be listened to and acted upon (Marzanski, 2000).

Drawing upon data from a study of persons who are in the early stages of dementia and family physicians providing care, the purpose of this research is to examine communication practice between physician and dementia patient. This research will also examine the influence that a companion has on the medical encounter. Guiding this research is the sociological literature on physician-patient interactions and the social dynamics of dyads versus triads.

In the next chapter, I explore the basis on which these power variations rest, how such power differences affect the interaction between physician and patient, and how older and/or dementia patients resist the dominance of physicians. Where as chapter III is devoted to reviewing the literature pertaining to physician-patient relation, the goal of chapter IV is to address the purpose, design and methods used for this research. Chapter V covers in detail the results of both the physicians' questionnaire and the patients' interviews while Chapter VI deals with the discussion, limitations and recommendations. The brief conclusion serves to bring the dominant themes and arguments together.

Chapter II

THEORETICAL PERSPECTIVES ON PHYSICIAN-PATIENT ENCOUNTERS

“Let me start with my fear of doctors-which is not a fear of physical pain but more a fear of being silenced, of being made feel like a child, of being told directly or indirectly that I ought not to question, and that I need not understand-that’s the doctor’s business, not mine. A fear of not being given all the relevant information that I ought to have; a fear of loss of control to authority and expertise of medicine”
(Janet, quoted in Sherwin, 1998, p: 1).

This chapter examines some different theoretical perspectives on power differences between physicians and patients in the medical encounter. With respect to the physician-patient relationship there are two competing theories, the consensus-model of Parsons (1951) and the discrepancy-model of Freidson (1970). Extending these models of interaction, the view of Szasz and Hollender (1956), who postulate that the seriousness of the patient’s symptoms is the determining factor in physician-patient interaction, will be introduced. To understand how the patient experiences the illness and how the lived experience comes to be represented in the medical encounter, it is important to consider Smith’s work (1990) on the “disparities”. Finally, the theoretical view of Simmel (in Wolff, 1950) on dyads and triads will be addressed. Even though Simmel’s perspective on triadic relationship can be applied to many situations, it needs to be emphasized that Simmel’s work on dyads and triads has not yet been applied to medical encounters. I will begin, however, with a brief overview of a functionalist perspective on medical encounters.

Functionalist Perspective on Medical Encounters

According to functionalist theory, being sick is dysfunctional because it threatens to disrupt the stability of the social system. Physicians thus function to restore the equilibrium by both curing and preventing disease. The consensus-model, based on functional theory, assumes a harmonious relationship where the physician is leading and the patient is following (Parsons, 1951). High status and control in relation to the patient characterize the physician's role. There is a normative pattern of trust; the physician will be attentive to the needs of the patient. In turn, the patient has to cooperate and do everything the physician advises to become healthy as quickly as possible. Such perspective formed the basis for Parsons's theory of the sick role.

The sick role views the patient-physician relationship within a framework of social roles, attitudes, and activities that both parties bring to the situation. Parsons' discussion begins with the notion that the sick person suffers a disturbance of capacity. Once the incapacity is recognized, the sick person moves into the sick role. According to Parsons, occupants of the sick role are exempt from responsibility for the incapacity since it is beyond their control and they are therefore exempt from normal social role obligations. The patient, however, is expected to recognize that to be ill is inherently undesirable and that he or she feels obligated to try to get well. Finally, the person in the sick role has an obligation to seek technically competent help and to cooperate in the process of getting well.

The physician's role, on the other hand, is one of being the technical expert who is qualified and defined by society as prepared to help the patient. The goal of the

physician thus is to make acceptable to the patient the things the physician must do in order to perform his function (Parsons, 1951). The goal of the patient-physician encounter therefore must be to promote some significant change for the better in the patient's health. The power and status of physician and patient, however, are not equal. The role of the physician is based upon an imbalance of power and technical expertise favorable exclusively to the physician. Such an imbalance is necessary in order for the physician to promote positive changes in the patient's health. The role of the physician, thus is seen as socially beneficent, and the patient-physician relationship as inherently harmonious (Parsons, 1951). This Parsonian "activity-passivity" frame of reference underpins much of the older patient-physician visits.

Also within a functionalist framework, Szasz and Hollender (1956) add an additional perspective on the physician-patient interaction. These scholars postulate that the seriousness of the patient's symptoms is an important factor in the physician-patient encounter. Depending on the severity of symptoms, Szasz and Hollender argue that physician-patient interaction falls into one of three models: activity-passivity, mutual participation, and guidance-cooperation.

The *activity-passivity* model applies when the patient is critically ill and decisions often have to be made quickly. Decision-making and power in the relationship are mostly on the side of the physician, as the patient is passive and cannot contribute much to the interaction. The *mutual participation* model, conversely, is applicable to patients who have a disease such as breast cancer. Here the potential for negotiation or partnership often is present. With breast cancer, for example, where various treatment

options might exist, and where there is often sufficient time to negotiate, patients can become effective advocates or partners in care. Finally, the *guidance and cooperation* model arises when the patient is suffering from an acute illness and remains alert. The patient who feels sick seeks the assistance of the physician and is ready and willing to cooperate. The patient does not possess the knowledge and thus allows the physician to take control and perform the healing function. Seeking the advice of an expert, the patient places the physician in a position of power. The patient acknowledges that the physician possesses knowledge of his bodily processes, thus resulting in a more powerful position. This model closely follows Parsons' sick role perspective with an emphasis on the patient's obligation to cooperate fully with the physician and to recovery from his ailments. Parsons' sick role, however, has been subject to criticism.

While the sick role concept fits acute, curable illnesses, it is not easily adapted to the features of chronic illnesses (Lupton, 1994). Chronic diseases, such as dementia and cancer, are by definition not temporary, and often the patient cannot be expected to get well as Parsons' model suggests, no matter how willing the patient may be to cooperate with the physician. Critics further argue that Parsons typifies patients as compliant, passive and grateful, while physicians are represented as universally beneficent, competent and altruistic. More recently, assumptions underlying the patient-physician relationship have shifted from the physician as professional provider of medical knowledge and the patient as unquestioning recipient of medical knowledge, to the patient as a more active participant in medical decision-making (Haug et al., 1983; Haug, 1994). Today, this "doctor/patient-negotiating model" (Haug, 1996) is increasingly

commonplace due to economic influences of managed health care, direct marketing of pharmaceutical products to consumers, and rapid growth of medical information via the Internet (Fortinsky, 2001). Patients ask questions, seek explanations, and make judgments about the appropriateness of the information and treatment physicians provide. Functionalist theory therefore can be criticized as being paternalistic, as too readily assuming that patients should place their trust in the physician, as paying insufficient attention to the patient's perspective, or to the patient's ability to challenge, negotiate, and collaborate with the physician

In sum then, Parsons' concept of the sick role details the obligations of patients and physicians toward each other. Patients cooperate with their physicians and physicians attempt to return patients to as normal a level of functioning as possible. The relationship is one of mutual agreement, with physicians being portrayed as active and patients as passive.

Conflict Perspectives on the Medical Encounter

In contrast to Parsons' consensus model, Freidson (1970) argues that there is an inherent discrepancy between the expectations of the patient and what the physician can actually offer. Freidson agrees with Parsons that there exists a large gap in status between patient and physician. This gap serves the controlling function of physicians in medical encounters. Freidson, asserts, however, that only part of the physician's control is used to advance the patient's interests; the physician also uses control to maintain his institutional authority. Much of the claims of professional expertise in medicine rests on "knowledge" of disease and has significant effects in terms of the distribution of power

and authority. Patients look to physicians for guidance because they possess medical knowledge that the majority of patients do not have. Medical knowledge, moreover, is thought to be “scientific,” meaning more reliable, “objective,” and less variable than other forms of knowledge or patients’ beliefs. This perspective places the physician in absolute control of the medical encounter. It contributes to a feeling of superiority for the physician while the patient feels subordinated. The model of the physician as authority figure and the patient as subservient has been challenged by Haug and other (1983).

Haug and colleague (1983) proposed a new more egalitarian perspective called the *negotiation* model. This negotiation model implicitly empowers patients to act as equals in any interaction with physicians. By challenging physician authority, patients are asserting their right to be autonomous actors in a medical encounter. Joint decision-making and negotiations to resolve any differences between the physician and the patient can further characterize this model. They postulate that each party to the interaction brings different resources to the encounter, and is prepared to negotiate an acceptable set of terms for the relationship, which may include agreements on both diagnosis and treatment. Neither participant thus is automatically in charge. In the end, the physician provides only advice, while the patient makes the decision on what action to take, including taking no action at all. Age factors in the adoption of more egalitarian interaction between physician and patient where the younger cohort of better-educated patients are less likely to be as compliant. Some older patients may reject this equality and simply want the physician to tell them what to do.

Older patients may have different expectations of the physician and their own role in the medical encounter than younger patients (Haug, 1994). Some older patients might still ascribe to the notion of the physician taking charge and might accept the more submissive stance implied by Parsons' sick role (Haug et al., 1983; Haug, 1994) and thus are comfortable with the "old-fashioned", familiar style of "doctor in charge" (Haug et al., 1983, p. 223). Haug (1994) also argues that it is important for physicians to show respect for an older patient's dignity. Showing respect for an elderly patient involves not interrupting the elder when he/she is talking, not talking at the same time as the patient, not becoming impatient if the elder is slow, and giving enough time to the medical encounter.

Older patients with chronic illnesses, moreover, are frequently accompanied on their medical visits by informal caregivers (Haug, 1994). From a clinical and health care delivery perspective, it is important to understand third-party family members' experiences and expectations in relation to their own health care needs. Reassurance is an important source of support for the stressed companion while giving credit for providing useful information about the elderly patient helps build a strong relationship between the companion and the physician. As Haug notes, family members may even become hidden patients, with their own needs to be met by the physician. More recently, Woods (1999) has argued that patients with dementia rather than companions are the hidden patients, not because of the effect of the disease but because their experience of the disease is ignored.

Waitzkin (1984) extends these conflict perspectives by arguing that the “micro-level” interaction between physician and patient occur in a social context, which is shaped by “macro-level” structures. For Waitzkin, a Marxist-oriented researcher, the role of medicine is to hide the social and political determinants of ill health. He maintains that physicians support a capitalist status quo by rendering the illness as individual resulting in much ill health. He states, for example that “certain features of doctor-patient encounters ‘medicalize’, and therefore depoliticize, the social structural roots of personal suffering” (p. 339). He further argues that in their position of dominance over patients, physicians can make statements that reinforce the dominant capitalist ideologies by directing patients’ “personal troubles” away from “social issues.” This is a perspective supported by Smith (1990), who focuses on the influence of gender.

Smith (1990) argues that there is a discrepancy between the patient’s lived experience and how the physician translates the patient’s story into a clinical account. Smith suggests that physicians, through their medical discourse, translate the lived experience, or primary narrative, into clinical “data”. Translating a patient’s narrative into a clinical account almost always involves eliminating or editing out certain aspects of the story that might not be considered relevant by the physician. In other words, the physician negates those parts of the story that do not “belong” to the clinical account and only keeps those segments that do. The result is two “voices”: The legitimate “voice of medicine” which involves only the technical details of disease and treatment, whereas “the voice of the life-world” includes elements of the patient’s everyday social relationships and activities that comprise the context of the medical encounter are

discounted. Smith argues that the voice of the life-world is lost in the process of describing and analyzing the patient's narrative into technical or medical concerns. By questioning, by interrupting, and by shifting the direction of conversation from non-technical problems to technical ones, physicians exclude the social roots of personal problems. The physician privileges objective and technical approaches over subjective ones when translating data into theories. Such technical emphasis, for example, can be seen in biomedical theories of dementia.

Biomedical theories of the causes and experiences of dementia describe dementia as a "disease" and as the loss of "normality" (Bond et al., 2001) without examining the experience of a dementing illness. The patient with dementia becomes a "case" whose lived experience is bypassed and who is clinically labeled as "patient suffering from dementia". The medical voice explaining dementia offers a nearsighted view of dementing illness, focusing only on those aspects that can be explained as brain disease while neglecting much of the daily experience of chronic illness and intellectual impairment, both for the person with dementia and his or her caregiver. Using Smith's "actuality-data-theory circuit", we can explore the break between the lived experience and the clinical production of data.

All in all, according to the conflict perspective on medical encounters, medicine is viewed as helping to legitimize and reproduce social class structure and the economic system. The large gap in status between physicians and patients further serves the controlling function in medical encounters. It thereby maintains the position of dominant interests, and in the process, achieves power for its members. Physicians during their

interaction with patients, for example, may define health as the capacity to work productively, for “the healthy person is the person who produces” (Waitzkin, 1984: p. 340).

The traditional asymmetrical relationship based on the competence gap, with the physician in charge as an agent of social control, nevertheless, does not hold universally. Freidson’s theory of discrepancy, for example, allows for some negotiation to take place between physician and patient. Increasing the patient’s voice, however, can be a threat to professional autonomy. One method of preserving professional control is limiting communication and maintaining uncertainty among patients. Another method of maintaining physicians’ power is ignoring or eliminating patients’ lived experiences (Smith, 1990).

A limitation of both the consensus and conflict perspectives are that they both tend to decontextualize the encounter into that which occurs between the physician and the patient without making reference to accompanying individuals.

The Sociology of Triads and Its Impact on Medical Encounters

In his examination of the dyads and triads, Simmel (in Wolff, 1950) notes that the interactional dynamics of a two-person group changes completely when a third person is present. Simmel further argues that triads tend to segregate into a pair with the more active participants of the group forming a solidary bond while isolating the least active participant. This theorist reasons that a triad, or three-person group, differs from a dyad. If one person leaves, the group will survive in the form of a dyad. Since one person cannot destroy the group, the group can achieve domination over the individual. The

triad thus can impose its will upon one member through the formation of a coalition by the other two members. Although it is important to note that Simmel did not apply this thesis to medical encounters, his arguments about dyads and triads are, however, very powerful and can be applied to many individuals that compose groups, including interaction between physicians, patients and companions.

In medical practice, for example, efforts to make patients submit to medical “cooperation” often involves the formation of coalitions, with two stronger members possibly uniting against the weaker third member or one member trying to manipulate each of the others to gain special power. Three types of strategy are open to the third participant: playing the role of mediator between the other two and helping to keep the group intact; turning a disagreement between the other two to his advantage, or intentionally creating conflicts between the others for his or her advantage. Because these sorts of coalitions could not occur in a two-person group, the entrance of a third person into a dyadic group changes the nature of the relationship (Adelman et al., 1987). The logic of Simmel’s dyad and triad theory further applies to the forming of coalitions in medical encounters. The consequences of group size for medical interaction between individuals who bring a companion to the medical encounter emerges frequently in the older population and in the dementia population in particular.

Health care triads and dementia.

The concept of “health care triad” has emerged in recent decades to describe encounters and interactions among older patients, family caregivers, and physicians (Adelman et al., 1987; Adelman et al., 2000; Haug, 1994). Older adults visit physicians

more often than do younger persons and the frequency is expected to continue to increase for the foreseeable future due to the aging population (Beisecker, 1996). The increasing longevity of the population also means a substantial rise in the prevalence of dementia, particular, Alzheimer's disease. Patients with dementia progressively lose their cognitive functioning as the disease process advances overtime, and consequently, are accompanied by a family caregiver. In the few studies on older patient-physician communication patterns researchers found that many physicians see patients with dementia as "incidental subjects and passive recipients in the process of their dementia" (Keady et al., 1999). Such an attitude may lead patients with dementia to be more passive and allows physicians to make decisions for them. Neither the magnitude of a Parsonian dementia patient-family caregiver-physician interaction nor its consequences have been systematically studied. Simply put, "no theory to explain behavior during geriatric medical encounters has become widely accepted." (Beisecker, 1996, p:24).

Conclusion

The physician-patient relationship is undergoing a paradigm-shift away from the traditional paternalistic model towards a new form of decision-making, which explicitly recognizes the patient's autonomy. Shared information about values and likely treatment outcomes is an essential prerequisite, but the process also depends on a commitment from both parties to engage in the decision-making process. The physician has to be prepared to acknowledge the legitimacy of the patient's preferences, and the patient has to accept shared responsibility for the treatment decision. Some physicians, based on the competence gap, alienate patients' participation in medical decision-making.

Although Parsons optimistically claimed that the competence gap could be bridged by the normative pattern of “trust”, other analysts were less hopeful. Freidson, for example, argued that physicians’ special social position of institutionalized privilege is threatened by the demand for their actions and decisions be explained and justified to patients. Physicians, however, have the ability to control information and thus support dominance and subordination in medical encounters. More recently, assumptions underlying the physician-patient relationship have shifted from physician as professional provider of medical knowledge, to patient as a more active participant in medical decision-making. Increased consumerism is accentuated in the older population. Still, some older patients with a lifelong deference to physicians find it unsettling to be expected to interact on an apparently equal footing. These patients came of age during times when the physician was a traditional power figure, someone to be revered and obeyed (Haug et al., 1987).

One major characteristic that distinguishes the medical visits from many other encounters is that often a third person accompanies the older patient to the physician. Parsons’s sick role model is based upon a traditional one-to-one interaction between patient and physician. Parsons thus focuses on the dyad. The physician-patient interaction is different when a companion enters the medical relationship. A criticism that indeed, can be leveled against all previous outlined theories.

Current medical encounters most likely portray a physician-patient relationship based on that of Szasz and Hollender’s mutual participation model in which patients and physicians share responsibility for decision-making and treatment outcomes. The

interaction that takes place, however, appears to be strongly affected by age differences and levels of cognitive impairment. Older patients, in general, tend to be more passive in dealing with physicians as authority figures. Despite different patient behavior than that portrayed in Parsons' model, patients with dementia sense they have traveled back in time to a 1950's model of treatment. Patients with cognitive impairment feel that little physician-patient relationship exists (Marzanski, 2000). Physicians, for example, frequently treat these patients as absent when they are physically present, thereby denying the existence of the human subject.

The aim of this research was to examine physicians' attitudes and practices in regard to telling patients a diagnosis of dementia and to explore the effect of being told the diagnosis of dementia from the perspective of the person with dementia. The researcher will be using a conflict analysis of physician-patient interactions; particularly Smith's work on how the patient's lived experience with dementia comes to be represented by physicians.

As has been noted by Smith, patients and physicians have different conceptions of the reasons for an encounter. Patients seek the care for an illness, defined in subjective terms, while physicians evaluate symptoms in terms of disease, supposedly drawing on objective facts in scientific fashion. Physicians' ability to preserve their own power in physician-patient relationships may depend on the ability to translate the patient's lived experience into a clinical account, emphasizing physical and biological parameters while viewing patients as "cases" rather than individuals. Physicians tend to discount the importance of patients' narratives in their reliance on technological forms of assessment,

as if the scientific way of knowing is the only way of knowing anything. Applying the theoretical lens that physician-patient interaction is rooted in a power relationship, chapter III will further explore how physicians maintain their power by controlling the flow of information to their patients resulting in uncertainty about the diagnosis, the course of the illness, and possible treatment. This is especially true for patients diagnosed with dementia.

In geriatric medical visits, the patient is frequently accompanied to the visit by a third person resulting in a triadic relationship. The current literature on triadic medical visits lacks research on how this relationship is played out when the patient has dementia. The earliest work done on dyads and triads was by Simmel (in Wolff, 1950). Although Simmel did not apply his thesis to dyadic medical encounters, nor to an even more complex phenomenon, that of triadic medical visits, his analysis of small group interaction may be applicable to the physician-dementia patient-companion relations.

Chapter III:

PHYSICIAN-OLDER PATIENT RELATIONS

The quality of communication between older patients and their physicians is critical to the provision of medical care (Adelman et al., 2000). Research on physician-patient communication in general is not new, however, it is only recently that researchers have paid attention to interactions between physicians and their older patients. The goal of this chapter is to highlight a number of communication issues that are particularly pertinent to medical interaction with older patients. After discussing how both physiological impairments as well as ageist attitudes may produce or maintain power imbalances on the part of physicians, the chapter will turn its attention to how the introduction of a third party within the medical encounter may alter the dynamic between older patients and their physicians. Building on this, a typology of roles will be introduced in relation to third party dynamics. Finally, the implications of these practices and dynamics in relation to patients suffering from dementia will be discussed with special attention given to full-disclosure.

Communication Issues with Geriatric Patients

Despite overwhelming evidence documenting the growth of the population of older adults (Ellingson, 2002) and their extensive use of health services, little is known about how physicians relate to elderly patients (Meeuwssen et al., 1991; Beisecker, 1996; Tates et al., 2001). Visits with older patients differ in significant ways from physician interactions with younger patients (Adelman et al., 1987). Compared to younger patients,

for example, communication with elderly patients is more likely to be complicated by sensory deficits, functional limitations, and negative attitudes.

One of the most important sensory changes that occur in a large number of older people is a decrease in hearing (Adelman et al., 2000). Visual cues are also vitally important in normal interaction. Given that a large percentage of elderly people do have hearing and visual problems, effective communication may be compromised (Beisecker, 1996). Many older patients have functional limitations as well. These limitations make it difficult for patients to negotiate the demands of a medical encounter. Getting to the office, for example, can be emotionally and physically taxing. Physician visits for some frail older patients, indeed may be so difficult to co-ordinate that they may tend to see the physician less frequently (Ellingson, 2002). Few studies have focused on physician-older patient communication (Greene et al., 2000). The research conducted is characterized by attention to the older adult population as a subgroup of all patients, and there is a lack of sufficient attention to the special concerns and needs of the older patient group (Adelman et al., 1991).

Hasselkus (1994) examined patterns of increasing dependence in combination with the authoritarian traditions of medical care and found that physicians frequently make unwarranted assumptions about older patients' loss of function. Greene and colleagues (1986) revealed that physicians were less egalitarian, less patient, less engaged, less respectful, and less supportive in discussions of patient-raised topics with older patients than with younger counterparts. This reflects, to a certain extent, ageism amongst physicians. Haug (1996) argued further that ageism, the system of destructive

false beliefs about the elderly, is believed to play a significant role in physician-elderly patient interaction. Ageism may cause physicians to discount certain complaints of older patients, to ignore treatable conditions inappropriately attributed to normal aging, and to generally consider elderly patients more difficult to deal with (Beisecker, 1996).

