LAY PERCEPTIONS OF HEALTH AND HEALTH CARE IN SMALL TOWN ONTARIO

LAY PERCEPTIONS OF HEALTH AND HEALTH CARE

A STUDY IN SMALL TOWN ONTARIO

BY

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ABSTRACT

The focus of this research is to examine people's perceptions around issues of health and health care. Using the qualitative research method of in-depth interviewing, the perceptions of twenty-four individuals are explored. This sample is taken from a middle class, white collar community in Southern Ontario. The major emphasis of this work is upon re-creating a human experience in order to come closer to understanding how people's attitudes and beliefs influence their health seeking behaviour.

This research found that health is a taken for granted state which is important for daily functioning. It is a difficult term for people to explain and it was found that changing the term to healthy made it easier for the informants to describe. Some of the determinants of health were explored and it was found that behaviours such as exercise, diet, and drinking alcohol as well as occupation and environment were all perceived as factors which could shape the types of illnesses people suffer. The only behaviour which was seen as a determinant of health was smoking. The informants saw other factors as having a greater influence on determining their health. These were fate, fault (blame), and family(heredity).

This study also explored illness behaviour and perceptions about physicians and health care. People are aware of the signals that their bodies give thus signifying

that something is wrong. People feel that they go to considerable extent in treating their own illnesses before they seek medical care. They also have expectations about their physician and failure of the physician to meet these expectations can result in a disruption in treatment or termination of the relationship.

The Canadian health care system is seen by these informants as being the best in the world. People are very proud of this country's system for the delivery of health care. They are concerned about the health care crisis but perceive a reduction in government spending on health as being irresponsible. This work uncovers many of their ideas about problems in the delivery of health care services and possible solutions to these problems.

This work seeks to contribute to the body of knowledge about lay perceptions. It is one of a few formal studies of its type done in Ontario. It represents an additional dimension to the investigation of the delivery of health services. By coming closer to understanding the human experience of health and health care, we can assist in creating a health care system that not only treats illness and diseases but also delivers health to all.

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CHAPTER ONE

Introduction

1.1 Context

In Ontario, there is a vision. The 1977 World Health Assembly stated that the primary social goal of governments and of the World Health Organization should be to achieve "health for all by the year 2000." When the Honourable Jake Epp released Achieving Health for all: A Framework for Health Promotion(1986), this vision of health was adopted by the Canadian government as the primary goal for provincial health ministries. In 1987 the Spasoff Report, Health for all Ontario, established health goals which have provided the crucial foundation for future strategic health planning in Ontario. One of the goals established in the Spasoff Report is to encourage behaviours which support health. It was felt that if the lifestyle behaviours known to contribute to morbidity were reduced or eliminated, then use of the health care system would also decline. Since behaviours are seen to be important to the determinants of health, Ontario health promotion campaigns are encouraging the public to adopt healthy behaviours.

Behind human behaviour lies a complex network of attitudes, perceptions, and beliefs which provide the basis for human response. In this study, people's

perceptions and experiences around issues relating to health and health care are examined. Behaviour, we find, is never an automatic response. In order to use the health care system, an individual goes through a complex mental evaluation of the process before they will seek care. If health care is to be sought, how an individual perceives illness will influence the type of help sought as well as their perceptions of the benefits to be gained from seeking help (Fitzpatrick, 1984a). The goal of this research is to describe a set of lay perceptions of health and health care and to suggest how they may present an additional dimension in the investigation of the delivery of health services in Ontario.

1.2 Lay Perceptions

The study of illness behaviour has traditionally been one which views the process of becoming ill as being quite simplistic and obvious (Calnan, 1987). Until recently, lay concepts of health have been a neglected dimension in the study of health and health care (Eyles and Woods, 1983). Presently, lay concepts of health are usually assessed based upon how well they conformed to appropriate biomedical behaviour (Stacey, 1988). Traditionally, health research has viewed lay perceptions of health as unscientific or as ideologically questionable. This is presumably because the deliverers and the consumers of health care do not often share the same ideas concerning health related issues. Yet increasingly, lay perceptions and opinions are being viewed by the medical community as valid ideologies.

This study does not focus on how well lay beliefs fit with popular medical

ideologies but upon the lay perceptions themselves. It is important to understand lay perceptions because research indicates that people do not just seek medical care without any preconceptions or expectations. People bring to the hospital, or to the doctor's office, a stockpile of opinions and theories about how illness is caused and what can be done. People draw upon their own experiences and the experiences of significant others (lay referral system), in order to 'deal with' a complaint. If they do not like the attitude of their physician or if s/he does not meet their expectations, then treatment may not be possible because any suggestions made by the physician are disregarded and/or criticized.