Cohort socialization, or the learning of norms, attitudes and values by persons born during a particular period, also impacts older patient-physician interactions. Active patient involvement can be hindered by physicians' characteristics, such as age, gender, years in practice, or type of setting. As described by Haug and Ory (1987), older cohorts of physicians were trained in a period when the model physician-patient relationship was one of dominant physician caring for the submissive patient. Older patients, based on their socialization, are more likely to respect the dominant physician role, not to question his expertise and to obey his orders.

Adelman and colleagues (1991) have argued that since older patients, in general, have less education than their physicians, they are placed at a disadvantage within the physician-elderly patient power relationship. These researchers reported that the degree to which physicians allow patients to tell their own story has influenced both the qualities of data-gathering function and patient outcomes such as satisfaction and compliance. Physicians seem reluctant to let patients tell their stories and in general allow them to express only about one third of their most important concerns (Hasselkus, 1994; Ownes et al., 1996). The more persons are able to express their concerns fully, however, the more likely they are to comply, and the better are their outcomes of care. The older patient-physician relationship thus mirrors Szasz and Hollender's (1956) "activity-

passivity” model in which the patient leaves the decision-making to the physician and where the patient complies with the physician’s orders.

It can be argued that the young-old population¹ has begun to dismiss the more passive approach of the generations before them. The “physician knows best” formula is beginning to be challenged, although this has not translated well to older patients (Beisecker, 1988). Many older persons are still not interested in knowing the details of their illness and are happy to have their physicians guide them and make decisions for them (Lofaso, 2000). For some older individuals, asking questions might be considered a challenge of the physician’s authority, against which they have been socialized. If the physician’s authority is accepted as ultimate, the expression of an opinion might be considered disrespectful (Glasser, et al., 2001).

Putman (1996) for example, reports that older patients are less likely to challenge the authority of the physician, yet Ong and others (1995) suggest that future cohorts of older individuals may not be similarly inclined. Beisecker and Beisecker (1996) have described younger patients as more likely to have a consumerist attitude and therefore are more likely than older counterparts to ask questions. Hasselkus (1994, p. 294) defines consumerism in medicine as “challenging the physician’s ability to make unilateral decisions-demanding a share in reaching closure on diagnosis and working out treatment plans.” The assertive attitudes of younger patients may have the unintended effect of creating tensions within medical relationships. Older patients might adhere to the passive

¹ The aged population can be divided into three age categories. Those 65 to 74 are often called the “young-old,” while individuals between the ages of 75-84 are referred to as the “old”, and finally, the “old-old” are those persons 85 and over (Haug et al., 1987).

or submissive patient role where younger patients prefer to be active participants in a medical relationship. The difference between younger insistent and older passive patients is not only an attitudinal one, but is further indicated by less assertive and controlling behaviors such as topic changes or direct challenges to the physician on the part of older patients (Beisecker, 1988).

Even if exposed to the need for a more humanistic relationship style, today's physicians are influenced by time constraints placed on the visit duration (Emanuel et al., 1995). For Emanuel the consequences of time pressures go to the very core of the physician-patient relationship by undermining trust; inhibiting patients from revealing concerns, particularly those of a sensitive psychosocial nature; and inhibiting their physicians from responding appropriately. In an increasingly managed health care environment, physicians have less time for older patients. Older patients, however, move and respond more slowly than younger counterparts and thus need more time for the physician visit.

Emanuel and colleagues (1995) suggest that the socio-emotional rather than the technical aspects of care are most likely to be abandoned under time pressures, further reinforcing the most alienating aspects of the biomedical model of care. The influence of time constraints on the physician style and patient communication may have the unintended effect of reinforcing the physician dominant role that most older patients are accustomed to experiencing, which reinforces their passive or submissive role.

In sum, the key themes that emerge from the literature on older patient-physician relations are ageism, cohort socialization, power inequality, differences in passive and

consumerist attitudes, and time constraints. One facet of the physician-patient relationship that has to date received only occasional attention is that involving a three-way interaction.

Companions in Physician-Geriatric Patient Interaction

Older patients are frequently accompanied to the medical visit by a third person, usually the patient's spouse, adult child, or a hired professional caregiver (Adelman, et al., 1987, 1991; Beisecker, 1988; Haug, 1996). Although there are no large data bases to estimate how often a third person is actually present in medical encounter, a small study by Adelman and colleagues in 1987 found that 20% of older patients were accompanied by a third person to a geriatric clinic. Some of the possible coalitions that may form during the medical encounter are: patient and child versus physician, physician and child versus patient, and physician and patient versus child. In the coalition of physician and child versus patient, there is a great possibility that the patient will be ignored. The authors further suggest three major roles for the third person: the advocate, the passive participant, and the antagonist. Both the advocate and antagonist role can be divided into several subtypes. Advocacy can manifest itself in different way. The third person might be patient activist or promoter, a patient extender, or a patient physician mediator. The antagonist role has two subtypes, the saboteur or under-miner and the opportunist. All these roles are based on the patient's perspective.

The roles of a third person can also be explained from a physician's perspective. In that case, the third person can be a physician promoter or a physician antagonist. Measuring the roles and effects of the third person is a difficult and complex task. For

example, when assessing physician informing behavior, it is important to note to whom the information is directed, the patient or the companion. In order for researchers to identify the third person as an advocate and promoter, for example, they must listen for many questions asked by the third person about patient-raised topics. The authors concluded their article by stating that a triadic relationship is not going away and hence, “geriatric physicians need guidelines to follow to determine the potential benefits and possible negative consequences of the third person’s presence” (734).

In 1987, there was very little empirical exploration of the roles and effects of the third person. All of the major literature of those days focused on the physician-patient relationship. Adelman and colleagues’ research was one of the first to address the triadic relationship in medical visits. This study is suitable as a stepping-stone for a more in-depth study of the traditional dyadic relationship to a triadic encounter that includes either an adult child, as spouse or formal caregiver. Its weakness is the lack of examining caregiver roles and functions during medical visits. Another weakness is the year that the study was performed making some of the information outdated.

The third person can potentially play many roles during the visit depending, for example, on the duration of the encounter, the particular content of the interaction, and the health status of the patient (Glasser, et al., 2001). In doing so, they might either facilitate or inhibit the development and maintenance of a trusting physician-patient relationship (Adelman et al., 1991). As will be revealed in the next section on companions in medical encounters, the presence of a third person in a medical visit can have a potentially positive, as well as a negative impact on the patient. It will also

become clear that no matter how minor the involvement of the third person during the visit, his or her presence significantly changes the basic dyadic relationship (Hasselkus, 1994).

Roles of Companions in Older Patient-Physician Encounters

Typologies of roles.

Several studies of the role of third persons in the physician-patient interaction examine the functions that accompanying persons play and offer typologies of roles of behaviors performed by companions (Rosow, 1981; Adelman et al., 1987, 2000; Hasselkus, 1992, 1994; Glasser et al., 2001). One of the first studies to address how companions functioned in interactions is by Rosow (1981). He argued that adult children accompanying their parents to visits with physicians act as interpreters of language, facilitate the exchange of factual information, explain and clarify meaning for both physician and patient, participate in negotiation of treatment, and provide emotional support to patients.

Based upon analysis of taped interactions between physicians and patients, Hasselkus (1992) found that companions acted in two primary roles. The first role, similar to Rosow's (1981) findings, is the "interpreter" whereby the companion participates in the interaction by correcting, adding to, prompting, answering for, and paraphrasing patient's comments, which may signal to physicians patients' needs for assistance. The role of "interpreter" is directed mainly towards the patient. The second role is the "practitioner," particularly when patients have marked impairments. In the practitioner role, the companion tends to interact with the physician as another

practitioner would, having extended dyadic communication with each other during history taking, decision making, and instruction giving. The role of “practitioner” is more aimed towards the physician.

Other research that assessed patients’ perceptions revealed that patients reported three primary roles of the companion: advocate, passive participant, or antagonist (Adelman et al., 1987). When the third person is supportive of the patient, the companion represents the *advocacy* role. The accompanying person might, for example, demonstrate efforts to help the patient understand what is being discussed, including the patient in the discussion, thus affirming adult capabilities as well as the patients’ rights in medical encounters. This third person actively and assertively encourages and empowers the patient. Similarly, the advocate might feel a responsibility to become a “facilitator” between physician and patient. Hasselkus (1994) reported that caregivers clearly attributed responsibilities to themselves when they paraphrased the physicians’ questions to help the patient understand.

The *passive participant* is a third person who is present but minimally involved in the encounter (Adelman et al., 1987). This individual may not be very knowledgeable about the patient’s disease or might be an older individual who has been socialized that the physician is the most powerful member of the triad, possessing the knowledge and the means to treat the patient. The passive participant thus disengages from the interactional dynamics between patient and physician. The passive companion does not challenge the authoritarian model of the physician-patient relationship.

The *antagonist* is a third person who works against the patient or the physician on either overt or covert levels. This person may be openly hostile or rude toward the patient and the patient's agenda is either discounted or ignored. The antagonist tries to take advantage of the patient or the physician or both (Glasser, et al., 2001). The antagonist, for example, may come to the visit with his or her own agenda. Issues raised may not reflect the older patient's needs and health concerns. Both physician and patient are at risk to be ignored in such medical encounters (Hasselkus, 1992). As Glasser and others (2001) concluded, additional people in the medical encounter have more than simply an additive effect on the communication processes; rather, the impact is one of increased complexity derived from the competing roles and necessary re-definitions of control and capability.

The impact of third person.

The work of American researchers Greene and colleagues (1994) provides the best information regarding the impact of a third person on communication between physicians and older patients during the medical encounter. To examine the dynamics of dyadic versus triadic visits, these researchers compared a matched sample of two-person and three-person medical encounters. It was noted that patients in triads were frequently referred to as she or he by physicians rather than by their proper name. It was further revealed that patients were less assertive in triads than in dyads and less shared laughter and joint decision-making took place in triadic than in dyadic encounters. The presence of a third person appeared to be somewhat compensatory in that the average number of topics raised during visits was no different when dyadic and triadic medical encounters

were compared. This compensation may have occurred at the patient's expense, however, in that physicians relied on the third person for information that otherwise could have been elicited from the patient.

Greene and colleagues (1994) further uncovered that the physicians and the companion often talked about, rather than with, the older patient during the medical visit. These researchers suggest that this behavior may tend to isolate patients and reinforce their dependency. It can thus be concluded that the presence of a third person has an impact on the patient but not necessarily on the physician. One possible reason for this finding is the physician's authoritarian position in the medical encounter. The physician, with his established authority and power, silences the patient. Glasser and colleagues (2001), for example, found those patients with companions received no more time than those without. Since the third person took some of the speaking time, patients actually ended up with less time as individuals. Moreover, patient's permission was usually not directly sought for the companion's presence to continue throughout the interaction with the physician, and this raises ethical issues about privacy and patient's rights (Adelman et al., 1987).

Patients in triads, on the other hand, expressed no less satisfaction with the visit than patients in dyads (Greene et al., 1994). The researchers deem it possible that patients who were accompanied to the visit invited the third person, who therefore served a needed role from the patient's perspective. There is thus a potentially positive function for the third person. The less assertive patient, for example, may have invited a third person to attend the medical visit to serve as an advocate.

It has been argued that physician-companion coalitions have been efficient in keeping patients more actively involved in the decision-making process. For this reason, physicians value involvement because of time pressure (Rosow, 1981). In health care systems that are increasingly “managed”, physicians struggle with time limitations constraining open communications which not only changes the nature of the dyadic older patient-physician interactions, it impacts on triadic communications as well. There are clearly benefits for older patients when a companion is present as an advocate for the patient’s interests, there are also limitations. Physicians, limited in their time, need to divide their attention between the patient and the companion. The interactions with a companion present do not appear to affect the length of a visit, they result in ignoring and/or limiting the patient’s questions (Waitzin et al., 2000).

To sum up thus far, these studies collectively highlight the importance of the third person in the medical encounter of older patients as well as the opportunities and challenges that their presence imposes. Companions are frequently participants in the medical encounter. They are even more likely to be involved in the management of chronic diseases in older adults and when patients have dementia. The severity of a patient’s illness, the age of the patient, and cognitive impairment are important variables affecting physician-patient communication. The challenge, as illustrated by Greene and colleagues (1994), however, is to not compromise the physician-patient relationship, while attempting to meet the needs of all parties involved, including the person with dementia. Harris (2002) who discusses the subjective experience of dementia, however, argues that people who have been diagnosed with dementia are still muted, and although

they may sometimes be heard, often they are not truly listened to. How then does dementia affect communication between the physician, patient, and companion?

Communication Issues between Physicians, Individuals with Dementia and Companions

“My doctor asks me how I am, nods when I tell him, and then asks me to step outside. He and my wife discuss me and then call me back and tell me what to do”
(Spencer, quoted in Harris, 2002, p. 41).

Marginalization of individual with dementia.

A complex communication discourse that can happen in triadic relations can become even more challenging when the individual is experiencing signs and symptoms of dementia (Cohen, 2001). Once a person has been diagnosed with dementia, a caregiver is often needed during a medical encounter simply because the person may no longer be able to verbally communicate his or her needs to the physician. Medical encounters involving persons with dementia and their companions show a progression whereby the physician interacts more with the companion and less with the patient as the disease worsens (Beisecker et al., 1996). The person with dementia becomes marginalized and this in turn may lead to the loss of normative adult participation in the communication aspects of the medical visit.

The triadic visit thus seems to represent a dimension of threat to the adult status of the patient (Hasselkus, 1994). The scenario of an older person being accompanied into the medical encounter by a family member, for whatever reason, is likely to convey a strong signal of dependence. Hasselkus, an American researcher, revealed that in interviews in which the patient has an obvious cognitive impairment, direct involvement of the patient was limited to the physical examination phase of the visit.

Hasselkus (1994) examined the three-person clinic visit as it relates to the nature of self-care independence and threats to the adult status of the older patient in the clinic setting. Data consisting of verbatim transcripts from 40 medical visits that included a physician, older patient, and family caregiver were examined for self care-related behaviors and interaction patterns. The data are examined to gain new understanding of clinic behaviors by the physician, the family member, and the older patient as they relate to dependence and independence. Further, the relationship between these clinic behaviors and observable patient impairment is explored in this triadic medical context. Categorization of the clinic visits into three levels of patient impairment revealed shifting patterns of interaction, with the most ambiguities about capacity and responsibility reflected in those visits that included a patient with mild to moderate impairment.

Initial efforts by the physician and caregiver to facilitate the patient's meaningful involvement in the interactions soon gave way to extended dyadic exchanges with periodic reengagement of the patient. Marked impairment in the patient was accompanied by a strong pattern of interactions between physician and caregiver, sometimes to the almost total exclusion of the patient. When the patient had no noticeable cognitive impairment, the discourse tended to be more equitable divided among physician, family member, and patient. In this circumstance, health care capabilities and responsibilities were treated as properties that were sometimes avidly negotiated by all three people; yet an inexplicable tendency for the physician and caregiver to address each other instead of the patient was often still present.

This is an excellent study that includes many narratives of medical visits illustrating the relationship between patient, caregiver, and physician. It addresses, if only very briefly, the issue of cognitive impairment and other impairments postulating that the physician and the caregiver tend to interact as two practitioners in an extended dyadic exchange during the history taking and decision making phase of the medical visit. Clearly, such an interaction pattern ignores the patient's own concerns and facilitates the companion's gatekeeper role. As American researchers Haug and Ory (1987) state, severe impairment from dementia will "virtually preclude meaningful encounters with a care provider" (p.12).

Haug and Ory's (1987) research on triadic medical encounters found that the interactions between the physician-dementia patient-caregiver indeed changes, with increasing attention being paid by the physician to the caregiver while communication between physician and dementia patients decreases. Marked impairment in the patient thus is accompanied by a strong pattern of interactions between the physician and the caregiver, to the almost total exclusion of the patient. When the patient experiences mild cognitive impairment, the discourse tends to be somewhat more equitably divided among physician, third person, and patient. A tendency for the physician and companion, however, to address each other instead of the patient was often still present.

Changing relationship back from triad to dyad.

Several persons with early stage dementia who were interviewed by Harris (2002), an American researcher, complained that physicians seldom communicate with them; rather, the communication was directed towards the companion. The triadic

medical interaction became dyadic in nature contributing to a feeling that the physician and companion were colluding to take away the patient's independence and relegates them to the role of an "object". Harris argued that there are multiple factors that influence communication between dementia patients and their physicians. One factor is the biological effects of cognitive impairment affecting the communication of the person with dementia. Equally important is that the typical form of the medical encounter tends to be a physician-companion dyad even though the patient is present. This suggests that physicians may have a tendency towards infantilizing patients with dementia.

In recent years there has been a growing acknowledgement that individuals with dementia have rights. This trend towards an emphasis upon autonomy in discussions about dementia is best illustrated by the topic of sharing the diagnosis of dementia (Woods, 1999). Although it appears that patients want to hear the truth about their conditions, in reality, diagnosis disclosure is not as straightforward or as common as we might expect.

Disclosing the Diagnosis of Dementia

The traditional paternalistic argument has always been, and continues to be, that the physician knows the true interests of the patient with regard to disclosure of "bad news" much better than the patient himself does, no matter what the patient may say he wants (Pinner, 2002). "The health care process portrays physicians as parent-like, strong figures who are permissive, supportive, objective, and ethical. Patients in this scheme act as relatively weak, dependent, childlike figures" (Hasselkus, 1996, p: 293). Consistent with the tendency to subordinate the dementia person, sharing the diagnosis for dementia

is seen as merely futile (Pinner, 2002). To date there still remains controversy about the value of making a diagnosis of dementia or communicating it to the afflicted individual.

Reasons why physicians do not disclose the diagnosis.

Many physicians feel uncomfortable with the communication process resulting in reluctance to disclose the diagnosis of dementia to the individual with the illness. Physicians have stated several issues that surround the disclosure for dementia to caregivers and individuals with the illness including the fear of causing distress and the fear of destroying or reducing hope or motivation. There is also concern about specific detrimental outcomes such as depression, suicide, or catastrophic reaction. Some evidence in the literature suggests that many physicians fear that disclosure might precipitate suicide (Rohde et al., 1995).

There is no conclusive evidence to justify any of these concerns. There are two studies involving a series of cases of dementia in which the individuals with the illness were told their diagnosis. In the first, no individuals seem to have been harmed by the information, although they did use various psychological mechanisms to protect themselves. These included denial, dissociation of affect, externalization, and displacement (Meyers, 1997). The other study showed that individuals' most common worries related to fear of others finding out, fears of social embarrassment, long-term dependency needs and not being listened to (Husband, 2000).

The objective of the research by British researcher Husband (2000) was to find out from people with dementia what they were worried about in relation to their diagnosis, and how they changed their behavior in relation to these worries. Both

physicians and caregivers express reasonable concerns that learning a dementia diagnosis may lead to distress, stigmatization, and depression, although there is little empirical evidence to support this view (Meyers, 1997). Lack of consensus among physicians about disclosure creates a situation where little is known of the effects on people learning they have dementia, or the ways in which they try to cope.

The qualitative study consists of a case series of 23 individuals newly diagnosed with dementia with a mean age of 68.9 years. The social stigma of dementia was an issue for all participants. People were ashamed of having dementia and felt that it was humiliating. They were concerned with maintaining secrecy and often lived in fear of other people finding out. They believed that others would treat them differently as though they were in a “second childhood” or “an idiot”. They were also concerned that they would become “stupid”, suggesting the potential for negative beliefs about the self. Participants were further worried about the long-term consequences, often expressing fears based on their previous, negative experiences of dementia or dementia care, with relatives or friends. The majority of people were worried about no longer being consulted or listened to, believing that once you develop dementia then your views “didn’t count” (546), particularly with physicians.

The worries reported by the participants in this study are of interest in terms of possible intervention to improve self-esteem, enhance well-being, and facilitate continued engagement in social communities.

The author addresses a gap in research by giving individuals with dementia a voice. Until the emergence of “person-centered” approaches to dementia care, the

experiences of people with dementia were an almost completely neglected area of research. There is, however, more to the story of dysfunction than simply the presence of brain damage resulting from dementia. Husband's study calls attention to the impact that the social and personal world of the dementia person can have on his or her behavior. The author has proposed that the person's social milieu can provoke reactions, both positive and negative, in the individual with dementia. Explaining in more detail a "person-centered" approach would have strengthened this research.

Another reason that has given rise to concern is the difficulty of accurate diagnosis. Drickamer and colleague (1992), drawing on their clinical experience in America, have summarized the reasons both for withholding and for disclosing the diagnosis. The reasons for sharing the diagnosis include: respect for the autonomy of people with dementia and the person's right to know; and their ability to plan for the future with respect to both health care and finances. Reasons for withholding the diagnosis include: its uncertainty and the variability of the prognosis; the absence of medical treatment; its potential to cause distress; the inability on the part of the person with dementia to understand the implications; the person's inability to cope with knowing; and family members not wanting their relative to know.

Drickamer and colleague effectively challenged physicians' concern for an accurate diagnosis. These researchers argued that, although the histological diagnosis is often uncertain in life, physicians still have the option of being "truthful" with their patients, making an honest presentation of the information as it is perceived and known. Such a challenge strengthens their study. Not only including the debate that it is good

practice for every patient to be informed about the illness and its implications but stressing that it is equally important to accept that some patients do not want to know the nature of their illness and thus informing them might be harmful is another strength of Drickamer and other's study. Their debate about the issue of informing persons with dementia is a further example of the importance of dealing with each person as an individual.

How do physicians actually practice?

A number of studies have investigated physicians' attitudes and practice. Rice and colleagues, for example, conducted a study in 1994 investigating medical practice by old age psychiatrists. Their findings indicated a wide variation in practice where caregivers were almost invariably told the diagnosis. Over 80% of psychiatrists responding to a questionnaire stated that they rarely informed severely demented patients. In contrast, they reported nearly always sharing diagnostic information with patients with mild dementia. Another 40% reported sometimes telling their mildly affected patients. Not surprisingly, practice regarding informing spousal caregivers differed in the opposite direction, with the relatives of more severely affected patients being more likely to be given the diagnosis. In cases where a diagnosis was given, few physicians followed this with information on the prognosis for the individuals.

The psychiatrists' reluctance appears to be operating on a mechanism of a wish to protect, but from what? Investigating patients' views on the matter of disclosure could complement this survey. It is important to remember though that the survey by Rice and colleagues was conducted in England in 1994. Since that time, advances in the accuracy

of diagnosis of dementia, as well as the introduction of new anti-dementia drugs, have stimulated a debate on whether individuals should be informed of their diagnosis. With the increasing awareness and the opportunities offered by drug therapies physicians may feel that they have something to offer following a diagnosis for dementia.

In 1998, Vassilas and colleague investigated the practice of general practitioners, asking them their practice in disclosing the diagnosis of dementia or terminal cancer to their patients. Two hundred and eighty one physicians returned a questionnaire. The results showed that only 5% of general practitioners always told patients and 34% often told patients the diagnosis of dementia. Interestingly, when asked if they told patients with terminal cancer, 27% always told and a further 67% often disclosed the diagnosis of cancer. Of 10 factors that influenced their decision to tell patients of their diagnosis of dementia, physicians rated the three most important as certainty of diagnosis (153 physicians), the patient's wish to be told (113 physicians), and the patient's emotional stability (90 physicians). The researchers suggested that as large numbers of patients with dementia are diagnosed in primary care, never seeing a specialist, general practitioners need to be actively involved in this debate. A study by British researchers Johnson and colleagues in 2000 supports these findings.

Johnson and colleagues (2000) used a questionnaire to survey the current practice and attitudes of old-age psychiatrists and geriatricians to disclosure of the diagnosis of Alzheimer's disease. The benefits of disclosure were examined, as were some of the concerns, fears and perceived potential harm. The results suggested that only 40% of specialists in health care for the older adults regularly tell patients their diagnosis and that

20% saw no benefit in telling the patient. However, 72% of the respondents reported that they would wish to know themselves if they were suffering from the illness.

Interestingly, 50% of those who believed that patients did not want to know wanted to know themselves.

In a recently published study, American researchers Boise and colleagues (1999) conducted focus groups with physicians to learn about barriers to adequate dementia diagnosis. This study investigated how primary care physicians assess patients for dementia and identified barriers to dementia diagnosis in the primary care setting. Seventy-eight physicians in three geographic areas participated in 18 focus groups.

Reported barriers included physician failure to recognize and respond to symptoms, limited time, perceived lack of need to determine a specific diagnosis, and negative attitudes toward the importance of dementia diagnosis and management. Three significant findings from this study were: (1) physicians were reluctant to determine a specific diagnosis because of the stigma attached to the term Alzheimer's disease; (2) physicians believed it was futile to determine a diagnosis unless and until effective drug therapies were available for their patients; and (3) family caregivers exercised considerable control over the degree of diagnostic aggressiveness pursued by the physicians.

The major strength of the study by Boise and colleagues (1999) is that they use interview rather than survey techniques. Their study, however, does not include the views of caregivers, nor of persons with dementia and thus does not shed any light on the

quality or content of the medical encounter after the diagnosis for dementia has been made.

There is growing empirical evidence that general practitioners are reluctant to share the diagnosis with people with dementia. To date little research has examined what physicians tell their patients and their families. The purpose of the study by Downs and his colleagues (2002) relied on data gathered from an opportunistic sample of 114 physicians practicing in Scotland who were attending a training course in care of people with dementia.

Findings of the study suggest that physicians withhold a considerable amount of information from people with dementia, information otherwise shared with the person's family caregiver. Physicians were more likely to provide family caregivers with a fuller picture of what is happening to their relative than to tell the person himself or herself. Consistent with previous research, physicians reported that they tended to disclose the diagnosis to family members but withheld it from the person with dementia. Physicians were more likely to disclose the diagnosis using medical terms and discuss the likely progression with the family caregiver than with the person himself or herself when discussing the illness. Instead physicians tend to "normalize" the experience for people with dementia and "protect" them from potentially frightening medical information.

The study suggests that future research should include qualitative as well as quantitative information when examining the issue of diagnosis disclosure, as simplistic forced choice answers may yield misleading findings. Future research must ascertain the

preferences of people with dementia for the substantive content and manner of delivery of information about their condition.

Few studies have investigated the manner in which physicians approach the person with dementia regarding the issue of revealing the diagnosis. This is an excellent study that addresses the issue of not only the communication between physicians, caregivers and the person with dementia, but also what the physician tells the person with dementia and their families. The authors failed however, to examine preferences of people with dementia, what they want to know about a diagnosis, if they want to be told, and what the effect diagnostic disclosure might have on them. Finally, the researchers concluded that physicians did not provide people with dementia and their families with relevant, balanced information both about their impairment and the range of available services to support them in actively living with his impairment.

Physicians, in a more recent American study by Connell and colleagues (2004) reported several obstacles to providing a diagnosis of dementia, including not having enough time for a comprehensive assessment during a typical medical visit and being inexperienced in dealing with diagnostic uncertainty. A total of 39 physicians participated in eight focus-group interviews. The study also examined the attitudes of 53 caregivers toward assessing and diagnosing dementia. The study found that caregivers and physicians differed in their reporting, particularly in regard to emotional response. Caregivers recounted a highly negative emotional response to the disclosure for dementia, whereas many physicians reported that families handled the information well. Caregivers also encountered barriers when seeking a diagnosis, including the time-

consuming nature of the process, not knowing where to turn for help, and sometimes the patient's reluctance to go to a physician. Caregivers reported benefits in obtaining a specific diagnosis of dementia as well. Benefits included a sense of relief by letting them know what is wrong, promoting adaptation and coping, and enhancing communication during medical visits.

A major strength of Connell and colleagues research is their usage of parallel open-ended questions for both physicians and caregivers in order to provide us with an in-depth examination of attitudes toward assessing and diagnosing dementia. Comparing perspectives may inform strategies for disclosing a diagnosis for dementia not only for physicians and caregivers but can also be applied to the present study about the individual's perspective on receiving the diagnosis for dementia. Overall, physicians tended to evaluate their own efforts more highly than did caregivers. Knowing this information might be useful for analyzing the current research.

What do caregivers want to know?

An earlier British study by Maguire and colleagues (1996) examined the views of relatives of persons with dementia and report the results of their attitudes to the disclosure of the diagnosis. A total of 100 consecutive family members accompanying patients with diagnosed Alzheimer's disease to a memory clinic were asked three questions by the assessing physicians. First, should the patient with Alzheimer's disease be told their diagnosis. Second, would they themselves want to be told their diagnosis should they develop Alzheimer's disease. Finally, would they make use of a predictive test for

Alzheimer's disease should it come available. They were also asked to state the reasons for their decisions.

Only 17 family members said that the patient should be told the diagnosis. 83 said that they should not be told. The main reason given was that the diagnosis would upset or depress the patient. In contrast, 71 family members wanted to be told their diagnosis should they develop Alzheimer's disease; most stated that it would be their right to be told their diagnosis. Seventy-five family members would use a predictive test for Alzheimer's disease; 42 of these said it would give them the opportunity to make provisions for their future and thereby reduce the burden on their families.

This research is a good example of the missing voice of the person with dementia. This study deals with family members only and demonstrates that certain concerns of the post-Parsonian literature, such as full disclosure of information to patients and patients' negotiation and collaboration with physicians, are of minimal relevance for patients with dementia. Family members not only think, but also act as if the person with dementia is incapable of making any competent decisions. Interestingly, the majority of family members want to be informed about the illness if they would suffer from dementia. Obviously, family members did not think about what the person with dementia is feeling. Individuals in the early stages of dementia often wonder what is wrong with them causing great anxiety. Woods (1997), for example, has argued that people with dementia are the "hidden victims", not because of the effect of the disease but because their experience of the disease is ignored. This research would be improved by eliciting the perspective of people with dementia.

Physicians, in order to avoid the family's sense of hopelessness and grief associated with a diagnosis of dementia, limited the amount of information they provide about dementia because they have difficulty delivering bad news, especially in light of the limited treatment options and generally poor prognosis (Maguire et al., 1996). A finding that is supported by earlier research by Connell and colleagues (1996).

The study by American researchers Connell and colleagues (1996) bridges the gap by investigating caregivers' attitudes toward obtaining a diagnosis for dementia. Two hundred and thirty three spousal caregivers participated in this study by returning a questionnaire. The objective of Connell's research was to examine the attitudes of caregivers about the process of obtaining a diagnosis for dementia. Several questions about attitudes toward diagnosis, as well as items that assessed benefits and obstacles to obtaining a diagnosis were included in the survey. It was found that more than 75% of the participants rated the benefits of obtaining a diagnosis as very important. Knowing what caused their spouses problems gave them the opportunity to get information about dementia, to participate in drug treatments, and to plan for the future. Some of the obstacles in obtaining a diagnosis for dementia included the amount of time it takes to get the diagnosis, difficulty accessing knowledgeable physicians, and lack of referral to a specialist.

Adding two open-ended questions at the end of the survey and the quotes selected to illustrate each theme definitely strengthened the study. Examining caregiver's attitude will further benefit the current research in eliciting individuals' experiences with

obtaining a diagnosis for dementia. Most, if not all barriers experienced by caregivers might be applicable to persons with dementia as well.

What do persons with dementia want to know?

In a recent study by American researchers Adelman and colleagues (2004) older, cognitively intact persons and their caregivers were asked about their desired discussion of memory when visiting the geriatrician. The researchers found that memory was discussed in 62% of dyadic visits and in 55% of triadic visits. In those visits in which memory was not discussed, about 35% of the patients would have wanted to discuss memory. In this study, many of the older individuals, as well as their family members expressed a desire to discuss memory. Some of the individuals who participated in this study felt that it was the physicians' responsibility to raise questions about cognitive functioning. This finding might explain why physicians raise the topic more often than older adults. Physicians, however, do not make questions about memory problems a standard practice. One of the barriers to addressing the issue of memory is physicians' lack of comfort and/or lack of knowledge about how to initiate the discussion in a sensitive way.

By examining the views of older, cognitive intact individuals Adelman and colleagues will help us gain some insight into the views of elderly individuals with dementia. This article thus is one of the core research findings that can be used to expand the current study of the individual perspective.

The debate about the desirability of disclosing or withholding the diagnosis of dementia, however, is growing as more individuals are diagnosed at the earlier stages of

the illness (Fortinski et al., 1995). This trend is encouraged by recent advances in drug treatments which can be effective in staving off some of the most negative effects in the early stages (Woods, 1999). Very little research, however, has been done about the preferences of individuals with dementia, the effects of disclosing the diagnosis directly to them, or the ways in which they try to cope. Existing sociological studies of dementia seldom deal with afflicted individuals themselves.

Marzanski (2000), a British researcher, is one of the first researchers who addressed the issue of disclosure of a diagnosis of dementia from the person's perspective. The objective of Marzanski's study is to discover what individuals with dementia feel is wrong with them, what they have been told and by whom, and what they wish to know about their illness. Thirty persons with dementia and agreed to participated in this study. All of them had a clinical diagnosis of dementia. All participants gave verbal consent and answered a set of standard questions regarding information they had received about their illness. The answers were recorded verbatim and were the subject of further analysis. Three questions were asked: (1) what do you think is wrong with you, (2) what have you been told about your illness, and (3) what would you like to know.

The majority of the participants with dementia declared they would like to know what was wrong with them or wished to get more information if they already knew. More than half of the participants further preferred that their physician give them information about their illness. Yet, twenty out of 30 participants reported that nobody had ever talked with them about their illness. Fourteen out of 30 participants were able to give the correct diagnosis or, at least, were able to describe adequately their main

symptoms. No participant, however, used the word “dementia”, although the majority complained about memory problems.

Marzanski concludes that his study seems to suggest that physicians “really ought to ask patients with dementia whether they wish to know more about their diagnosis” (p: 108). Each person must be approached individually and his or her choices respected what ever the level of his or her impairment. Physicians need to repeat the information again and again, which implies that they must have the requisite communication skills to provide information in various ways. The effect, however, of telling or not telling individuals with dementia their diagnosis remains unknown and requires further research.

Until now, there was not any published study exploring the wishes and preferences of individuals with dementia. Marzanski is one of the first researchers who addresses the issue of disclosure of a diagnosis of dementia from the person’s perspective. The researcher involves not only the view of the person in the early stages of the illness but also the individuals with later stages of the disease. Another strength is the fact that Marzanski stresses that besides the right to know, there is also the right not to know. Although many persons with dementia would like to know the truth, this researcher also emphasizes the importance of the rights of those who do not want to know. The individual’s perspective has been largely ignored in studies of dementia. The person with dementia is often relegated to the status of object rather than legitimate contributor to the research process. This study will be used for the current research to gain a deeper understanding of persons’ views regarding their illness and care.

A recent study by American researcher Young (2002) illustrated that while individuals who received a diagnosis may experience distress, withholding a diagnosis can also cause distress. Young further found that almost all of the 24 participants in her study were dissatisfied with their medical encounters. These persons experienced two types of frustrating interactions. Regarding the first, they were concerned about physician's failure to pursue medical interventions. Physicians were portrayed as unknowledgeable, letting the illness take its course, and not trying to manage it. The second type of medical dissatisfaction arose from the nature of the medical encounter, especially as it involved communication and interaction. Based on the dementia person's subjective experience, these individuals revealed that physicians viewed them as empty shells of their former selves, so that the attention focused on the needs of the companion, not the dementia patient. Young further argues that physicians frequently withdraw from dementia persons and focus instead on their companion. The addition of a family member leads the physician to rely on the companion for information that otherwise could be obtained from the older individual with dementia, relegating the person to the role of passive participant (Greene et al., 1994). The person with dementia is seldom asked direct questions and frequently, they are not told directly of the diagnosis.

Researchers are beginning to provide more information on the views of persons with dementia about the issue of diagnosis (Pratt et al., 2003). The aim of their British study was to explore the effect of being told the diagnosis of dementia from the perspective of the person with dementia. In order to elicit the perspectives of persons with dementia on the process of receiving the diagnosis, these researchers used a

subjective approach. Pratt and others addressed several concerns including the debate about disclosure, disclosure practices, the under representation of persons with dementia in research and the need to develop psychosocial understandings of the experience of people with dementia.

Pratt and colleague (2003) propose a psychosocial model for understanding the experience of patients with dementia. These researchers postulate that living with dementia involves two aspects; the patient's desire and ability to know the diagnosis and the social context surrounding the person with dementia. Both these aspects are necessarily linked and represented as two axes. These two axes divide the model into four quadrants: detachment, distress, maximizing coping, and decline and denial. The patient's lived experience can be placed in any of these "quadrants" based on the combination of social context and the individual's response. The researchers argue that an un-supportive social context can lead to distress in the person with dementia while a supportive social context may result in stronger coping skills. One example to illustrate the impact of a social context on the individual's experience is that of sharing the diagnosis. In terms of sharing the diagnosis with a person with dementia who has the desire and ability to know his or her diagnosis, not telling the diagnosis may contribute to feelings of distress.

Conversely, disclosing the diagnosis to a person with dementia who does not want to know also may cause anguish. Physicians have a lot of power over deciding what to tell individuals about their diagnosis, prognosis and available support. Physicians, representing the social context, who are not supportive, can become a powerful obstacle

for persons with dementia. If disclosure practices do not reflect the wishes of the person with dementia, this can result in psychological distress.

It is important to remember though that the right to know one's diagnosis includes a right to refuse to be informed. As stated previously, on average, older persons are not interested in knowing the details of their illness and are happy to have their physicians guide them and make decisions for them (Glasser et al., 2001). Some older individuals may prefer to ignore the truth completely or to select only those parts of it that they want to know.

There are, of course, important ethical principles to consider in disclosure including the individuals "right to know" as well as that of withholding information to prevent harm (Meyers, 1997). The moral doctrine of diagnosis disclosure is derived from a respect for person's autonomy as well as beneficence (Gillon, 1985). Considering the principle of respect for autonomy and the principle for non-maleficence, one finds that these two goals are not necessarily incompatible but often lead to different decisions about what information is given (Meyers, 1997).

In sum, the physician-dementia patient-companion interaction is a dynamic process along a continuum from the time of diagnosis until death of the patient. The assumption exists that a dyadic physician-patient interaction, once dementia is diagnosed, becomes a triadic interaction. The analysis of the literature on triadic medical encounters, however, shows a clear pattern of dyadic interaction between the physician and the caregiver, sometimes to the almost total exclusion of the patient.

The communication pattern between physicians, patient and companion, particularly as to whether dementia patients should be told their diagnosis, supports the views of Parsons and Freidson who posits a large gap in status and power between patient and physician. There is also the assumption that people with dementia are unable to communicate in a meaningful way, invalidating their participation in decision making about their own care, as well as rendering their lived experience and their perspective as being impossible to research. Conversely, when individuals with dementia are encouraged to report their feelings, talk about problems, and share the ways they deal with anticipated loss, valuable information can be gathered. Physicians and caregivers must, however, be able to enter into the world of people with dementia, to recognize the different ways they express themselves. They must be willing to hear the voices of individuals with dementia. Physicians, in particular, may better serve dementia patients by treating them respectfully, as individuals, and encouraging them to express their feelings.

This literature review reveals that individuals with dementia do not have much control over the communication interactions. As one man said angrily: “Any answers you want, ask my wife, just as the doctor does” (George, quoted in Young, 2002, p: 40).

Summary

There is a growing interest in the research area of disclosure of dementia (Johnson et al., 2000). A number of studies of primary care physicians’ practice in this area suggest that individuals with dementia are often not told their diagnosis or prognosis (Marzanski, 1996), though patients with mild dementia are told more often (Rice et al.,

1994). There are a limited number of studies to date investigating the practice of physicians, asking them their practice in disclosing the diagnosis of dementia to their patients (Vassilas et al., 1998; Johnson et al., 2000; Connell et al., 2004).

Literature about interaction between patients with dementia, companions, and physicians is largely based on survey research with family caregivers, supplemented by a smaller body of research with family physicians. Based on these studies, there is some evidence from healthy adults that they would like to know if they had a diagnosis of dementia (Erde et al., 1988; Barnes et al., 1997; Maguire et al., 1997). To date, very little research has examined the medical encounter from the perspective of the person with dementia (Connell et al., 2004). Only a couple of studies have specifically investigated patients' view on disclosure (Marzanski, 2000; Pratt et al., 2003). Despite the central importance of diagnostic information for people with dementia and their families, relatively little research has examined what they are told about their condition. There is a need to continue to develop an understanding of the experiences of family physicians and individuals with dementia, particularly in relation to issues such as diagnosis disclosure.

The rationale for the present study thus is to explore the effect of informing the person that he or she has dementia from the perspective of the family physician, as well as the effect of being told the diagnosis for dementia from the perspective of the person with dementia. The study will examine family physicians' practices of disclosure and it will explore how people who have been told they have dementia feel about having being told and about the way they were told. Building on studies by researchers like Adelman et al., Drickamer and others, Marzanski, Young, Pratt et al., and Husband, such

information will help address the gap in the literature about the effect of being told the diagnosis and will guide best practice in diagnosis disclosure.

The focus of the next chapter will be on the methods used for this study beginning with outlining the three objectives, followed by the choice of method, recruitment of participants, data collection, ethical considerations, and finishing with the analysis of the data.

Chapter IV

STUDY METHODS

The purpose of this exploratory study was to determine family physicians' and patients' attitudes and preferences toward the assessment and diagnosis of dementia, particularly the manner in which the diagnosis was disclosed. The research also examined the experience of individuals with the illness when a diagnosis of dementia was given. Finally, the study explored the effects of the presence of a third person on the physician-dementia patient medical encounter. It is important to note that in this study companions were not interviewed. Including companions runs the risk of marginalizing individuals with dementia even further by rendering their accounts of receiving the diagnosis for dementia as invalid or at best unreliable. The individual's personal response to how the diagnosis for dementia was experienced might be overlooked, corrected or silenced on the grounds of perceived impaired judgment and assumed inability to understand, articulate or remember what was experienced on either a practical or emotional level. The researcher thus decided to listen to the voices of individuals with dementia rather than to the companions' accounts.

In this study, the term dementia rather than Alzheimer's disease was used so that all persons with dementia were included in this research. To further simplify the discussion, only a "primary" family caregiver was assumed in the health care triad, even though multiple family caregivers may be involved in physician interactions. The physician furthermore was assumed to be the family physician of the person with dementia although it is possible that some persons with dementia might receive the diagnosis from a specialist such as a neurologist or geriatrician. To decrease the

confusion surrounding this issue, the general term physician will not be used. Instead, whenever possible, the researcher will address the physician as either family physician or specialist. Physicians were also given identification numbers while all persons with dementia were given a pseudonym name to ensure confidentiality. As previously mentioned, the research was guided by a conflict perspective focused on therapeutic triads.

Objectives

The study specifically addressed the following research objectives:

1. To examine family physicians' attitudes and practice in regard to disclosing and discussing the diagnosis of a disease affecting memory and thinking, e.g. Alzheimer's disease
2. To examine persons' preferences about the process of obtaining a diagnosis of dementia, including perceived benefits and obstacles to obtaining a diagnosis and suggestions for improving the process
3. To examine the extent to which an accompanying person can facilitate communication and/or can become a barrier to communication from the perspective of:
 - a) The physician
 - b) The person with dementia

Choice of Methodological Approaches

A qualitative approach was used to answer the research questions. The motivation for doing qualitative research, as opposed to quantitative research, is based on the appropriateness of qualitative research to help understand people within the social and cultural contexts in which they live (Greenhalgh et al., 1997). Further, the goal of this research was to understand this phenomenon from the point of view of the participants and its particular social and institutional context – which can be lost when such data are

quantified. Finally, this qualitative study was exploratory in nature and thus required as rich information as possible which is not always possible when collecting quantitative data. The decision was therefore taken to adopt a qualitative research strategy as the best means by which to elicit subjective perspective of both family physicians and patients with dementia.