Perceptions are the particular ideas we have that allow us to experience and give meaning to the world in which we exist. Perceptions are people's personal and individualistic interpretations of their own reality. People's perceptions have a logic of their own but when the context of their lives is taken into account, their beliefs seem perfectly valid. Kohn and White (1976) tell us that perceptions:

> constitutes man's [sic] capacity to receive and communicate information... from the psychobiological system, to compare it with information from the external social system and with information stored in his memory, and to detect imbalance.

Any bodily change can be perceived as not being normal to the individual and therefore called an illness. The identification of a bodily state as being an illness is defined by the individual's own conception of what is normal. Normality is defined and delimited by cultural or individual factors which draw upon individual or group

experiences and conditions (Kleinman *et al*, 1978). People can perceive certain symptoms as a punishment, a relief, or a threat, depending upon the context in which they live.

1.3 Framework

This thesis is an investigation of the perceptions held by a group of 24 individuals. Using the qualitative research method of in-depth interviewing, issues such as illness, disease, the determinants of health, the causes of illness, and seeking health care are examined. At times, these perceptions appear to be contradictory or lacking logic. Nevertheless, they provide the dynamic perspective of the consumer of the health care system. To conclude the research, the perceptions that this group has about the health care system and health care expenditure are also examined. It is hoped that this descriptive research will not only contribute to the already existing research on lay perceptions, but perhaps will be able to assist in achieving Ontario's vision of the future - health for all.

CHAPTER TWO

Literature Review

2.1 Geographic Context

One sub-field of social geography is the study of health and health care, otherwise known as medical geography. In the past, the geographic approach to studying health and health care was rooted in location theory. However, Pyle (1976) states that there is an increasing awareness of the importance of using sociological explanations for understanding the geographical aspects of health and health care. The incorporation of spatial patterns formed by social phenomenon influences a fresh viewpoint of the relationships between medicine, health and society (Eyles and Woods, 1983).

Recent work in geography seeks to include the socio-economic forces, as well as people's beliefs and values in order to gain understanding of the relationship between human behaviour and the environment in which people live (Dyck, 1990). Eyles and Woods (1983) claim that in studying health behaviour we not only use the individual as the basis of analysis, but we must also take into account the importance of their social, economic, and political settings within which ill health and use of the health care system occur. Use of health care is influenced by localities with

distinctive distributions of housing, services and employment.

One area which Eyles and Woods feel has been neglected by medical geographic research is the study of lay concepts of health and illness. This is an unwarranted exclusion because the health-enhancing and health-damaging activities that particular people engage in occurs within certain social groups or networks. From the experience of living within these localized forms of networks, people generate a shared knowledge about illness, health, and disability (Cornwell, 1984: Eyles and Donovan, 1986). The analysis of social networks, which contains both a spatial and a temporal element, and how these networks contribute to the defining of illness and the use of health care is "an eminently social geographic project" (Eyles and Woods, 1983: p244).

2.2 Lay Perceptions Research

Within this chapter, we will look at several studies of lay perceptions. Previous to these studies, much of the information about lay perceptions focused on how well people understand the biomedical view (Stacey, 1988). Traditionally, lay perceptions have been viewed by health researchers as unscientific or ideologically suspect. Much of past biomedical research was centred upon how to persuade people to comply with medical treatments. When lay perceptions did not agree with what biomedicine thought to be appropriate health behaviour, the perceptions were considered to be erroneous or ignorant.

The approach taken by the following studies on lay perceptions is one

which realizes and appreciates that people think about and explain the misfortunes and ailments which afflict their bodies in their own peculiar ways. Lay perceptions are seen as social constructions and that normality is a relative concept (Engel, 1977). Researchers are beginning to recognize the relevance of understanding the social, psychological, and behavioral dimensions of health and illness, as well as the biological dimension. It is felt that people, in thinking about health and explaining health phenomena, incorporate all of these components. Increasingly, lay perceptions of health and illness are being viewed as valid ideologies by medical professionals as it becomes more obvious that each individual develops their own theory about illness causation in order to account for their particular circumstances.

Eisenberg (1977) and Engel (1977) argue that the dominant approach to health and illness in modern western societies has usually been one that seeks a 'bio-medical' explanation of disease. Thus:

> the dominant model of disease today is biomedical, with molecular biology its basic scientific discipline. It assumes disease to be fully accounted for by deviations from the norm of measurable (somatic) variables. It leaves no room within its framework for the social, psychological, and behavioral dimensions of illness (Engel, 1977: p196).

Health, according to the World Health Organization (1985), is 'a state of complete physical, social, and mental well being and is not merely the absence of disease or illness'. Morbidity and mortality can be identified or measured in order to determine how healthy a population is. However, this is not the whole of health.