The choice of qualitative method must be made in the context of particular research questions and sample populations. A range of qualitative research methods was considered and several rejected as inappropriate for this study. These included observation, focus groups, and wholly unstructured interviews. It was decided that a self-administered questionnaire with some open-ended questions would be suitable for physicians. Questionnaires have the potential to reach many physicians, do not take too much time to answer and are cost effective. Conversely, it was decided to use semi-structured interviews for the persons with dementia. Semi-structures interviews retain the flexibility necessary to allow patients with dementia to define their experiences, and thus would be the most appropriate tool.

Study Participants and Recruitment

Participants in this study included family physicians and persons with early stage dementia. The main region for recruitment for family physicians was the Niagara Region. Focusing on the local rather than provincial region made it easier to do any follow-up with the participating family physicians. Family physicians were included in this study because they are typically the first resource that patients contact when facing symptoms of dementia. They were recruited with the assistance of a local neurologist

who not only supplied the interviewer with a list of names of family physicians practicing in the Niagara Region but also wrote a letter of recommendation for this study to family physicians practicing in the Niagara Region. One hundred and twenty questionnaires were sent out to family physicians. Eleven responses were received initially; after telephone reminders a further 3 were received. Though this is a low response rate, it reflects the typical response to a family physician directed survey. Family physicians ranged in age from 30 to 65, seven were male; seven were female. On average the family physicians had been in practice for 15 years and saw 24 patients with dementia in a given year.

Participants with early stage dementia were recruited with the assistance of several directors of Alzheimer Societies across Canada. The inclusion criteria for potential participants was that the person had been given a diagnosis of some form of dementia, that they had been told their diagnosis, and that they were able to freely provide informed consent. Once the initial contact with a particular participant was made he/she was asked if he/she knew any other person that might be interested in participating in this research. Three people declined to continue with participation, either because of too much emotional distress or because of their inability to talk with some level of insight about their experience. Nine individuals, 6 men and 3 women from across Canada ranging in ages from 49 to 80 years agreed to participate. They were contacted by phone and time and location for the interview were determined.

Data Collection

The family physician questionnaire (see appendix I) consisted of 9 multiple-choice questions and 8 open ended questions. The first part of the questionnaire focused on the disclosure process. Next, questions dealt with the provision of information and referrals to other services. The last part asked physicians how a companion might facilitate or hinder communication. Return postage was provided for all physicians' mailings.

Semi-structured interviews lasting approximately 1 hour were conducted with persons with early stage dementia who lived in communities across Canada. The in-depth interviews were conducted in person or by telephone depending on where the person lived. Prior to the actual interview, each participant received an interview guide (see appendix II) to help him or her prepare for the interview.

A set of common questions was asked during each interview. Participants were first asked to describe some of the problems they encountered before they went to see a physician. This introductory question was followed by questions about diagnosis, any accompanying person and their suggestions how to improve the process of receiving the diagnosis. Although these common questions provided the basic structure for each interview, additional probes were used to expand and clarify the description of each individual's experience as needed.

Ethical Considerations

The McMaster University Research Ethics Board approved the study protocol. Participating family physicians did not sign a consent form as return of the questionnaire

was deemed to be consent. In the case of the interviews with persons with early stage, all persons with dementia reviewed and signed consent forms prior to initiation of the research interview. The contents of the consent form was read and explained to the participants with early dementia to ensure that they did understand in what research they were participating. Participants who were interviewed by phone received the consent form either by mail or by e-mail and were asked to send it back to the researcher. In the researcher's judgment, the participants were voluntary and knowingly giving informed consent and all of them possessed the legal capacity to give informed consent for their participation. It was stressed that each participant was free to withdraw at any point during the discussion and could refuse to answer questions that made him or her feel uncomfortable. Participants were also asked permission to tape-record the interviews.

Data Analysis

Family physicians' written comments, recorded in space provided in the survey instrument, were transcribed verbatim. These comments reflected family physician's experiences about sharing the diagnosis of dementia with the patient, as well as benefits and challenges of informing the patient of a dementia diagnosis. Following the completion of each interview with dementia persons, the tapes were transcribed verbatim, read while a combination of coding was used. The researcher began the coding process by making hard copies of the transcripts. Each transcript was read several times in order to identify and code initial meaningful data units while further coding was used by employing NUD*IST QSR N4 qualitative data management software (1997).

Unit data chunks were coded. Initial coding labels were written in the margins of the transcripts. Analysis included open coding of transcripts, sorting codes with the QSR N4, multiple searches for coded excerpts, and theme development. Analysis continued until no new major information on the characteristics of the category was forthcoming. Some of the information/themes that emerged included: advantages of receiving a diagnosis, challenges to providing a diagnosis; suggestions for improving the diagnostic process; and informing and/or directing patients to appropriate resources. The researcher then divided these themes into sub-themes using the following questions: what factors might affect the family physicians' decision to disclose the diagnosis of AD; with whom they discuss the diagnosis (patient or care giver); the degree to which they discuss the diagnosis and prognosis of AD; what terms they employ; whether they think most patients would want to know; whether they would want to know themselves if they were to develop AD; and what are some potential benefits of disclosure. Definitions of the emerging theme and sub-themes were written with typical examples from the interviews to ensure clarity in communicating meaning.

The same process was repeated for the participants with dementia. Based on the individuals' interviews, some of the themes the researcher looked for included: process of getting a diagnosis; advantages and disadvantages of receiving a diagnosis; the disclosure of diagnosis; and what communication challenges the person with dementia experienced when obtaining a diagnosis; and these themes were divided into the following sub-themes: lack of sufficient information; referral to community services; follow-up visits; and finally, what advice they have for physician in order to improve the diagnostic

process. Both the themes and sub-themes were written with typical examples from the interviews to ensure clarity in communicating meaning. All of these themes and sub-themes are addressed in chapter V in which the researcher reports on the findings of this study.

Chapter V

RESULTS

Physicians are in a unique position to help patients and their family members reduce the risks of adverse outcomes by carefully explaining the illness process and linking patients with appropriate community support services. Persons with dementia, conversely, want to know to know what is wrong with them, yet the literature review shows that only about half of all them were told what caused their problems while family members who accompany the individual with dementia are told the diagnosis almost uniformly.

This chapter will focus on the three objectives of this study, beginning with the physicians, followed by those of the participants with dementia, and ending with both physicians' and patients' perspectives of the role of companions. While the patients' section addresses their experience with obtaining and receiving the diagnosis for dementia, the last segment will turn to the effects a companion might have on the interactions between physicians and patients with dementia.

Beginning, however, with the physicians' sample, consisting of 14 participants, the questionnaire data is divided in two distinctive themes namely assessment and disclosure. The disclosure theme has five sub-themes called: terminology; benefits of obtaining diagnosis; barriers to receiving diagnosis; provision of information and services; and finally, suggestions for improvement.

Family Physicians

The aim of the first part of this study was to examine family physicians' attitudes and practice in regard to disclosing and discussing the diagnosis of a disease affecting memory and thinking, e.g. Alzheimer's disease.

Initial Assessment

Based on the family physicians' answers, it became clear that both patients and families play a key role in bringing cases of suspected dementia to the attention of physicians. Seven of the 14 family physicians reported that 100% of their patients and/or family members were the first ones to report changes in their condition. The remaining four family physicians responded that in 90% of the incidents it is either the patient or family member who brings the dementia to their attention. As one family physician stated:

“I am never the first. If I was first, I could work out my suspicion with the patient and his or her family” (FP-3).

The above finding of the key roles of both individuals with dementia and their families play in alerting family physicians that a problem with memory exist is supported by Boise and colleagues (1999). These researchers reported that 90% of patients and/or caregivers bring suspected cases of dementia to the attention of physicians.

Although many family physicians reported that patients and family members were the ones to bring up the possibility of Alzheimer's disease when first discussed, a number of them had their own suspicions. The remaining 3 family physicians were the first to raise the possibility with the patient and family indicating that physicians recognize early signs of dementia among their patients.

Nine of the 14 family physicians believed that the disease could be stabilized for a period of time, if treated early while the remaining five family physicians responded that the condition could improve for a period of time.

When asked whether or not family physicians performed any regular screening procedures for Alzheimer's disease among their older patients, eight of the family physicians said that they do not conduct any screening while the remaining six family physicians mainly perform a Mini Mental Status Exam (MMSE). Five of them blamed constraints in clinical practice, in particular the lack of time, as a serious barrier to routine screening as underscored by the comment of this family physician:

“Unfortunately, I have not implemented any screening process (formal) unless the patient or family brings it to my attention. Mainly this is due to time constraints” (FP-13).

Family physicians interviewed by Connell and colleagues (2004) blame time limits as the main cause for not performing any formal screening in patients with possible dementia. Another study by Adelman and others (2004) found that only 62% of primary care physicians discuss memory problems in medical visits. Physicians, thus, may not recognize the symptoms of dementia or recognize the importance of assessment and diagnosis of dementia.

Once family physicians were aware of early signs of dementia, however, all of them recognized that it was important to carry out a diagnostic work-up. There was a general consensus among all 14 family physicians on recommended procedures for the diagnosis for dementia to follow. It was found that family physicians were knowledgeable about recommended assessment procedures although there were some

variations in their practices. Only three of the family physicians, for example, would order imaging testing or consult with a specialist. All family physicians, however, performed a physical examination and administered laboratory tests to screen for reversible forms of dementia. One female physician stated that these were standard procedures for all her cases of dementia:

“I first rule out organic causes, do blood work, such as complete blood cell count, blood chemistries and B12 testing. I do a complete history and physical exam, and with the patient’s permission, I ask if the patient could return with a family member to collaborate the stories and gather information” (FP-14).

The performance of standard testing is consistent with research performed by Glasser and colleague (1998) who studied the views of physicians regarding how well they perform routine activities once suspecting dementia. These researchers found that physicians rated their abilities regarding diagnosis and treatment as very good. Corroborating the patients’ stories with family members can further be interpreted as physicians viewing patients as incapable of communicating effectively and thus, physicians tend to withdraw their attention from the person with dementia and focus instead on the caregiver. Young’s (2002) research supports this finding

Four of the family physicians used the results of the Folstein Mini-Mental Status Exam (MMSE) as a tool for communicating with the patient and family about the changes in the condition, as highlighted by a young female family physician:

“I meet with the patient and family (spouse) of the patient to discuss changes in the MMSE” (FP-8).

Disclosure of Diagnosis

Once the diagnosis was made, all family physicians were consistent in reporting a responsibility to inform the patient and/or family member of their findings. Eleven of the family physicians reported that they always inform both the patient and family member while only one of them disclosed that he does not share the diagnosis with his patients, yet informs the family member. One reason for this different result could be the physician's age. Only the oldest physician, 65 and over category, stated that he does not share the diagnosis with his patients. This finding, supported by Rice and colleagues (1994), may reflect a generational difference in the perception of the disease, a paternalistic desire by the physician to protect his patients from the harsh reality of their condition, or a fear of destroying hope or motivation.

Furthermore, the same family physician believed that most patients do not want to know their diagnosis; yet, all fourteen physicians responded that they would themselves wish to know if they developed the condition. The following quote by illustrates the wish to be informed:

“...I would probably sense that something is wrong, and I believe in being straight forward so that I can use the information to plan ahead (advance directives, treatment, long-term care)” (FP-13).

One family physician, however, clearly identified that she would tailor her response to the patient with Alzheimer's disease depending on factors such as his/her level of perceived awareness or insight, illustrated by the following statement:

“Depends on patient's level of comprehension at the time of diagnosis” (FP-14).

The family physicians maintained that most patients would want to know their diagnosis and felt that they have the ethical obligation to respect their patients' wishes as emphasized by a young female physician:

“...yes, patients often sense something is wrong, and ethically, I must tell when the patient is still able to understand diagnosis” (FP-2).

Family physicians' obligation to sharing the diagnosis with individuals with dementia and their family members is supported by Boise and colleagues (1999) who found that the majority of the participating family physicians felt a responsibility to inform patients and families of their findings

Terminology Used to Inform Patient and Family

Family physicians were then asked to indicate from a list of medical diagnoses, such as Alzheimer's disease and dementia, and euphemistic terms, such as memory problems and confusion what terms they used when informing patient about the illness. Some family physicians chose their terms carefully when giving a diagnosis to the patient and family member. Six of the family physicians used euphemistic terms to describe the illness as illustrated by the following quote of one physician:

“I use memory impairment. Alzheimer's is a diagnosis of exclusion, it could be other types of dementia” (FP-9).

Eight of the family physicians, however, disclosed that they use the term Alzheimer's disease rather than memory loss. These family physicians felt that the term Alzheimer's disease was a more straightforward and, thus, more helpful term to describe the dementia as suggested by the following comment:

“I always will be direct and use the term Alzheimer's” (FP-14).

The study by Johnson and colleagues (2000), however, reported that only 25% of specialists always used clear terminology while the rest used a variety of terms.

Benefits of Obtaining a Diagnosis of Dementia

Several benefits of obtaining a diagnosis emerged from the content analysis. Twelve of the family physicians reported that disclosure provides the opportunity to discuss power of attorney for care and finances, to direct the patient and family to appropriate resources and, in particular now, to gain access to new treatments such as Aricept. Connell and colleagues (2004) report similar benefits of obtaining a specific diagnosis of dementia including referral to services. One physician identified the potential for adaptation as positive, explaining that helping the patient come to terms with the diagnosis was equally important:

“Most important component of successful treatment is the patient’s acknowledgement of the disease and accepting the diagnosis” (FP-1).

The benefits of disclosing the diagnosis for dementia have been summarized by research of Drickamer and colleague (1992) and supports the above findings.

Barriers to Diagnosis of Dementia

In response to the question about some of the challenges of informing patients about a diagnosis, three of the family physicians stressed the potential for emotional distress or mood disturbances as highlighted by saying: “may feel upset, depressed, fearful, or hopeless.” Eleven of the family physicians experienced lack of time as a major challenge. These physicians indicated that sharing a diagnosis with the patient and family member requires more time and effort than treatment of other patients. As one physician stated:

“The 10 or 15 minutes you have, it just is not enough time to explain the diagnosis and prognosis to patients and their families” (FP-3).

Family physicians, in the study by Connell and others (2004), came to the same conclusion and were very frustrated by the lack of time for performing a comprehensive assessment during a typical medical visit.

Provision of Information and Services

Family physicians were further asked what information sources they might provide or recommend for patients in order to educate them about Alzheimer’s disease. While only three of the family physicians would seek a second opinion of a specialist, eleven of them responded that they would make a referral to another healthcare professional. Results indicate that ten of the 14 family physicians disclosed they would refer patients to either an Alzheimer support group or to the Alzheimer Society. Four of the family physicians listed educational materials provided by their office as an important information source for their patients. Only two of the family physicians reported referring their patients to Internet sites, medical reference book, or magazine and newspaper articles.

Findings by Glasser and colleagues (2001) research, however, contradict the previous outcome. Family members frequently reported that family physicians provided very limited information about the disease and few referrals to community-based services.

Suggestions to Improve the Process of Disclosure.

Family physicians were also asked to share any suggestions they might have in regard to improving the process of disclosing a diagnosis to patients and their family

members. Three of the family physicians replied that they had no suggestions how to improve the process. Eleven of them, conversely, did provide some suggestions ranging from “one sheet handout explaining A-Z in simple terms its diagnosis and potential for improvement” (FP- 1) to “constant communication and available resources in the community” (FP- 4). One physician summed up all these suggestions in the following statement:

“LOTS of INFO, spoken and written, suggest both patient and family members come, take time to explain and offer clear plan of action, suggest support groups, Alzheimer Society” (FP-13).

Furthermore, two of the family physicians identified the issue of hope as significant in suggesting improvements in the diagnostic process. One physician stated: “Try to minimize loss of hope and fear” (FP- 10) while another physician echoed these words by saying: “Never give up hope” (FP- 5).

In summary, thirteen of the 14 family physicians did inform patients about the diagnosis while ten of them reported that they used a comprehensive diagnostic approach. Family physicians also identified barriers to diagnosing; as well they reported fairly high levels of referral to social workers and counselors, to educational materials located in their offices, and to the Alzheimer’s Society.

Individuals With Dementia

The goal of the second part of this study was to examine persons’ preferences about the process of obtaining a diagnosis for dementia, including perceived benefits and obstacles to obtain a diagnosis and suggestions for improving the process. The next

section addresses the person's experience with obtaining and receiving the diagnosis for dementia.

Nine individuals with dementia participated, and their experiences can be divided into three broad themes; the person's initial awareness, receiving the diagnosis, and accessibility of information and services. These three themes are further divided into smaller sub-themes. The awareness theme consists of several sub-themes including suspecting, 'crisis', and confirming. Receiving the diagnosis for dementia is divided into reactions to diagnosis, advantages and disadvantages of receiving a diagnosis of dementia while the segment dealing with provision of information and services is separated into four different stages including lack of sufficient information; referral to community services; follow-up visit; and finally, suggestions for improvement of the diagnostic process.

Awareness

The nine participants' experience in seeking a diagnosis initially was marked by uncertainty about the appropriate interpretation for the various symptoms they were experiencing. Most of the participants noticed symptoms that they could not explain resulting in consulting medical services, undergoing examinations, and final diagnosis. Once the decision to seek assistance had been made, several common experiences, such as suspecting, covering-up, and revealing were described by individuals with dementia.

Suspecting

Receiving confirmation of what caused their problems began by becoming aware of minor and seemingly trivial “slips” and “lapses” in memory. These warning signs, however, were initially ignored:

“... Atypically, I’ve always had a little of the dysfunction I suffer. I couldn’t solve the problem of which shoe went on which foot until someone wrote R and L in my shoes...” (Mark).

“... I experienced problems with doing my income tax but also became forgetful... Well, I think there is another thing. My father died. I was very much affected by that... Really, really devastated me... and so you could say that I was derailed” (Rob).

“You know I was getting short fused and got a temper... but I blamed the age difference between me and my wife and I thought that there was something wrong with my wife. I blamed it on her...” (Paul).

Marzanski (2000), who wanted to know what persons with dementia thought what was wrong with them, reported that over 50% of participants either denied any problems or gave implausible explanations of their predicament, such as: old age or loneliness thus supporting the previous findings.

Some of the individuals with dementia were afraid that receiving the diagnosis for dementia would lead to stigma thus influencing their decisions to talk to others about their problems. Almost half of the participants were concerned with maintaining secrecy and lived in fear of other people finding out. This in turn made these individuals with dementia hide “in the closet”:

“...as of now, not many people have decided to come ‘out of the closet’ so to speak, to tell others their story, to tell people what is wrong with them. Why is this? It is because dementias, like Alzheimer’s disease, still have terrible stigmas attached to them. So much so that the person diagnosed with dementia is not only traumatized by it, but feels ashamed of it, and hides from the world” (Laura).

Some individuals with dementia believed that others would treat them differently as though they were “incapable” or “stupid”. Five individuals with dementia indeed experienced others talking down to them and thus infantilizing them. As a result, these individuals made conscious and deliberate efforts to compensate for their difficulties and to hide them from family members, friends and colleagues. Mark did just that:

“It struck me that while I may forget relatives, co-workers, or the way to the restroom, I certainly found I could think fast enough when concerned, and come forth with a believable bluff”.

Laura continuously found herself apologizing for her mistakes, rather than acknowledging that there might be a “medical” problem causing her to curse and swear:

“I truly had not realized that I was swearing. It took a concentrated effort to stop. I would substitute “Jeepers” each time I got upset instead. Soon, I became passionately known as “Jeepers J” among my co-workers”.

“At work I edited people’s reports. I allowed myself to take work home taking three times as much time, triple checking anything to do with math...I was trying to get other people to interact with clients because I was having trouble to do so...” (Lisa).

Despite growing concerns that something could be seriously amiss, eight of the participants had no idea what caused their problems as the following excerpts show:

“I did not realize what was happening. I just thought that I was tired, overworked and stressed. I had an excuse for everything” (Laura).

“I blamed it on old age. I thought this was normal and was not concerned. I did not like what was happening but just blamed it on old age” (Patrick).

“The first thing I thought well, you know getting older my memory is going but then I thought there is something more to it... but I just wanted to get answers” (Daniel).

“I had a “milogram” some years previously which gave me a lot of trouble at the time and thought it was connected to that. Dementia was the last thing on my mind” (Jim).

‘Crisis’

As incidences occurred with greater frequency or severity, participants could no longer rationalize or ignore the fact that something was not right. Slowly their lives began to fall apart:

“... what started to make the ball rolling was after an incident at the curling club. I became very confused and some of my colleagues noticed as well and told my wife. That was last year September. We became quite concerned and told my family physician. So I made the appointment and that is when I demanded some more action...” (Rob).

“...getting lost when out misreading traffic lights and proceeding when it was unsafe to do so, nearly being knocked down several times... life was one bewildering mess that I could make no sense of...” (Jim).

“...my memory was going and I said maybe it was because of all the stress but then I still thought it was not right, I should be able to have at least a pretty good sense of memory. This is not right...” (Daniel).

As the above quotes illustrate, the decline in everyday life competencies might cause stigma for many individuals with dementia resulting in a decreased quality of life, social withdrawal, and lower self-esteem as reported on in the study by Husband (2000).

Receiving the Diagnosis for Dementia

After disclosing the diagnosis, persons with dementia and their families shared various responses. The responses, for example, included acceptance of what was suspected, relief at learning what was causing their problems with memory and/or behavior, denial and depression. The process of confirming will be addressed next.

Confirming

Typically, family physicians are the first port of call but often they are reluctant to consider dementia as a possibility. One participant talked about the hesitation of her family physician in making a diagnosis and her reluctance to consider dementia and dismiss symptoms:

“My doctor, she just thought that I was a little over sensitive to my family history, and you know, we continued this kind of her not thinking that it was and me thinking very strongly that it was... I think it is very sad that they are not paying attention, they do not want to diagnose, that’s the feeling I have. There are some who do not want to diagnose Alzheimer’s early on. If you are going to leave it to the late stages, anybody can diagnose it. So, I think an early diagnosis is extremely important” (Nancy).

Some physicians, who used tactics such as discounting and normalizing, gave participants a false feeling of security:

“... Our family physician suggested to us that there was nothing to worry about, just keep him busy with brain exercises... He kept on saying it is this retire symptom. So I thought thank goodness nothing to worry about”... (Rob).

“Then I went to a neurologist. He told me I probably had nothing to worry about, but suggested I go to a neuro-psychologist for testing. There,...around the time of my 58th birthday, I discovered that something was drastically wrong...” (Mark).

“...they hand you a pile of keys and they say you can’t possibly have Alzheimer’s because you remember what the car keys are to be used for. So naïve, so totally naïve, I wished they would stay out of it...”(Lisa).

As the previous narratives illustrate, persons with mild signs of cognitive impairment, particularly when they are young, are often not taken seriously and the early warning signs of dementia are attributed to aging, stress and/or depression. These individuals described terror in not knowing what was wrong with them and having their concerns discounted by their physicians. Pratt and colleagues (2003) reported that many

persons with dementia had to fight for the right to know their diagnosis thus supporting the experience of many of the participants in the current study.

It is no surprise that waiting for the diagnosis is a stressful time. For many, the process took a year or even two following first contact before a confirmed diagnosis was reached. The following words of four participants indicate the uncertainty and limbo they and their families experienced:

“During the next year I would have five visits there for thorough evaluations and testing. And then after a year the doctors gave me my diagnosis of Frontotemporal dementia” (Laura).

“...within about a year she was sending me to a specialist... A year between first symptoms and finally receiving the diagnosis...! A very stressful time indeed” (Nancy).

“It was a frustrating year. It took time although I was fast tracked, but still it took 6 months to get in and it was excruciating...” (Lisa).

“The doctor told me that it could be from a heart attack but sent me to a specialist anyway. We had to wait three months before we got the appointment” (Patrick).

Several participants expressed frustration that they did not receive a proper diagnosis sooner. As such, they felt that it represented a lost opportunity to begin to come to terms with the future; a finding supported by Husband’s research (2000).

Reactions to Diagnosis

For many participants receiving the diagnosis was the last part of a long process of tests and procedures. The participants remembered some of these procedures, particularly the use of scans and memory tests.

“I had a MRI of my head done because, while these symptoms were happening, the sole of my right foot was going numb” (Laura).

“When I was at the doctor’s that was when he asked me all kinds of questions” (Patrick).

“I went back to her (*physician*) in April of this year and was re-tested and found that my scores were lower...” (Daniel).

“...thus she sent me on to a neurologist and that one sent me to a neuro-psychologist just for a full battery of tests..” (Nancy).

All participants wanted a potential diagnosis for dementia to be disclosed to them.

Indeed, all nine individuals received a diagnosis for dementia. It must be stressed, however, that all participants received the “bad news” either from a neurologist or psychiatrist and not from their family physician.

Manner of Giving Diagnosis

The participants were first asked to share what terminology their physicians used when they received their diagnosis for dementia. All participants were told that they either had probable Alzheimer’s disease, Alzheimer’s disease, or Frontal Temporal

Dementia:

“It is suspected that I have Alzheimer’s disease because my doctor told me of course it is probable because they need to do a brain autopsy and of course I will not allow them to do that” (Rob).

“I was sent for yet another opinion and it was decided that I had the early stages of Frontal Temporal dementia” (Laura).

Although all participants appreciated knowing what was wrong with them, six reported that they were very unhappy with the manner in which the diagnosis was presented to them. As the participants’ responses show, the effects of telling people may have less to do with whether they were told as with how they were told, a finding also reported by Downs and colleagues (2002):

“The specialist dropped the bomb, told me that I have Alzheimer’s disease and then began to talk in circles not addressing the diagnosis at all” (Patrick).

“They just told me this is Alzheimer’s and sent me home. That is all they said” (Daniel).

“The doctor can be very blunt, the way he did it...although I am sure that he knows what he is doing, I feel that the way he just dropped the news, I felt that was too much...(Rob).

Three of the participants preferred the direct approach. They appreciated being confronted with what the symptoms were suggesting.

“Dr. W. broke the ice by showing me how the MRI picked up the polyp in my nose. Then he got down to business” (Mark).

“Up front and honest. Tell me what is wrong with me, do not leave out anything but stay with us, help us through, give us time to digest. Do not turn in circles and not talking about it anymore, hiding behind the circle, being afraid to come in. That made me very angry (Jim).

Patrick did not feel acknowledged either because he felt that the specialist was not seriously concerned about his predicament:

“The physician tried to explain a bit more but he left the room 4 times, 4 times! It was like I was non-existing, not important enough.”

Several participants talked about the fact that they felt unprepared when receiving the information. They often used the word “shock” to describe their predicament:

“It was such a shock to both of us, we could not ask any questions. We were just dumb-founded. Could not think of it because we were not expecting this” (Rob).

“What difference does it make what the diagnosis is? My life has been destroyed” (Mark).

“I felt very depressed and went in and out of denial, grief, disbelief and anger, until I finally came to some form of acceptance...” (Laura).

“I felt shocked and unbelieving. I just wanted to get home and crawl into a dark corner. I thought my life had come to an end” (Jim).

“I felt overwhelmed, numb, and disappointed. I had hoped that it was not this disease, something that I would be told was wrong with me and then go home and fix it...” (Patrick).

In Husband’s (2000) report on some of the initial reactions of persons with dementia to disclosure also found that these individuals experienced shock, fear, and anger. Although receiving a diagnosis caused reactions negative reactions, withholding a diagnosis also lead to much distress. Not knowing what was wrong or changes in their ability left unexplained caused increased stress as well. Some participants thus felt a sense of relief and validation from the diagnosis as it provided an explanation for the changes they had observed within themselves, a finding supported by Pratt and colleague (2003):

“I was stressed when I was suspicious, I was relieved when it was confirmed... Relieved because I felt we finally were addressing the problem rather than pretending that it was not a problem... The neurologist allowed me to feel good about myself...” (Nancy).

“I was so relieved, you know, because you know something is wrong and it is getting worse, absolutely no doubt. And not being able to convince your doctor. That was very hard” (Lisa).

“...but just knowing what was wrong with me. There was relief in the understanding why I was doing the things that were hurtful. It was not me but it was the disease” (Paul).

At the time of diagnosis, one participant could neither remember how she felt nor what the neurologist had told her. Over time, however, she began to feel better mainly because of the medication she had been prescribed. Laura had this to share:

“The words of the diagnosis did not faze me. I learned later that I had what is called ‘non-plussed’ reaction. I could not have cared one way or the other about what they were telling me, and I certainly did not understand the ramifications of having such a diagnosis. I was in what I refer to as dementia land.”

Even though Laura did not understand the information that was given to her at the time of diagnosis, the neurologist did disclose the diagnosis for dementia to her and her mother.

Research by Pratt and colleague (2003) stressed how appropriate disclosure of the diagnosis for dementia eliminates distress and promotes positive coping strategies.

Almost all participants, after being told their diagnosis for dementia, nevertheless, felt deeply disappointed with the physicians' communication:

"I am not satisfied with how the doctor communicated the diagnosis to me or to my wife for that matter. Even at the second visit, I did feel that he did not spend enough time with us. And my own doctor, well he tells things differently from one visit to the next, leaving me even more confused. Not good. There is lots of room for improvements" (Patrick).

Some individuals blamed the lack of time specialists and family physicians have as the culprit of the communication problems:

"Still, I do not want to complain too much. I do understand how busy they are. I blame the government for all of this. They keep the money away and then think that the system will function well" (Patrick).

"I do not want to blame him. I do not want to blame anything on him. I feel quite comfortable with him and I want to keep it that way" (Rob).

"...the only thing I can think about is time, time is a factor. They need to see an x number of patients but..." (Daniel).

Interestingly, although many participants were unhappy with the communication between themselves and the specialists, many stressed that the relationship with their family physician was excellent. Paul, for example, was happy with how his physician followed up with him after he had received the diagnosis of Frontal Temporal Dementia or FTD:

"I want to stress whole-heartily that we are blessed with our doctor. I have heard so many horror stories about others who do not care, do not have time or I do not know, but our doctor is wonderful. He is caring, a wonderful person. He is

interested in me. He listens to me...whenever I want to see the doctor, he would see me unscheduled or squeeze me into his busy schedule and never make me feel rushed..."

"I see her for the annual exam and then for other situations that might occur. She is also available to me and is very supportive. She takes the time to listen and she takes over from the specialist...between myself and her, the rapport is very good. Any concerns I have I can go to her and she will listen and give advice to me" (Daniel).

"Now my family doctor was fantastic and from the moment I said my head is not working right. Right away she said, you want a CT scan? Every little complaint was taken seriously and was investigated..." (Lisa).

"I am so blessed to have a doctor who has the knowledge that he does. He treats me with dignity and as an equal. He allows me to make decisions about my care. This makes me feel empowered...He spends a lot of time listening to me" (Laura).

Both Jim and Nancy, however, shared quite a different experience when describing the relationship with their family physicians:

"My physician has never mentioned the word dementia to me. I only see her when something is hurting me" (Jim).

"My specialist is in charge from the neck up and she (*family physician*) is in charge from the neck down...She ignores what is happening, and I do not bring it up anymore. I gave up trying to talk to her about it" (Nancy).

In sum, the majority of participants felt that there was lots of room for improvement in regard to communication between specialists and themselves. This finding corresponds with earlier research by Marzanski (2000) who reported that many individuals with dementia strongly critiqued physicians' medical practices. This researcher found that persons with dementia had significant amounts of information withheld from them by physicians, yet, family members were provided with information. Not informing individuals with dementia about their illness not only caused

dissatisfaction with communications but also caused psychological distress. Several individuals, however, reported to have an excellent relationship with their family physicians. Pratt and colleague (2003) likewise reported that physicians who were supportive of individuals with dementia became useful resources to them.

In sum, communication between physicians and individuals with dementia is important, but being readily available, giving hope, and showing compassion is equally significant.

Advantages of Receiving a Diagnosis for Dementia

Of the people interviewed most could identify a number of advantages gained by learning the diagnosis. These included practical matters such as being able to make plans for the future and taking care of financial and legal matters. Nancy, for example, wrote a letter to her husband after the communication between them became difficult:

“I wrote him a letter and you know, that must have been hard for him to receive that but it allowed him to share with me how scared he was. We came back to being a team again”.

Other advantages included being able to understand the changes within themselves and in behavior, which provided the opportunity to find a positive approach to the diagnosis.

“The only thing I need to be careful of is that people do not push me, or shout at me. I cannot stand this and it angers me very quickly. I lose control. I run away. I am getting better now. At one time I could not stand noise, now I can handle it. Taking everything in consideration, really, I am better now than before” (Paul).

One female participant stressed the benefits of medication.

“...There was just so much confusion around me, it was just awful. I had almost no social life. Half the time I was not sure if I was saying the right thing. It was really a miserable time. Then I got Aricept and a friend of mine commented on how improved my speech was and my stamina was better. I felt reborn, o yes! It still makes me cry. I never want to go back to that stage” (Lisa).

For some people it provided an opportunity to make the most of their time. When participants could accept the fact that they may decline at some point there was often the attitude of concentrating on their remaining strengths and abilities. This included becoming involved in volunteer work, planning trips, and educating others about the illness. Following is Nancy's narrative:

"I have turned into a different direction, a different career. I had to leave teaching that I love. But I still feel that I get to educate and that is important to me. I feel that there are 10,000 teachers out there who can teach the subjects that I taught but there are very few of us who are adequate speakers who can educate and feel comfortable in front of a crowd".

Some participants found that by knowing their diagnosis, they were able to access increased amounts of social support. For many people it was helpful to have someone to talk to if they wanted to. Some individuals, such as Laura and Daniel, spoke very passionate about attending early support groups where they could meet other people with dementia:

"...and within the last few months, we already have 9 early stage people, the majority under the age of 65! We are sharing our thoughts about rehabilitation or how to regain lost functions. We are encouraging each other to live positively, and to laugh, love, hope, and enjoy each day as it comes" (Laura).

"I attend the support group, the early stage AD support group and I see them as my family. Because they go through a similar disease than myself and their experiences relate to me. What they share in the group I can relate to as well as they can relate to what I experience" (Daniel).

Pinner and colleague (2003) came to the same conclusion emphasizing that disclosing the diagnosis early in the disease process allows individuals with dementia to live life and play an active role in planning for the future.

Disadvantages of Receiving a Diagnosis for Dementia

All the participants identified some disadvantages from knowing the diagnosis for dementia. The most frequent identified disadvantages included stigma, depression, and thoughts of suicide:

“It’s a struggle to get through each day. I tire easily, mentally and physically, even after doing simple things. People tend to trivialize how you feel, patronize you” (Laura).

“I drifted in and out of depression. Losing interest in life until I was reduced to sitting at home all day long staring at a blank TV screen as I couldn’t even be bothered to switch it on...”(Jim).

“I’d lose my ability to drive, to budget, to speak coherently, to dress myself, to use the toilet. I thought I must plan to die when I still can do so with dignity” (Mark).

For many individuals with dementia, however, depression and thoughts of suicide were replaced with acceptance of the illness as illustrated by the following quote:

“In some ways it is as if I were depressed. Yet, I am not, on the whole, depressed. The world does not seem grey, life does not seem pointless, I do not usually feel down on myself...those feelings have become faint and dull” (Mark).

Research by Pratt and colleague (2003) supports this finding. The disadvantages thus did not outweigh the opportunities provided by knowing the diagnosis. As Lisa stated:

“I continue to think that the glass is half full rather than half empty”.

Provision of Information and Services

Lack of sufficient information.

The importance of information is portrayed in the answers of the participants. They described the contrast between on the one hand being sent home without having received any information about what to expect next and, on the other, being approached

by a physician who immediately supplied information about what would happen both now and in the future. Five participants reported that they did not receive adequate information and referral after they received the diagnosis. These individuals stated that the specialist neither discussed prognosis and/or next steps, nor did they provide information about community-based services.

“It was very frustrating to both of us, but especially to my wife not receiving any information...getting information was very difficult yet it is so important to get that information. To get the leads. Maybe not all the information at one time but leave the door open to come back for another appointment” (Daniel).

“By whom? My physician has never mentioned the word dementia to me...They did not say much but tended to ask questions only. I got my information from publications” (Jim).

“The specialist did not converse with me. He took me out of the room to an examining room and in the meantime he talked to my wife who was with me. He told my wife that there would be a gradual deterioration and that it eventually is going to wind up like Alzheimer’s but that there is no telling how long this is going to take” (Paul).

“Tell me how long the disease will last, not only that there is no cure and then wander off to some other things that have nothing to do with telling the diagnosis. I would like to know how it will affect my memory...and the dreams I am having, do they have anything to do with my illness?” (Patrick).

Laura, on the other hand, felt that the specialist gave her way too much information to digest:

“We can’t think or speak fast enough to let you know what our opinion is. Try to give us time to respond, to let you know whether we really want to do what you’ve proposed. Being forced into things makes us upset or aggressive, even fearful”.

“I felt that it was too much. We just looked at each other, we could not think, we could not ask, we, I do not know...just too much” (Rob).

“I felt that it was too much. We just looked at each other, we could not think, we could not ask, we, I do not know...just too much” (Rob).

Two individuals with dementia reported that they did not want any more information at the time of diagnosis.

“No, not initially when we went for testing. I felt uncomfortable at that time, did not want to deal with the possibility, maybe in denial” (Patrick).

The above statements highlight the need for an individual approach by physicians, a finding supported by Marzanski (2000). This researcher stresses the importance that each person with dementia must be approached individually and his or her choices respected whether or not he or she wishes to know more about the illness.

Lack of referral to community services.

Individuals with dementia also were asked what community-based social service referrals their physicians had made. Only two of the nine participants had received such referrals to community services. Not being referred or connected to community sources was another cause of distress. Daniel had this to say:

“He did not tell me about the Alzheimer Society. That was a bit of a disappointment. I mean, even if he would have a list with, okay, here is the society, they deal with dementia...Here is a list of support groups that deal with dementia. That would have been helpful”.

“It was his assistant who connected us with the Alzheimer Society and that person gave me the information I needed” (Patrick).

“The physician did not tell us that we could get information on the Internet, nor did he talk about the Alzheimer Society or support groups” (Rob).

Lack of connecting the participants to community support thus was experienced as negative but also unnecessary:

“They should either give my wife or myself a list who to contact...” (Daniel).

Seven of the participants stressed the importance of support but their physicians failed to inform them where to find such service. Not knowing where to get help, Daniel looked for support closer to home:

“My wife is the best support that I have. My children are so young. My oldest one is 16, the middle one is 15 and my youngest is 12. They are at that age where they really do not understand”.

Patrick had the same experience:

“My wife is a great support for me. She helps me, talks about it and also informed the children about it. They are all helping me”.

Lack of follow-up medical visit.

It was not uncommon either for participants to express dissatisfaction with physicians about the lack of suggesting a return visit to follow-up and monitor their condition.

“Even the specialist he just said well you know, I will see you in a year. He did not say anything about medications...” (Daniel).

“I only see the specialist once a year” (Nancy).

“It pisses me off a little that I still haven’t heard from Dr. C...” (Mark).

“I feel that I could see the doctor more often than just once every 9 months” (Rob).

Quite a few individuals spoke of their despair when left with the dementia diagnosis and nothing more. Six participants would have liked another appointment with the specialist. When the individuals with dementia were not offered a follow-up visit, they felt lost and wondered what to do next. Some people wanted more advice or another opportunity to ask more questions:

“But really, I do not have a lot of guidance from the doctor, if we are doing the right thing or if we should be doing something different...” (Rob).

“...he prescribed medication and I misunderstood the directions...And after taking the medication for about a week , then I went to my family physician and he said are you sure you are supposed to take the medication in that way?” (Daniel).

Pinner and colleague (2003) in their research suggested that disclosure for dementia must not be seen as a one-of-event, but as an ongoing, dynamic process and a fundamental part of the care of the person with dementia. The initial meeting is often overwhelming, so opportunities for follow-up sessions with additional family members should be arranged, something very few physicians, particularly neurologists, do not seem to have time for.

Suggestions for Improving the Diagnostic Process

In response to the question about improvement, most individuals with dementia suggested a follow-up appointment and placed such a meeting high on their list of suggestions:

“Maybe after two weeks when things have been absorbed and then talk or answer our questions. I was told to come back after a year. Nothing in between” (Daniel).

“My wife wanted to ask questions and so we went back for an extra interview so our questions would be answered. But it was not volunteered, we needed to ask” (Rob).

Five participants reported that they would have liked to have the diagnosis disclosed in a more compassionate and gentle manner:

“...if he would have talked to us even if my mind would not pick it up. It would have given me time to get a hold of myself and maybe could have asked some questions what do I do. Surely, there must be something we can do, not just say go home and accept it” (Rob).

“Break it into me like that in small steps over a period of time. Give the patient time. Do not rush them through the appointment. Do not confuse them, give it one step at the time. I sometimes feel like I am standing on the outside looking in on a conversation about me but I am not part of it. Yet, I am the expert. I know what is happening” (Paul).

“I think if the doctor would just gently tell us this is possible Alzheimer’s and we are fortunately living in a time right now that there is medication that is showing great promise to many people. I would not sent them just off. I think, doctors telling people with this diagnosis to partner with the Alzheimer Society. A win-win situation for all involved” (Nancy).

Four participants felt that physicians could benefit from extra training so that the diagnosis for dementia can be delivered in the most compassionate and effective way:

“Physicians seem to have little training in dementia and seem ill at ease as they don’t know what to say. They need proper training in medical school” (Jim).

“Most people find it a big shock to get the diagnosis. I think that a compassionate doctor helps to make it easier. Most neurologists that I know lack compassion and they deliver a hard diagnosis. I think that they would need empathy and compassion training early on in their medical school so they could continue this in their practice when they have to give bad diagnoses to people” (Laura).

One participant stated that the setting was an important factor. A supportive environment would be beneficial for helping to create a better atmosphere:

“I would have preferred a sitting room type scenario rather than a cluttered office. I would have liked a little more time as to what the diagnosis meant to the rest of my life. I would have liked my wife to have been there” (Jim).

Three individuals, furthermore, stressed the importance of hope.

“...I would say that whether the information comes from the family physician or the specialist, I think that they really do have to emphasize that there should be hope and not to give up. That every effort will be made, so many dollars are put into this research, studies etc. that eh, hopefully, that there will be answers forthcoming. There must be this message of hope” (Daniel).

“He could have said that it is in the early stages. There are lots of things we can do. There are medications you know. But you cannot think. There was no message of hope, and I believe that there is hope” (Rob).

Many factors can influence the person's reaction to the diagnosis for dementia, including the sensitivity with which information is presented, the previous personal experience with dementia of other family members or friends, and mental preparation for receiving the diagnosis (Husband, 2000). In conclusion though, sharing the diagnosis for dementia, when handled in a sensitive manner, can help individuals with dementia feel informed and hopeful.

Companions in Physician-Dementia Patient Interaction

The final part of this section will address the effect of a companion on the interactions between physicians and patients with dementia. Both the benefits and obstacles of having a companion present during the medical visit will be highlighted, beginning with the perspectives of physicians and ending with the views of individuals with dementia. The objective was to examine the extent to which an accompanying person can facilitate communication and/or can become a barrier to communication from the perspective of:

Physicians' Perspectives

In geriatric medicine, physician, patient, and caregiver form a triad. This three-way relationship has a significant impact on the interaction between physician and patient (Greene et al., 1994). Turning now to what the participating physicians had noticed in their medical practice about triads, it was found that the presence of a family member was normative among patients with dementia. When asked to guess how many family members accompanied patients with Alzheimer's disease, nine of the 14 physicians estimated that anywhere from 80% to 100% of their patients bring a family member,

caregiver, or friend to the medical visit while the remaining five physicians reported numbers ranging from 50% to 80%. All physicians reported the effect of the companion's presence as generally favorable. Advantages of companion presence included the following:

- facilitates communication (all physicians)
- provides support and encourage patients (FP-14)
- assists in decision-making (FP-9)
- helps patients to verbalize questions and voice concerns (FP-3)
- provides information to the physician (FP-1)
- interprets information for the patient (FP-10)

As one female physician wrote:

“I can corroborate patient's “story” with family, family can ask questions that the patient might not want/think to ask, can plan with companion and patient, companion can be support for patient during the visit” (FP- 13).

The presence of a companion, however, has the potential for negative effects on communication between physicians and patients as well. Although most physicians felt that the presence of a companion facilitates communication, five of the 14 physicians disclosed that some companions “take over the conversation and speak for the patient” (FP- 7) resulting in a situation in which the patient becomes more and more the silent third party in the medical visit. A female physician gave an example of such mechanisms of marginalization:

“...family members may attempt to dominate the conversation and this makes it hard to gather the patient's perspective, leaving the patient feel uninvolved and less important...” (FP-11).

It can thus be concluded that companions who are highly active in interactions provide important information and perspectives, but they also may marginalize patients' views, a finding supported by Hasselkus (1994).

The Perspective of the Person with Dementia

In this study, all but two participants were accompanied by either their spouse or in one case, by her mother. The overwhelming impression was that the presence of a third person was not only beneficial but that the companion most often took on the role of advocate as identified by Adelman and colleagues (1987). Several quotes are particularly illustrative:

“Thanking that my wife was there...I felt good that she was there. I felt reassured...I was in that state of shock, I probably would have walked out ...going I wished I had asked that question...I would have been more angry and frustrated with myself ...” (Daniel).

“For me, having my wife there was good. I felt protected, somehow stronger. When he dropped the bomb, it was not only me who got hit. My wife as well and that was of comfort to me” (Patrick).

“My wife was there as well. It was certainly helpful because she...she helped me share the shock of finding out that I could possibly have Alzheimer's” (Rob).

“Because I could not remember what was being said and I needed that person with me to remember” (Laura).

Two of the participants, on the other hand, were by themselves when they received the diagnosis. While Nancy chose not to have a companion with her at the time of disclosure, Jim wished he had been given that choice:

“I am very independent. And I did not feel that I had any need for support” (Nancy).

“I would have liked my wife to have been there. She was told in advance of me” (Jim).

In sum, most participants experienced the presence of a companion as positive, particularly in providing support during the disclosure of the diagnosis. It can thus be concluded that there is a positive function for the third person, a finding supported by Greene and colleagues (1994).

The final chapter of this research will deal with the discussion, future implications, and the conclusion.

Chapter VI

DISCUSSION

The present research provided an in-depth qualitative examination of the perspectives of both family physicians and persons with early stage dementia about their experiences in the assessment and diagnostic disclosure process. It is one of the few studies that has focused on patients' preferences as the recipient of the news rather than solely on the physicians' perspective.

It is important that readers note the dates of citations presented throughout the discussion part, as this section encompasses referrals to articles/research about dementia published from the early 1990s to the present. As knowledge about dementia has expanded over the years, that knowledge is bound to have shifted opinion and practice, and it is important to keep in mind the historical context when interpreting research results.

With this in mind, the results of this study reveal areas of both convergence and divergence in the attitudes and experiences of the two groups. I will begin first with some of the theoretical insights linking these back to the literature and the current research, followed by a discussion of some of the implications of the study findings. The chapter concludes with suggesting some future recommendations.

Contributions of the Study of Physician-Patient Relations and Triads

As noted in chapter II, Parsons' (1951) sick role theory contended that patients were expected to comply with physician treatment that created an asymmetrical, yet functional physician-patient relationship. Freidson (1970), however, explained how the

culture of medical education sustained professional dominance over patients, but also recognized trends emerging to challenge this dominance (Haug et al., 1983). More recently, assumptions underlying this relationship have shifted from physician as professional purveyor of medical knowledge and patient as unquestioning recipient of medical knowledge, to patient as a more active participant in medical decision-making (Haug, 1994).

Traditionally, the ideal physician-patient relationship was paternalistic. Ong and colleagues (1995) have argued, however, that this authoritarian model of health care has been replaced by the idea of shared decision-making. The findings of the current study show that most participating family physicians indeed informed their patients about the diagnosis of dementia. Readers should be aware though that only a small number of family physicians participated in the current study, thus social desirability to give the 'right' answer might be an issue.

Some of the individuals with dementia, however, differed in their reporting. Often younger, these individuals with dementia were not taken seriously and the early warning signs were attributed to aging, stress and/or depression. Their physicians, mainly neurologists, maintained paternalistic attitudes in regard to taking the complaints of patients with dementia seriously. Other physicians did not ask if the person with dementia preferred to have a family member present at the time of diagnosis. Physicians never discussed as to how much information the person with dementia would like.

Patients look to physicians for guidance because they possess medical knowledge that the majority of patients do not have. Physicians thus have power over how much

information they will share with their patients. Haug and colleague (1987) argued that in order to preserve professional control, some physicians intentionally withhold information from their patients. Limiting communication and maintaining uncertainty furthers the power of the physician over the patient by “perpetuating the mystification of medical care” (Haug et al., 1987, p: 23).

In this study, individuals with dementia expressed a strong desire for medical information. The majority of individuals with dementia reported dissatisfaction with the amount of information they received. Whether physicians withheld information to preserve power or because they were uncomfortable sharing information about dementia to their patients was not clear.

Most of the individuals with dementia in this study complained that they were not offered a follow-up visit in which they would have had an opportunity to discuss in more detail what to expect as the disease progresses. Physicians, thus, hold power over patients even if they accept the idea of sharing information with patients. It can therefore be concluded that patients may be able to get more information than before, but they are still dependent on physicians as long as the information giving process is assessed and managed by physicians.

Smith (1990) postulated that within the medical world, acceptance of the primary medical interpretation of the disease ignores the social issues facing individuals with dementia. According to this researcher, a key feature of the consultation is the assertion of control in which the physician takes over the patient’s problem and sets about controlling what should be done. Physicians typically limit the focus to medical issues

and social situations are regulated to marginal topics of conversation. Persons with dementia seek care for an illness, defined in subjective terms, while physicians evaluate symptoms in terms of disease, supposedly drawing on objective facts in scientific fashion. The much more common tendency of physicians to order laboratory tests to guide diagnostic decisions may reflect a “medicalization” of dementia, which favors biomedical over psychosocial factors underlying clinical symptoms (Lyman, 1989; Miller et al., 1992). Physicians more accustomed to the biomedical aspects of diagnosis may not see the clinical utility of using structured interviews with patients to gather information about, for example, coping mechanisms.

As might be expected, the results of this current study indicate that interactions during the visit were strongly focused on medical aspects of dementia. Family physicians concentrated on informing patients about the medical aspects, such as the results of blood work, MMSE or CT scan. Family physicians thus missed an opportunity to listen to the patient about his/her subjective experience of the illness. The individual’s personal response to what is happening tends to be overlooked on the grounds of perceived impaired judgment. Individuals with dementia were not given the opportunity to bring much of their social world into the medical setting. And when allowed, patients’ social concerns were often medicalized so that they were addressed only within a disease-monitoring framework rather than within a social context. An important aspect of physician-patient interactions, thus, is missing if the psychosocial aspects of persons’ lives are not incorporated into the medical encounter (Smith, 1990). The results therefore indicate that omission of the social context of people’s illness experiences is a major

weakness of medical encounters, and that strengthening the voice of persons' psychosocial issues is a goal for the future.

One of the major characteristics that distinguishes the physician-patient medical encounter is that often the older adult is accompanied by a third person (Adelman et al., 1987). Sociologists have for some time considered the important differences between dyadic and triadic groups. Simmel (in Wolff, 1950) described how group size affected the structure and function of the group. This sociologist argued that when a dyad changes to a triad, the form of interaction might alter. In the triad, there may be strategies that lead to competition, alliances, or mediation.

Among older patients, it is estimated that 20% who seek physician care are accompanied to medical visits by a family member. Seven of the nine participants were accompanied by a family member which is much higher than reported in previous research for average family visits (Labrecque et al., 1991; Hasselkus, 1994; Adelman et al., 2000).

In the earliest work in geriatric medical visits, Rosow (1981) described the different coalitions that are likely to form when the older patient is accompanied to the medical visit. Greene and colleagues (1994) investigated how the presence of a third person affects communication between the physician and the patient. A striking finding of the current study is related to the prominent role companions played in the diagnosis and treatment process. Although companions are likely to play multiple roles in a single visit (Adelman et al., 1987), the most common role of the companions in this study was that of advocate.

Participating family physicians reported that they value companion presence and involvement of family members. Family physicians were able to acquire additional information and assist in decision-making. Family physicians further reported that families were frequently the first ones to draw their attention to an existing problem with their family member. Boise and colleagues (1999), for example, found that symptom recognition represents a significant barrier to the diagnosis of dementia. They further used companions as mediators and as a buffer for telling the bad news to patients. Participating family physicians, thus, experienced the family members' assistance as helpful, and ultimately, encouraged optimal patient care. It is important to note that the data received was based on self-reported information and as such, the results reported might be biased. Companions, however, also marginalized patients' views by speaking for them, a finding supported by Ellingson's research (2002).

Not only were family members the primary source of initial recognition of the individual's symptoms, they further acted as a great source of support for the person with dementia. Much research has shown a tendency for physicians to patronize, stereotype, and dismiss concerns of older adults and/or individuals with dementia (Adelman et al., 1990; Beisecker, 1996; Haug, 1996). It is thus not surprising that some companions seek to help individuals with dementia accomplish objectives by advocating for them. As Beisecker (1996) has commented, the companion tends to become the pivotal person in the medical visit. While this is often effective, it also raises the troubling possibility of further, albeit unintentionally, marginalizing individuals with dementia by speaking for them. In this study, however, the interaction of the companion did not result in silencing

the individual with dementia, but rather lead to a strengthening of the interview. From the perspective of the person with dementia, the presence of a companion was experienced as beneficial and helpful. The majority of individuals with dementia stated that their family members assisted them to understand what was discussed, to ask questions, and to offer support. Although the presence of a family member during the medical encounter in which the diagnosis was given did not lead to disempowerment of the person with dementia, the possibility of silencing the person with dementia in follow-up visits remains. Individuals with dementia, according to Fortinski (2001, p: 36), are seen by many physicians as well as companions as “incidental subjects and passive recipients in the process of their dementia.” The person with dementia thus finds him/herself at best marginalized or sometimes even invisible. It is important therefore to expand this study by observing rather than interviewing the individuals in a triadic medical encounter.

In sum, assumptions that physician knows best, making decisions on behalf of patients without involving them, feeling threatened when patients have access to alternative sources of medical information, these signs of paternalism should have no place in medical encounters. Successful partnerships are based on equal power and where physicians, patients, and companions share decision-making and responsibility. The physician is well informed about diagnostic techniques, prognosis, and treatment while the companion can supply the missing information, but only the person with dementia knows about his/her experience of the illness.

Contributions of the Study to the Practice related to Dementia

Noticing symptoms made many individuals with dementia suspicious that something was not right, although many were initially uncertain about the significance of early symptoms. Participants felt confused and distressed by not knowing what was causing their symptoms. Despite many participants noticing symptoms, only one participant suspected that he might have dementia. This meant that people considered a wide variety of explanations for the changes they were experiencing, such as old age, “retirement syndrome”, and brain tumors. Marzanski (2000) found that 50% of individuals with dementia either denied any problems or gave plausible explanations of their illness, thus supporting the findings of this research.

Family physicians reported that they did not have any reluctance to carrying out assessment. In fact, most family physicians were knowledgeable about which assessment procedures to perform. The performance of standard testing is consistent with research performed by Glasser and colleague (1998) who found that physicians did order routine standard procedures once dementia was suspected. As stated earlier, it is important to note that family physicians rate themselves highly on their knowledge and abilities regarding treatment and obtaining medical histories.

Some individuals with dementia, however, were frustrated with what they perceived to be resistance from physicians. These individuals, often younger than some of the other participants, encountered delays before eventual identification of the problem and initiation of treatment. This finding corresponds with the conclusions by Boise and colleagues (1999) who found that many physicians expressed negative attitudes toward

the need for early diagnosis and reluctance to carry through complete dementia assessment procedures. Another barrier to obtaining a diagnosis, which some individuals experienced, was physicians' belief that memory problems are part of normal aging. These physicians tended to "normalize" the experience for patients with dementia. Supporting these findings is research done by Pratt and colleagues (2003) who reported that many individuals with dementia had to fight for the right to know their diagnosis. Some well-meaning physicians may seek to spare patients, families, and perhaps themselves the grief associated with recognition of dementia. Ironically, not taking the complaints of individuals with dementia serious lead to increased rather than decreased distress.

Turning to the disclosure phase, one of the most compelling findings in this study was the clear preference among family physicians to disclose the news about the diagnosis for dementia to their patients. Most of the family physicians, as reported earlier, stated that they definitely and explicitly tell their patients that they have dementia. This conclusion is contradictory to previous research and might suggest a shift in attitudes. It is important to remember though that the sample of participating family physicians was very selective and therefore, this finding might be interpreted as being biased. Recent studies regarding current attitudes and practice of physicians on disclosing the diagnosis for dementia to their patients shows that only a minority regularly discloses (Rice et al., 1994; Vassilas et al., 1998; Johnson et al., 2000). As has been noted by Johnson and colleagues (2000), diagnostic disclosure in dementia seems to be shadowing a parallel issue in cancer. Decades ago, physicians routinely withheld a

cancer diagnosis from patients, whereas now there is a near universal consensus that a cancer diagnosis should be disclosed. Advances in diagnostic accuracy, prognosis prediction, and treatment effectiveness seem to be responsible for this shift in attitude. The same authors predict disclosure in dementia will follow a similar evolution.

Only one family physician reported that he preferred to disclose the diagnosis for dementia to the family rather than to the patient him or herself. Considering the finding that this family physician, in practice the longest time, was least likely to disclose the diagnosis for dementia to his patients, it is possible that frank discussions about the management and course of dementia are more difficult if physicians, individuals with dementia, and families have grown familiar over years or decades of office visits and related experiences. At the same time, older physicians' training occurred when the model of physician-patient was one of a dominant physician and a submissive patient, functionally justified by the professional's superior knowledge and the patient's relative ignorance and need for expert care (Parsons, 1951).

Literature on what persons with dementia want to know demonstrates that these individuals generally want to be informed about their diagnosis but that there can be a time of 'crisis' following diagnosis disclosure (Pratt et al., 2003). Findings from this study show that all persons with dementia wanted to know the diagnosis and that a specialist had informed them about their illness. Most participants easily remembered how they felt after being told the diagnosis. For the majority of individuals with dementia, this time was characterized by what seemed like a "crisis" stage, a time that required dealing with the immediate response to learning the diagnosis. Many

participants described a variety of feelings after diagnosis disclosure including shock, anger, and fear. Some individuals might have given physicians the impression that they responded well to the diagnosis. This hiding of emotions may be due, in part, to the fact that older individuals may feel obligated to adhere to an “unwritten social protocol in the context of a physician’s visit that dictates they be stoic, polite and unemotional” (Connell et al., 2004, p: 506).

Some individuals with dementia also experienced feelings of validation and relief. Providing a diagnosis, a medical label, to explain the often “puzzling” changes allays fears of “going mad”. This is a point made previously in the literature (Husband, 2000). Once a diagnosis is given, the symptoms need no longer be attributed to a disposition of the person with dementia, but rather to a physiological abnormality that is not under the patient’s voluntary control. The feelings participants experienced during this crisis time were often strong, and coming to terms with the dementia was a significant part of their lives. Most participants, however, were able to deal effectively with this crisis period and thus felt stronger and were able to concentrate on their remaining abilities and skills, a trend previously reported by Husband (2000).

In terms of how the diagnosis was shared, individuals recounted a wide range of experiences and reactions to how the news was delivered. Some of the participants appreciated a direct approach of having the physician come right out and tell them the results of the assessment. Other individuals with dementia, however, stressed the importance of having the diagnosis disclosed in a compassionate and sensitive manner and in such a way as to preserve a sense of dignity and hope for both themselves and their

companions. These individuals with dementia wanted to be eased into the bad news, preferably, over several sessions. This finding is supported by Pinner and colleague (2003) who argued that disclosure must not be seen as a one time event, but as an ongoing, dynamic process, and a fundamental part of the care of a person with dementia. The initial meeting is often overwhelming, so opportunities for follow-up sessions with additional family members should be anticipated.

Literature on physicians showed that not having enough time to provide a diagnosis of dementia and to schedule follow-up sessions was seen as a serious obstacle (Boise et al., 1999). Findings from this study confirm that physicians, particularly specialists, struggle with the same time constraints. Time constraints were also a significant barrier for the manner in which the diagnosis was shared. Previous literature by Pinner and colleague (2003) reported that physicians recognized the significance of the timing of the disclosure. One family physician in this study, for example, stressed that not all information about the diagnosis has to be given all at once. This finding was echoed by many of the individuals with dementia who would have liked another appointment in which they could ask some more questions. Their experience, however, highlights that physicians' time is limited and thus, follow-up appointments are the exception rather than the rule.

Literature on the manner in which the diagnosis is disclosed shows that some physicians are reluctant to disclose the diagnosis in front of a family member without the patient's explicit consent because of breaching confidentiality resulting in the scheduling of yet another appointment (Connell et al., 1996). Two of the individuals with dementia

in this study, however, experienced just the opposite where their family member was informed before they were told leaving both of them feeling betrayed and unimportant. Holroyd and colleagues (2002) found that although 49% of participants had been told their diagnosis, 93% of caregivers had been told. Rice and colleague (1994) also reported that disclosure to patients depended on their cognitive status but that disclosure to caregivers was nearly universal. Results from this study further suggest that, when a diagnosis of dementia is disclosed, the best situation is when the expectations and preferences of the patient are acknowledged and understood by the physician.

Literature shows that physicians and patients who have dealt with each other for a number of years might have very different interaction patterns from those who have met just recently or for the first time (Haug, 1996). Both physicians and patients know what techniques are useful for securing information from each other and what approaches will fail. Findings from this study show that for those individuals with dementia who, for example, prefer a gentle approach, having a physician “drop the bomb” was cause for great distress. Research by Pratt and colleague (2003) supports this finding. It is important for physicians to verify with all patients what they want to know and how they coped with “bad news” in the past.

Ideally, the manner in which the diagnosis is disclosed would be tailored to the individual needs, coping style, and capacity of the patient and family members. Physicians, for example, should ask patients if they want to have a companion present when the diagnosis is disclosed or if they would like to be by themselves. In the work by Husband (2000), 14% of patients were given their diagnosis first and alone, 21% received

the diagnosis with family present, and 65% received their diagnosis after it had been given to the caregiver. In this study, most of the individuals with dementia wanted their family member at their side when they received the diagnosis, although a small number expressed a desire to be the first to know or to control how much or when the family member should be told. Asking about preferences for disclosure, however, seems uncommon. Husband (2000) found that only 38% of caregivers had been consulted about whether to withhold or disclose diagnostic information, while the question whether individuals with dementia are consulted remains unexplored.

Literature shows that there may be wide variability in the language that is used to convey a diagnosis. Rice and colleague (1994) found that physicians tended to avoid the term ‘dementia’ and instead relied on phrases such as “failure of brain cells” and “brain shrinkage.” Among geriatricians and geriatric psychiatrists surveyed by Johnson and colleagues (2000), only 25% said they used explicit terms such as “Alzheimer’s disease” or “dementia.” Goodwin (2002) asserts that the word Alzheimer’s disease has specific meaning to individuals with dementia and families that of a disease that is incurable, involves progressive destruction of the mind, and is inherited. Most family physicians in this study reported that they always are direct and use the term Alzheimer’s disease. The number of participating physicians, however, was very small, and caution needs to be taken in interpreting this finding. The possibility of bias is quite possible in this particular physician sample. Several individuals with dementia, in contrast, reported that they do not like physicians to use the term Alzheimer’s disease because of concerns about stigma. The conclusion that individuals with dementia prefer the more general term

dementia resonates with earlier findings by Connell and colleagues (2004) who reported that caregivers felt that using Alzheimer's disease would devastate their family members.

Another issue that has received little attention in the literature concerns what information is provided to individuals with dementia and their families. Some studies have shown that, when individuals with dementia and families receive a diagnosis, they still receive little information about prognosis, available treatments, or management, even though thorough information on these topics is important (Holroyd et al., 2002).

Diagnosis further serves as an important entry point to support services. It enables the individuals with dementia to get some control over the situation, provides a basis for accepting and communicating with others about the reality of the illness and its effects, and sets the stage for financial and future health care needs.

Findings from this study show that many individuals with dementia did not receive proper information and consequently, did not know where to turn or what to do next, resulting in increased anxiety, stress, and sometimes depression. Participants reported that they received very little information from their physicians about the disease, treatment or research options, a finding that has been reported by many caregivers who participated in previous research (Connell et al., 1996; Fortinski, 1997; Glasser et al., 1998). Many of the individuals with dementia, thus, obtained additional information from the Internet, friends, or support groups. Secondary sources expanded information, which decreased uncertainty, allowed for hopeful alternatives, and gave some sense of control.

This study further shows that individuals with dementia rarely received referrals to community-based services such as the Alzheimer Society. Physicians, on the other hand, revealed fairly high levels of referral to community support services. One of the reasons could be that the sample of participating family physicians was very selective. These family physicians obviously were interested in participating in this research and as such, might not be representative of all practicing family physicians. Personal affairs such as power of attorney, choice in future care, and living wills were frequently mentioned by the participating family physicians as a benefit of sharing the diagnosis with patients and their companions, a finding supported by Connell and colleague (1996). The individuals with dementia, on the other hand, reported that they did not receive any such information from their physicians. The perception of insufficient information was reported to add stress, frustration, and uncertainty to the individuals' lives.

Many participants with dementia reported dissatisfaction with the communication process, in particular with the specialist who informed them of the diagnosis. These individuals with dementia were able to identify areas of poor practice reflecting issues such as not enough information being given to persons with dementia, the lack of follow-up, and contradictory information from different physicians. Literature shows that Pratt and colleague (2003) reported similar findings.

Some individuals with dementia explained that they sought advice from their family physicians first before receiving the diagnosis from a neurologist. It must be stressed that, although the majority of individuals with dementia were dissatisfied with the communication between themselves and the specialist, they were much more satisfied

with the family physicians' interaction. Some of the participants experienced exceptionally knowledgeable and understanding family physicians who were regarded as essential allies and social supports in their journey with dementia. Researchers such as Glasser and colleague (1998) on caregivers' satisfaction with the medical encounter reported that 73.3% of caregivers felt that their expectation about care from the family physician was satisfactory. Other individuals with dementia reported that, although they did not receive adequate information, they were relatively forgiving of the physician because of his/her busy schedule. For these participants, it seemed that they accepted the lower quality of care they received, as long as the physician had treated their concerns with interest and their best efforts. Social norms, however, might have made respondents reluctant to criticize their physicians, particularly, the older participants. Other researchers support this alternative explanation (Putman, 1996; Adelman et al., 2000).

In terms of making suggestions to improve the disclosure process, both family physicians and individuals with dementia suggested that the provision of hope and the need for hopeful messages was central to building strong relations. Several of the family physicians identified the issue of hope as significant in what they tell their patients. Rather than emphasizing the deficits and dysfunctions associated with dementia, these family physicians provided their patients with a more balanced picture and stressed the possibility of medications, thereby giving their patients hope. Individuals with dementia also expressed a continuing need for hope even when they knew that their illness was very serious. They wanted the door left open for the possibility of a miracle. Research by Boise and colleagues (1999) report similar findings.

In sum, disclosing the diagnosis early in the disease process allows individuals with dementia to continue to live life and play an active role in planning for the future. Disclosure, however, must not be seen as a one-time event, but as an ongoing, dynamic process and a fundamental part of the person with dementia (Pinner et al., 2003). Physicians should explore psychosocial factors, such as previous coping styles and interactions with family before informing the person about the diagnosis for dementia. Follow-up appointments may be a preferable time to discuss the diagnosis, prognosis, management, and treatment options in more detail. Monitoring the disclosure conversation and interviewing patients, family, and physicians after disclosure would provide details about similarities or dissimilarities in the perceptions of the process, recall information, and whether follow-up sessions lead to more beneficial outcomes (Pinner et al., 2003). In the end, an approach that incorporates individualized preferences may be most beneficial (Ahujn et al., 2000).

It is also worth pointing out again that the landscape of dementia care has changed dramatically in the past few years, and results from studies that were published as recently as the 1990s might not be replicated now, as diagnostic accuracy has improved, more treatment options have become available, and public awareness has increased.

Limitations

It is important to acknowledge certain limitations of this study. There were only a small number of family physicians, 14 out of 120, who participated in this research. Such a small sample of participants might not only lead to a social desirability and/or possibility of bias on the family physicians' part but also limits the generalization of the

findings. Those family physicians who did not return the questionnaire may have been less comfortable than their co-respondents in their ability to diagnose dementia, disclose the diagnosis to patients and companions, and manage the relationship with patients and family members. Another potential study limitation lies in its reliance upon the self-selected nature of the sample. This potential bias suggests that these family physicians are the ones most interested in dementia and, as such, are most likely to report favorable practices. Another important limitation of this study is the fact that only family physicians participated in this study. Based on the findings of individuals with dementia, all of them received their diagnosis from specialists, mostly neurologists, thus some issues pertain to specialists while others pertain to family physicians. The readers should be aware of this issue. Even though the intent of this study was to examine family physicians' views on diagnosis and disclosure of Alzheimer's disease, it needs to be emphasized that most of the participating individuals with dementia received their diagnosis from neurologists

It is important to reiterate that the individuals with dementia interviewed for this study may not be representative of all persons who are in the early stages of dementia. The sample is small and varied, comprised of only nine individuals. The findings thus may not widely generalize to the newly diagnosed dementia population and subjective views may lack validity. The results may have shown a bias towards participating in this research based on the high education level of persons with dementia. Individuals with dementia, who consented to the study, did understand the nature of the research and may thus have been more positively disposed to the openness of diagnosis disclosure than

those who declined to be interviewed. The present sample, nevertheless, is ideally suited for this exploratory study of attitudes toward a diagnosis among individuals in the early stages of dementia because each person directly experienced the process.

Future Implications

Based on the findings of this study, the researcher suggests a number of implications for practice. First, the researcher recommends that the diagnosis be shared over a number of sessions. Physicians should provide information about the diagnosis with an emphasis on retained abilities and strengths. Earlier research by Johnson and colleagues (2000) found that in physician-patient communications, patients often hear and recall information differently from that which the physician had wished to express. By ensuring a dynamic process of relaying information with regard to a diagnosis and further prognosis, this becomes a fundamental part of the care of a person with dementia. Many physicians have a fear of causing distress by telling the truth about the diagnosis; in turn, it could be considered an intrinsic part of physicians' work to address the distress and be there for the patient even if he or she does not take the diagnosis well. A good physician will always "give a ray of hope as well as discuss the implications of a grave situation (Johnson et al., 2000, p: 227). Communication through "patient-led" discussions would diminish any adverse emotional effects of sharing painful diagnostic information, a responsibility all physicians share (Meyers, 1997).

Second, innovative educational programs are needed to better inform both physicians and individuals with dementia about the availability of community-based services, treatment options, and opportunities for research participation. When available,

counseling and support groups can be suggested as ways of helping the person adjust to changed life circumstances. Findings from this study show that individuals with dementia were dissatisfied with the lack of information and referral to community support. This shortcoming, however, could be readily addressed through greater provision of reading materials about dementia and efforts at referral and education for the individual with dementia. It would certainly be of interest to see whether family physicians are receptive to inclusion of this type of information and referral effort to a greater extent. This would be one way to reach large numbers of individuals with dementia who never make their way to support groups, Alzheimer Societies, or other sources of useful information on dementia.

Third, there is a need to move to practices that have a psychosocial understanding of individuals with dementia. The findings from this research support moving from the “to disclose or not to disclose” question to developing a psychosocial approach to disclosure practice. To continue to develop family physicians’ understanding of the experience of individuals with dementia, it is important to not only consider the physical impact on people’s lives but also to consider the psychological and social factors.

In this study, the participant with dementia experienced symptoms for which he or she consulted the physician. The person with dementia described these symptoms based on his or her experience, thus subjectively. The physician examined the person with dementia, did order laboratory tests, and in the end, told the patient that the test results indicated dementia. The physician wrote the test results in his or her chart where they became medical or objective facts. The person with dementia, moreover, received the

label patient. From the perspective of the physician, sharing the medical diagnosis “of” dementia could thus be neatly divided into before and after the consultation (Pratt et al., 2003).

From the perspective of the person with dementia, receiving the diagnosis “for” dementia was far more important than passively receiving a single verbal message, far more than a moment of communication that divided time into “before” and “after”. Rather than a “one time event”, as portrayed by specialists who informed them of the diagnosis and labeled them as patients, for individuals with dementia, receiving the diagnosis was a “process”. This process consisted of building relationships with their family physicians, of living up to the individuals’ expectations of accompanying them on this difficult journey. Although receiving competent advice and medical care was at the top of every patient’s agenda, individuals with dementia also needed to be reassured that their physician cared about their personal well-being. Individuals with dementia, thus, expected their family physicians, to pay attention to the subjective experience of their illness through listening to their concerns, discussing medications and advance planning, and referring them to available community services.

Caring about the individual’s personal well-being means understanding the person’s objectives. For many, if not all participants in this study, quality of life is very important. Discussing the impact the diagnosis for dementia will have on a person’s lifestyle, as well as on his or her family’s well-being conveys the message that the family physician is interested in more than medical outcomes. Demonstrating an interest in how a patient copes with the illness will send a powerful message that the physician is

interested in the patient as a person. Although walking the fine line between not getting too emotionally involved with persons with dementia and conveying a caring attitude can be difficult, it is imperative for the person's well-being. When sharing the diagnosis for dementia, for example, family physicians who freely express their sadness and distress alongside their patients show that they appreciate the devastating impact of the news and will do whatever they can to help (Husband, 2000).

As part of this process, individuals with dementia could articulate their preferences for when and the way in which the diagnosis is disclosed. Knowing what to expect and having some input into the diagnostic and assessment process may greatly reduce the stress for the individual with dementia, his or her companion, and physician. The most effective way to determine the adequacy of physician-patient communication is to ask the patient. Seeking patient input on this subject not only provides physicians with important feedback but also sends a powerful message that the physician really does care about the well-being of his or her patient. While most individuals with dementia reported that the specialist did not respond to their concerns in a way they had hoped, most were very satisfied with their family physician. Therefore, more attention should be paid to those physicians who are doing it right so that other physicians can share in their successes.

Finally, this study showed that individuals with dementia do not interact with physicians in a vacuum. Instead, persons with dementia are embedded in a wider set of relationships such as with family members. It is clear that the typical conception of physician-patient interaction must be broadened to include the family caregiver. While

this is generally true of geriatric care, it is especially important in interactions with individuals with dementia, regardless of their age. When the physician cares for more than one person, the lines between the patient's and the family's needs may become blurred, sometimes resulting in marginalization of the patient.

Future Research

As Beisecker and colleagues (1997) noted, when persons with dementia can still understand and communicate their wishes, physicians will more than likely continue to interact with them and look to the companion for verification of facts needed. As the individual with dementia becomes increasingly unable to understand or answer physician questions, the physician may seek verification from the caregiver regarding facts and, eventually, exchange information only with the caregiver. Further research is needed on how physicians deal with the frequent need for on-the-spot calculations of the patient's capabilities in order to provide appropriate support to the individual with dementia as an adult member of the group. It is also important that future research will broaden the sample by including neurologists and family members. A more diverse and in-depth study could include some of the following questions:

- The kind of challenges family physicians encounter when providing a diagnosis; the kind of concerns and fears they have regarding disclosure
- The kind of suggestions family physicians might have for making the process of getting a diagnosis less stressful for patients and physicians
- The degree to which family physicians inform and educate individuals with dementia regarding the illness and/or directing them toward appropriate resources

- The degree to which patients want to know the diagnosis, the kind of information they want about the disease and the manner in which they want to be told
- The degree to which patients experience communication challenges with their family physician when trying to obtain a proper diagnosis
- The kind of suggestions they might have for making the process of getting a diagnosis less stressful for patients and physicians
- The degree to which individuals with AD feel they receive adequate information from their family physician about the diagnosis.

Conclusion

“I feel I am the same flame, but a smaller one.
I foresee the flame getting smaller and smaller,
But just as hot and yellow---Then going out
and leaving smoke and a glowing wick”
(Mark, participant with early stage dementia).

The Bridge between Paternalism and Autonomy

Informing patients about the diagnosis for dementia is one of the most difficult responsibilities in the practice of medicine. Although virtually all physicians in clinical practice encounter situations entailing bad news, medical school offers little information in how to discuss the diagnosis for dementia with patients and their families.

The approach to the physician-patient relationship is frequently summarized as “to identify the most effective strategies for breaking bad news to patients” (Girgis et al., 1995, p: 11). There is a tendency to reduce the relationship to an event of transmittance of information between an active sender, the physician, and a passive receiver, the patient. Typically the guidelines are focused on “breaking”, “telling”, “disclosing”, or

“giving” bad news. Traditional paternalism is discarded in favor of proclaiming patient autonomy as the core of medical ethics. This has undoubtedly been a step in the right direction, individuals with dementia are now better informed and more respected, as supported by this study. Still, despite paternalism’s inability to respect the patient as an individual, it is based upon some understanding of the patient’s dependency and the importance of a helping relationship. Autonomy on the other hand is focused on information processes and connected to separateness. This must be kept in mind, since being diagnosed for dementia implies becoming dependent and having to rely more on others, not the least the physician. Sharing the diagnosis for dementia thus cannot be reduced to communicative effectiveness between equals but needs to take into account the creation of a helping relationship as well.

It is undoubtedly of the utmost importance that the physician is well trained in communicative skills, but the task of the physician cannot be reduced to the sender’s perspective, such as delivering information. Participants in this study stressed the importance of a warm, caring, and supportive relationship as well. Communication skills are important, but it is equally important that physicians are readily available, kind and devoted. Individuals with dementia want their physicians to accompany them on this difficult journey.

From patient to person.

To continue to develop our knowledge of the experience of people with dementia, the psychological factors need to be understood not only in the context of biological aspects but also in the social context (Pratt et al., 2003). We need to build a bridge

between what Smith (1990, p: 143) described as “the disparities between how it was experienced and how it comes to be represented,” in other words, we need to link the diagnosis for dementia to the person’s lived experience. The implication of including the individual’s experience of dementia has been emphasized in the work of Kitwood (1997).

Kitwood’s (1997) approach continues to build from psychoanalytical traditions of understanding while incorporating the importance of social factors. His work is an important development in moving towards a psychosocial model of dementia, one that challenges the victim blaming values that underlie what Kitwood would have called a “malignant social psychology”. Developing a psychological understanding that includes social context needs to be explored, particularly in relation to the practice of diagnosis disclosure. Discussions about psychosocial issues inform the physician about the patient’s identity and allow the physician to enter the patient’s life world (Hasselkus, 1994). Especially in individuals with dementia, who have an increased likelihood of psychosocial rather than medical concerns, humane care is possible only when a comprehensive understanding of the person with dementia is achieved. Researchers such as Pratt and colleague (2003) did develop a model of dementia that takes account of a social model approach. Future research needs to build on this model in order to explore further the importance and impact of social context, as the practice disclosure exists in the social context of people.

In summary, to provide effective medical care for patients with dementia, physicians must recognize the effect of psychosocial factors on the person with dementia. Physicians must be prepared to care for and treat the individual with dementia and take

into account his or her illness experience. Lack of attention to the psychosocial domain will ultimately harm both individuals with dementia and their physicians. Problems of persons with dementia will remain “family” problems and the quality of their lives will be reduced; physicians will become bureaucratic managers, merely adhering to biomedical aspects of care, thus the therapeutic potential of the physician-patient relationship is undermined. The issue of sharing the diagnosis of dementia, as well as attention to psychosocial issues remains important area for future research, to enable a therapeutic alliance with individuals with dementia, their family members and physicians to be strengthened.

BIBLIOGRAPHY

- Adelman, R.D., Greene, M.G., & Charon, R. (1987). The Physician-Elderly Patient-Companion Triad in the Medical Encounter: The Development of a Conceptual Framework and Research Agenda. The Gerontologist, 27(6), 729-734.
- Adelman, R.D., Greene, M.G., & Charon, R. (1991). Issues in Physician-Elderly Patient Interaction. Ageing and Society, 11, 127-148.
- Adelman, R.D., Greene, M.G., & Ory, M.G. (2000). Communication between Older Patients and Their Physicians. In R.D. Adelman & M.G. Greene (Eds.), Clinics in Geriatric Medicine (pp.1-24). Philadelphia: W.B. Saunders Company.
- Adelman, R.D., Greene, M.G., & Friedmann, E. (2004). Discussions about Cognitive Impairment in First Medical Visits: Older Patients' Perceptions and Preferences. American Journal of Alzheimer's Disease and Other Dementias, 2, 1-17.
- Ahujn, A., and Williams, D.D.R. (2000). Disclosing the Diagnosis of Dementia. The British Journal of Psychiatry, 177, 565-567.
- Bahro, M., & Sunderland, E., (1995). How Do Patients With Alzheimer's Disease Cope With Their Illness? : A clinical Experience Report. Journal of American Geriatric Society, 43, 41-46.
- Barnes, R.C. (1997). Telling the Diagnosis to Patients with Alzheimer's Disease: Relatives Should Act as Proxy for Patient. British Medical Journal, 314, 375-379.
- Beisecker, A.E. (1988). Aging and the Desire for Information and Input in Medical Decisions: Patient Consumerism in Medical Encounters. The Gerontologist, 28(3), 330-335.
- Beisecker, A.E., & Beisecker, T.D. (1990). Patient Information-Seeking Behaviors when Communicating with Doctors. Medical Care, 28, 19-28.
- Beisecker, A.E. (1996). Older Persons' Medical Encounters and Their Outcomes. Research on Aging, 18(1), 9-31.
- Beisecker A.E., & Beisecker T.D. (1996). Research Issues Related to Physician-Elderly Patient Interactions: Introduction. Research on aging, 18(1), 3-8.
- Beisecker A.E., Chrisman, S.K., & Wright, L.J. (1997). Perceptions of Family Caregivers of Persons with Alzheimer Disease: Communication with Physicians. American Journal of Alzheimer's Disease, 12, 73-83.
- Boise, L., Camioli, R., Morgan, D., Rose, J.H., & Congleton, L. (1999). Diagnosing Dementia: Perspectives of Primary Care Physicians. The Gerontologist, 39(4), 457-464.
- Bond, J., and Corner, L. (2001). Researching Dementia: Are There Unique Methodological Challenges for Health Services Research? Ageing and Society 21, 95-116.
- Cockerham, W.C. (1998). Medical Sociology. New Jersey: Prentice Hall.
- Coe, R.M., & Miller, D.K (2000). Communication between the Hospitalized Older Patient and Physician. In R.D. Adelman & M.G. Greene (Eds.), Clinics in Geriatric Medicine (pp.109-118). Philadelphia: W.B. Saunders Company.
- Cohen, C.A. (2001). Dementia Caregiving: The Role of The Primary Care Phycian. Canadian Journal of Neurlogical Science, 28, S72-S76.

- Connell, C.M., & Gallant, M.P. (1996). Spouse Caregivers' Attitudes Towards Obtaining a Diagnosis of a Dementing Illness. The Journal of the American Geriatrics Society, 44, 1003-1009.
- Connell, C. M., Boise, L., Stuckey, J.C., Holmes, S.B., & Hudson, M.L. (2004). Attitudes Toward Diagnosing and Disclosure of Dementia Among Family Caregivers and Primary Care Physicians. The Gerontologist, 44(4), 500-507.
- Cotrell, V & Schulz, R. (1993). The Perspective of the Patient with Alzheimer's Disease: A Neglected Dimension of Dementia Research. The Gerontologist, 33, 205-211.
- Downs, M.G. (2002). How to Tell? Disclosing a Diagnosis of Dementia. Generations, 23, 30-34.
- Drickamer, M., & Lachs, M.S. (1992). Should Patients with Alzheimer's Disease Be Told Their Diagnosis? The New England Journal Of Medicine, 326, 947-951.
- Ellingson, L.L. (2002). The Roles of Companions in Geriatric Patient-Interdisciplinary Oncology team Interactions. Journal of Aging Studies, 16, 361-382.
- Emanuel, E.J., & Neveloff-Dubler, N. (1995). Preserving the Physician-Patient Relationship in the Era of Managed Care. Journal of American Medical Association, 273, 323-329.
- Erde, E.L., Nadal, E.C., & Scholl, T.O. (1988). On Truth Telling and the Diagnosis of Alzheimer's Disease. The Journal of Family practice, 26(4), 401-406.
- Fisher, S. (1984). Doctor-Patient Communication: A Social and Micro-Political Performance. Sociology of Health and Illness, 6, 1-27.
- Fortinsky, R.H., Leighton, A., and Wasson, J.H. (1995). Primary Care Physicians' Diagnostic, Management, and Referral Practices for Older persons and Their Families Affected by Dementia. Research on Aging, 17, 124-148.
- Fortinsky, R.H. (2001). Health Care Triads and Dementia Care: Integrative Framework and Future Directions. Aging & Mental Health, 5, (Supplement 1): S35-S48.
- Foster, N.L. (2001). Barriers to Treatment: The Unique Challenges for Physicians Providing Dementia Care. Journal of Geriatric Psychiatry and Neurology, 13, 70-78.
- Freidson, E. (1970). Profession of Medicine: A Study of the Sociology of Applied Knowledge. New York: Dodd, Mead & Company.
- Gillon, R. (1985). Telling the truth and Medical Ethics. British Medical Journal, 291, 1556-1557.
- Girgis A., and Sanson-Fisher, R.W. (1995). Breaking Bad News: Consensus guidelines for Medical practitioners. Journal of Clinical oncology, 13(9), 2449-2456.
- Glasser, M., Prohaska, T., & Gravdal, J. (2001). Elderly Patients and Their Accompanying Caregivers on Medical Visits. Research on Aging, 23(3), 326-348.
- Goodwin, J.S. (2002). Language and medicine: Thinking and Talking about Alzheimer's Disease. The Gerontologist, 42, 293-296.
- Greene, M.G., Majerovitz, S.D., Adelman, R.D., & Rizzo, C. (1994). The Effects of the Presence of a Third Person on the Physician-Older Patient Medical interview. Journal of American Geriatric Society, 42, 413-419.

- Greene, M.G., Adelman, R.D., Friedmann, E., & Charon, R. (1996). Older Patient Satisfaction during an Initial Medical Encounter. Social Science and Medicine, 38(9), 1279-1288.
- Greene, M.G., & Adelman, R.D. (1996). Psychosocial Factors in Older Patients' Medical Encounter. Research on Aging, 18(1), 84-102.
- Greenhalgh, T., and Taylor, R. (1997). How to Read a Paper. Papers That Go Beyond Numbers (Qualitative Research). British medical Journal, 315, 740-753.
- Harris, P.B. (2002). Living with the Symptoms of Alzheimer's Disease. In P.B. Harris (Ed.), The Person with Alzheimer's Disease (pp. 1-29). Baltimore: The John Hopkins University Press.
- Haley, W.E. Clair, J.M., & Saulsberry, K. (1993). Family Caregiver Satisfaction with Medical Care of Their Demented Relatives. The Gerontologist, 32, 219-226.
- Haug, M.R., & Lavin, B. (1983). Consumerism in Medicine: Challenging Physician Authority. Beverly Hills: Sage.
- Haug, M.R., & Ory, M.G. (1987). Issues in Elderly Patient-Provider Interactions. Research on Aging, 9(1), 3-44.
- Haug, M.R. (1994). Elderly Patients, Caregivers, and Physicians: Theory and Research on Health Care Triads. Journal of Health and Social Behavior, 35, 1-12.
- Haug, M.R. (1996). Elements in Physician/Patient Interaction in Late Life. Research on Aging, 18(1), 32-51.
- Hasselkus, B.R. (1992). Physician and Family Caregiver in the Medical Setting: Negotiation of Care? Journal of Aging Studies, 6(1), 67-80.
- Hasselkus, B.R. (1994). Three-Track Care: Older Patient, Family Member, and Physician in the Medical Visit. Journal of Aging Studies, 8(3), 291-307.
- Holroyd, S., Snustad, D.G., and Chalifoux, R. N. (1996). Attitudes of Older Adults on being Told the Diagnosis of Alzheimer's Disease. Journal of the American Geriatrics Society, 44, 400-403.
- Holroyd, S., Turnbal, Q., and Wolf, A.M. (2002). What Are Patients and Their Families Told about the Diagnosis of Dementia? Results of a Family Survey. International Journal of Geriatric Psychology, 17, 218-221.
- Husband, H.J. (2000). Diagnostic Disclosure in Dementia: An Opportunity for Intervention? International Journal of Geriatric Psychiatry, 15, 544-547.
- Johnson, H., Bouman, W.P., & Pinner, G. (2000). On Telling the Truth in Alzheimer's Disease: A Pilot Study of Current Practice and Attitudes. International Psychogeriatrics, 12(2), 221-229.
- Keady, J., and Nolan, M. (1999). IMMEL: Assessing Coping Responses in the Early Stages of Dementia. British Journal of Nursing, 4 (6), 309-380.
- Kitwood, T. (1997). The Experience of Dementia. Aging and Mental Health, 1 (1), 13-22.
- Labrecque, M., Blanchard, C., Ruckdeschel, J.C., and Blanchard, E.D. (1991). The Impact of Family Presence on the Physician-Cancer Patient Interaction. Social Science and Medicine, 33(11), 1253-1261.
- LoFaso, V. (2000). The Doctor-Patient Relationship in the Home. In R.D. Adelman & M.G. Greene (Eds.), Clinics in Geriatric Medicine (pp.83-94). Philadelphia:

- W.B. Saunders Company.
- Lupton, D. (1994). Medicine As Culture: Illness, Disease and The Body in Western Societies. London: Sage Publications.
- Maguire, C.P., Kirby, M., Coen, R., and Coakley, D. (1996). Family Member's Attitudes toward Telling the Patient with Alzheimer's Disease Their Diagnosis. British Medical Journal, 313, 529-532.
- Marzanski, M. (2000). Would You Like to Know What is Wrong with You? On Telling the Truth to Patients with Dementia. Journal of Medical Ethics, 26, 108-113.
- Meeuwssen, L.C., Schaap, C., and Van der Staak, C. (1991). Verbal Analysis of Doctor-Patient Communication. Social Science and Medicine, 32 (4), 1143-1150.
- Meyers, S. (1997). Telling Patients They have Alzheimer's Disease. British Medical Journal, 314, 321-322.
- Ong, L.M.L., DeHaes, J.C.J.M., Hoos, A.M., & Lammes, F.B. (1995). Doctor-Patient Communication: A Review of the Literature. Social Science and Medicine, 40(7), 903-918.
- Ownes, D.J., & Batchelor, C. (1996). Patient Satisfaction and the Elderly. Social Science and Medicine, 42(11), 1483-1491.
- Parsons, T. (1951). The Social System. Glencoe, Illinois: Free Press.
- Pinner, G. (2000). Truth-Telling and the Diagnosis of Dementia. British Journal of Psychiatry, 176, 514-518.
- Pinner, G., and Bouman, W.P. (2003). Attitudes of Patients With Mild Dementia and Their Carers Towards Disclosure of the Diagnosis. International Psychogeriatric Association, 15(3), 279-288.
- Pratt, R., & Wilkinson, H. (2003). A Psychosocial Model of Understanding the Experience of Receiving a Diagnosis of Dementia. Dementia, 2(2), 181-199.
- Prohaska, T.R., & Glasser, M. (1996). Patient Views of Family Involvement in Medical Care Decisions and Encounters. Research on Aging, 18(1), 52-69.
- Putman, S.M. (1996). Nature of the Medical Encounter. Research on Aging, 18(1), 70-83.
- Rice, K., & Warner, N. (1994). Breaking the Bad News: What do Psychiatrists Tell Patients with Dementia about Their Illness? International Journal of Geriatric Psychiatry, 9, 467-471.
- Rohde, K., Peskind, E.R., and Raskind, M.A. (1995). Suicide in Two Patients with Alzheimer's disease. Journal of the American Geriatric Society, 43, 187-189.
- Rosow, I. (1981). Coalitions in Geriatric Medicine. In M. Haug (Ed.), Elderly Patients and their Doctors (pp. 487-508). New York: Springer.
- Roter, D.L. (2000). The Outpatient Medical Encounter and Elderly Patients. In R.D. Adelman & M.G. Greene (Eds.), Clinics in Geriatric Medicine (pp.95-109). Philadelphia: W.B. Saunders Company.
- Sherwin, S. (1998). With Voices from the Network. In S. Sherwin(Ed.), The Politics of Women's Health: Exploring Agency and Autonomy (pp. 1-18). Philadelphia: Temple University Press.
- Silliman, R.A. (2000). Caring for the Frail Older Patient: The Doctor-Patient-Family Caregiver Relationship. Journal of General Internal Medicine, 28, S67-S71.

- Smith, D.E. (1990). The Conceptual Practices of Power: A Feminist Sociology of Knowledge. Toronto: University of Toronto Press.
- Szasz, T.S., & Hollender, M.H. (1956). The Basic Models of the Doctor-Patient Relationship. Internal Medicine, 97, 585-592.
- Tates, K. & Meeuwse, L. (2001). Doctor-Patient Communication. A (re)view of the Literature. Social Science and Medicine, 52(6), 839-851.
- Tennstedt, S.L. (2000). Empowering Older Patients to Communicate More Effectively in the Medical Encounter. In R.D. Adelman & M.G. Greene (Eds.), Clinics in Geriatric Medicine (pp.61-70). Philadelphia: W.B. Saunders Company.
- Vassilas, C.A., and Donaldson, J. (1998). Telling the Truth: What Do General Practitioners Say to Patients with Dementia or Terminal Cancer? British Journal of General Practice, 48, 1081-1082.
- Waitzkin, H. (1984). Doctor-Patient Communication: Clinical Implications of Social Scientific Research. Journal of American Medical Association, 252, 324- 345.
- Waitzkin, H. (2000). Changing Patient-Physician Relationships in the Changing Health-Policy Environment. In C. Bird, P. Conrad, & A. Freemont (Eds.), Handbook of Medical Sociology (5th Ed.). Chapter 18. New York: Prentice Hall.
- Young, R.F. (2002). Medical Experiences and Concerns of People with Alzheimer's Disease. In P.B. Harris (Ed.), The Person with Alzheimer's Disease (pp. 29-48). Baltimore: The John Hopkins University Press.
- Wolff, K. (1950). The Sociology of George Simmel. Illinois: Free Press.
- Woods, B. (1999). The Person in Dementia Care. Generations, 3, 35-39.

APPENDIX I
PHYSICIAN'S QUESTIONNAIRE



JBN Specialist Clinics

***Internal Medicine - Critical Care- Rheumatology – Respirology – Geriatrics – Diabetic Nephropathy
Allergy – Immunology - Asthma – Pediatrics – Pediatric GI
Health Clinics - Clinical Research - Cardiac Diagnostics***

***Dr. W.A. Nisker / Dr. J.C. Berlingieri / Dr. V. Pandith / Dr. A. Ladha / Dr. P. Sathya
Dr. D. Kloth / Dr. M. Messieh / Dr. M. Cyr / Dr. C.C. Barnes / Dr. R. Bobba***

September 10, 2004

Dear Colleagues:

Hendrika Spykerman, a graduate student in the Sociology of Ageing, at McMaster University, is studying the communication patterns between physicians and persons with dementia.

Hendrika is a nurse and has many years experience caring for persons with dementia. She is employed by the Alzheimer Society as a counselor and is available to patients and their families at our Memory Clinic, on a part-time basis. Her research examines how the diagnosis of dementia is communicated between physicians and patients. The enclosed survey will contribute to her master's thesis in Sociology. It will take about 20-30 minutes to complete.

There is a growing discussion among medical professionals about the merits of disclosing the diagnosis to the person with dementia. Some have attributed this growth to the fact that more and more people with dementia are being identified at earlier stages, a trend that will only continue with recent advances in better tests, and technology and drug treatments, which are currently indicated for use in the earlier stages of Alzheimer's disease.

This survey is an important step toward identifying facilitators and barriers to good communication, enhancing dementia care and improving quality of life of persons with dementia.

I hope that you will take this occasion to participate in Hendrika's study by completing the questionnaire.

Sincerely,

William A. Nisker, MD FRCPC

JBN MEDICAL DIAGNOSTIC SERVICES INC.

***2951 Walkers Line, Suite #301, Burlington, ON L7M 4Y1
905-331-3101 Fax 905-319-2499
email info@jbnmedical.com***

Study: Communication between Physicians and Individuals with Early Stage Dementia.

You are asked to participate in a research study conducted by Hendrika Spykerman, a second year master student in the Sociology program. Dr. Ellen Ryan, professor from the McMaster Centre for Gerontological Studies supervises Hendrika. The results of the research will be contributing to Hendrika's MA thesis.

If you have any questions or concerns about the research, please feel free to contact:
Dr. Ellen Ryan at (905) 525-9140 ext: 24995
Hendrika Spykerman at (905) 957-2536

PURPOSE OF THE STUDY

This study investigates purpose physicians' and patients' attitudes toward assessing and diagnosing dementia, particularly how the diagnosis is disclosed; it examines the experience of individuals when a diagnosis of AD is given; and it explores the effects of the presence of a third person on the family physician-Alzheimer's patient medical encounter.

PROCEDURES

If you volunteer to participate in this study, I would like you to answer the following questions and to return the completed questionnaire via e-mail to Hendrika. The survey will not exceed 20 minutes.

AVAILABILITY OF RESEARCH

A general overview of the results will be made available to all participants. You will receive a copy of the results by mail.

POTENTIAL BENEFITS

Opportunities for enhanced communication strategies between physicians and individuals with dementia.

Opportunities to establish best practice regarding diagnosis disclosure to people with dementia

Opportunities to increase awareness among physicians of the importance of early diagnosis.

PAYMENT FOR PARTICIPATION

You will receive a thank you note with the general overview of the results. You will not receive any financial payment for participating in this study.

CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Only the researcher will have access to the coded data. Responses of each individual participating in the study will be coded at once and will be stored in Dr. Ryan's office in a locked cabinet. All written data will be destroyed once the research is completed.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may exercise the option of removing your data from the study.

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights of remedies because your participation in this research study. This study has been reviewed and received ethics clearance through the McMaster Research Ethics Board (MREB). If you have any questions regarding your rights as a research participant, contact:

MREB Secretariat

McMaster University

1280 Main Street W., GH-306

Hamilton

Telephone: (905) 525-9140, ext.23142

E-Mail: ethicsoffice@mcmaster.ca

Fax: (905) 540-8019

Physician Survey

Please read the questions on the following pages carefully. If you require more space for writing your comments, please use an extra sheet of paper and append it to the end of the survey with the question number(s) clearly indicated.

If you prefer, you may wish to complete this questionnaire by email. If so, please contact me at **spykerhm@mcmaster.ca** and I will send you an electronic version of the questionnaire.

When you have completed the questionnaire, please return it either in the enclosed stamped self-addressed envelope or as an email attachment by **Monday, November 1, 2004.**

If you have any questions about this questionnaire, please contact me at **(905) 957-2536** or **spykerhm@mcmaster.ca**

Physician Questionnaire

1. In your opinion, which **one** of the following **best** describes probable Alzheimer's disease?

- a) a condition that can improve for a period of time, if treated early
- b) a condition that can stabilize for a period of time, if treated early
- c) a condition that cannot be helped much, if at all, even with treatment
- d) just part of the aging process
- e) an illness that affects the memory and not much else
- f) Other (Please specify) _____

2. Approximately how many of your patients have been diagnosed with probable Alzheimer's disease or related dementia **in the last five years**? _____

3. For what percentage of those patients **in the last five years** were you the first to notice the early signs of Alzheimer's disease and for what percent did you become aware only after the patient/family reported changes in his/her condition? Please give your best estimates.

a) ____% I was first to notice

b) ____% patient/family reported

4. Before any formal testing is done, what steps do you take when **you** are the first to notice early signs of Alzheimer's disease?

5. Do you conduct any regular screening procedures for Alzheimer's disease among your older patients?

a) If **yes**, what kind of screening do you do?

b) If **no**, what is the reason?

6. To whom do you usually tell the diagnosis?

- a) Patient
- b) Family member
- c) Both

7. What terms do you use when informing patients or family members about the diagnosis of Alzheimer's disease?

- a) "Alzheimer's disease"
- b) "Dementia"
- c) "Memory Impairment"
- d) "Forgetfulness"
- e) Others...(please specify)

8. Do you think that typically, most patients would want to know their diagnosis?

- a) Yes
- b) No

Please comment

9. If you yourself were suffering from Alzheimer's disease or a related dementia, would you wish to be told the diagnosis?

- a) Yes
- b) No

Please comment

10. In your opinion, what are some of the potential **benefits** of informing the patient about the diagnosis of Alzheimer's disease?

11. In your opinion, what are some of the **challenges** of informing the patient about the diagnosis of Alzheimer's disease?

12. Do you have any suggestions for making the process of getting and disclosing a diagnosis less stressful for physicians and patients?

13. Which of the following information sources, if any, might you provide or recommend for patients to educate themselves about Alzheimer's disease?
Please circle any that apply.

- a) Second opinion from another physician
- b) Access/referrals to other healthcare professionals
- c) Interaction with other patients diagnosed with Alzheimer's disease
- d) Medical reference book
- e) Magazine or newspaper articles
- f) Internet sites
- g) Educational material provided by your office
- h) Alzheimer's support group
- i) Other (Please specify)

14. Approximately what proportion of your patients with Alzheimer's disease are accompanied by a family member when they visit you? Please give your best estimate.

_____ % of patients are accompanied by another person

15. How does the presence of a companion affect your communication with the patient during the visit?

- a) facilitates communication
- b) hinders communication
- c) both

17. In what ways might a companion **facilitate** communication during the visit?

18. In what ways might a companion **hinder** communication?

The following questions are for demographic purposes only.

D1. How long have you been in active practice?

- a) Less than 5 years
- b) 5 years to less than 10 years
- c) 10 years to less than 20 years
- d) 20 years to less than 30 years
- e) 30 years or more

D2. How long have you been treating patients with Alzheimer's disease?

- a) Less than 5 years
- b) 5 years to less than 10 years
- c) 10 years to less than 20 years
- d) 20 years to less than 30 years
- e) 30 years or more

D3. In which of the following age ranges are you?

- a) 35 to 49
- b) 50 to 64
- c) 65 and older

D4. Gender: Male _____ Female _____

APPENDIX II
INTERVIEW TOOL FOR INDIVIDUALS WITH DEMENTIA

Survey:

Communication between Physicians and Individuals with Early Stage Dementia

Please read the following (we suggest that you print a copy of this form for future reference).

You are asked to participate in a research study being conducted by Hendrika Spykerman, a second year master student in the Sociology program at McMaster University. Dr. Ellen Ryan, professor from the McMaster Centre for Gerontological Studies, supervises Hendrika. This research has been approved by the McMaster Research Ethics Board.

If you have any questions or concerns about the research, please feel free to contact:
Dr. Ellen Ryan at (905) 525-9140 ext: 24995 e-mail: ryaneb@mcmaster.ca
Ann Anas at (905) 525-9140, ext 22688 e-mail: anasa@mcmaster.ca
Hendrika Spykerman at (905) 957-2536 e-mail: spykerhm@mcmaster.ca

The purpose of this study is to gain information about communication between persons with dementia and their physicians.

Participation in this study involves answering some questions in an interview, recorded on tape, about what you have been told about dementia, and by whom, and what you wish to know about dementia. Enclosed is a list of some of the questions the interviewer will ask.

Your participation in this study is completely voluntary. If you agree to participate in this study, you may withdraw at any time without consequences of any kind. You do not have to answer any questions you prefer not to.

Information relating to you will be kept confidential; no information will be released or published that would identify you.

You do not have to participate. Signing the consent form will mean that you are agreeing to an interview that will be recorded on tape.

The questions on the following pages are only meant as a guide for the actual interview to help you think about what you might want to say to the interviewer. Hendrika will call you to ask if you want to participate. If so, Hendrika will arrange a mutually convenient date and time for the interview. The interview will take about 60 minutes to complete

CONSENT

I acknowledge that the research procedures described above have been explained to me, and that any questions I have asked have been answered to my satisfaction.

I have been given the names and phone numbers of the researchers involved in this project who will be able to discuss any concerns or questions I may have about this project.

I hereby consent to participate in the above project.

Name (Please Print) Signature Date

In signing below, I acknowledge that I have described the project to the best of my abilities, and the participant who signed above has agreed willingly to take part in the project.

Researcher Signature Date

(Your participation is voluntary and you may skip any question you choose to or stop participating at any time.)

Please read the questions on the following pages carefully. If you prefer, you may include a family member to help you answer the questions. If you require more space for writing your comments, please use an extra sheet of paper.

Questionnaire

1. What were some of the first symptoms you noticed?

2. What did you think was wrong with you?

3. What have you been told about your illness?

4. Who was the person who told you what was wrong with you?

- a) Family physician
- b) Neurologist
- c) Geriatrician
- d) Other (SPECIFY)

5. At the time, did you want to know more about the diagnosis?

- a) Yes, go to question 6
- b) No, go to question 7

6. If yes, what would you have liked to know?

7. If not, what was the reason for not wanting to know more about dementia?

8. Did your physician ask you if you wanted to know more about dementia?

- a) yes
- b) no

9. Would you have liked to be told your diagnosis differently? If so, how would you prefer to have been told?

10. Would you like to get more information about your illness?

- a) yes,
- b) no

11. If yes, which of the following would be the most important to you to know?

- a) How long the illness will last
- b) How it will effect my memory and my ability to think clearly,
- c) How to cope with the illness
- d) What to expect as the illness progresses
- e) Medication treatments and what to expect from them
- f) Where to find help, services
- g) How to handle financial/legal planning
- h) How to manage the changes in your life
- i) How to participate in medical trials
- j) Other (SPECIFY)

12. Do you think that your doctor was interested in hearing your concerns?

- a) Yes, doctor wanted to hear
- b) No

13. Do you have any suggestions for making the process of getting a diagnosis less stressful for someone like you and the doctor?

14. At the time of diagnosis, was there another person with you?

- a) Yes, accompanying person was with me
- b) No other person was with me, you may go to question 19

15. If accompanied by another person, who was this person? Was it...

- a) Spouse
- b) Daughter
- c) Son
- d) Friend
- e) Other person (SPECIFY)

16. Do you feel that the visit was easier having someone with you?

- a) Yes
- b) No
- c) Both

17. Please explain why it was easier when you had someone with you

18. Please explain what made it more difficult when you had someone with you

19. Do you feel the doctor usually spends enough time with you discussing your condition, or not?

- a) Yes, spends enough time
- b) No

20. If not, do you feel your doctor spends enough time with your family discussing your condition, or not?

- a) Yes, spends enough time with family member
- b) No, does not spend enough time with family member
- c) Spends too much time with family member

21. How satisfied are you with the doctor's ongoing communication with you about dementia? Would you say you are...

- a) Very satisfied
- b) Somewhat satisfied

- c) Slightly dissatisfied
- d) Very dissatisfied

Please answer the following questions about yourself

P1. How old are you?

P2. What was the last grade of school you completed?

- a) Less than high school
- b) High school graduate
- c) Some college
- d) College graduate and more

P3. Are you...

- a) Married
- b) Single, living alone
- c) Single, living with another adult

P4. Gender: a) Male
 b) Female

APPENDIX III
ETHICS APPROVAL

McMaster University Research Ethics Board (MREB)

c/o Office of Research Services, MREB Secretariat, GH-306, e-mail: ethicsoffice@mcmaster.ca

CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH

Application Status: New Addendum Renewal REB File # **2004 002**

TITLE OF RESEARCH PROJECT: *Communication between Physicians and Individuals with Early Stage Alzheimer Disease*

	NAME	DEPT/ADDRESS	#EXT.	E-MAIL
Faculty Investigator(s)/ Supervisor(s)	E. Ryan	Gerontology HSC-4n77a	24995	ryaneb
Student Investigator(s)	H. Spykerman	Gerontology	9059572536	hspyk@hotmail.com

The application in support of the above research project has been reviewed by the MREB to ensure compliance with the Tri-Council Policy Statement and the McMaster University Policies and Guidelines for Research Involving Human Participants. The following ethics certification is provided by the MREB:

- The application protocol is approved as presented without questions or requests for modification.
- The application protocol is approved as revised without questions or requests for modification.
- The application protocol is approved subject to clarification and/or modification as appended or identified below:

COMMENTS AND CONDITIONS:

Reporting Frequency: _____ Annual Date: _____ Other: _____

Date: *March, 2004* Dr. D. Maurer, Chair, MREB: 