Blaxter (1990) states that health and illness are social as well as biological facts and that people are very aware of this. One of the first studies done on lay perceptions was by Herzlich (1973). From the sample comprised of predominantly middle class people from Normandy and Paris, Herzlich found that the respondents could clearly distinguish that illness was a negative concept which could be produced by particular lifestyle behaviours. Health was identified as having three dimensions. First, there was simply the absence of disease. Second, people have a 'reserve' of health which is determined by temperament and constitution. The third dimension was that health involved a positive state of well-being or equilibrium. Other researchers have found that health can be defined negatively, as the absence of illness, or functionally, as the ability to cope with everyday demands, or positively, as a state of well-being (Pill and Stott, 1982; Blaxter and Paterson 1982; Blaxter, 1990). In the modern world, the definition of health also contains a moral dimension. People have a duty to be healthy, and unhealthiness implies moral failure. Health, it appears, can be seen as entailing will-power, self-discipline, and self-control (Blaxter, 1983).

Crawford (1984) examined ideas of health among American adults living in Chicago. The majority of the respondents were from a white, middle class, background and a large component were under forty and female. From his interviews, Crawford discovered that health is a socially recognized and admired status and an important part of American identity. To achieve and maintain health required personal discipline. Crawford felt that the strong American cultural attitude of self-reliance and individualism influenced the lay definition of health. Obesity, for

example, expressed an individual loss of control or moral failure.

The definition of health as a positive aspect of well-being appears to be a characteristic of those who have a higher education level and who live in a comfortable situation. Alphonse d'Houtard and Field (1984) found that middle-class respondents were far more likely to view health as positive in terms of personal enjoyment. The working classes were more likely to view health in terms of use or service which is considered to be a negative and instrumental perspective.

Michael Calnan (1987) in a study of women in England did not find such a clear cut social class distinction. It appeared that working class women simply described health as the ability to cope with everyday life while their professional counterparts used a more multidimensional explanation. However, Calnan points out that this is most likely due to the survey methods employed by himself and it cannot be assumed that it represents any real differences in ideas.

In smaller and more intensive studies, Cornwell (1984) in her study of working class people living in Bethnal Green, found that the poorly educated respondents were able to express very complex ideas about health. The problem arises out of what Cornwell describes as the existence of private and public accounts. Private accounts are not given initially to the interviewer, and it is in the private accounts where medically inappropriate and antagonistic opinions and values are expressed (Cornwell, 1984).

One very consistent research finding in lay studies has been that whatever the social class, or educational level, people are, in fact, inconsistent. Nor, as

Williams (1983) explains, can we expect them to consistent. It is quite possible for an individual to hold two systems of thought on health related topics at the same time although they may be contradictory. Donovan (1986, 1988) in her study of Afro-Caribbeans and Asians living in London, England, found the people in her study supported Williams' view of being inconsistent. Although perfect health was not seen by her informants as being possible in practice, they perceived themselves to be quite healthy although they suffered from some serious illnesses. Donovan explains this contradictory impression as emerging from the lay acceptance of ill-health as being an expected and normal part of life.

Many individuals incorporate both biomedical models and cultural models when explaining disease and illness causation. Crawford (1984) noted that to some extent people will speak in the prevailing biomedical idiom but that usually their ideas go beyond matters with which biomedicine deals. Cornwell also discusses how over time the ideas of her informants have been influence by biomedical ideas, that the people have become medicalized. Zola (1986) tells us that the implication of the medicalization of society is that people no longer focus upon whether there is a particular health problem, but upon how and when they can be treated.

Blaxter's (1983) study of Scottish women showed how disease was part of their conception of illness but that the women had clear models of disease causation which were very similar to the ones held by biomedical science. The informants of Blaxter's study saw the common categories of cause to be infection, environment, and heredity. External agents such as housing conditions or the weather could increase

one's susceptibility to 'germs' but working conditions and the environment could cause disease. However, while Blaxter's respondents used many biomedical concepts and ideas, their logical framework appear to follow some other scheme than the traditional biomedical model.

Herzlich (1973) also supported the view that many of the popular ideas of the causes of illness and disease were simply variations on the themes found in bio-medical theories. This, he felt, is not because lay perceptions follow biomedical views but was most likely because they both evolved from a common stock of knowledge. Herzlich and Pierret (1986) examined historical writings by sick people who describe what they had experienced. From this research, they found that lay perceptions of illness extended beyond medical definitions and how certain ideas of causation have persisted over time. People and physicians have been attributing causation to air, climate, and seasons to such an extent that Herzlich and Pierret concluded that the social structure and health perception link is part of a two way relationship between biomedical and lay views.

Pill and Stott (1982) did a similar study on women between the ages of 30-35 years who were manual labourers in South Wales. From the interviews, Pill and Stott found that the women followed the biomedical beliefs about causation of illness and disease. Infection or germs were most commonly cited as the principal causes of illness after which followed lifestyle, heredity, and stress.

One example of biomedical and cultural conceptual overlap is made between illness and disease. Eisenberg (1977) was able to illustrate this distinction

as:

> patients suffer 'illnesses'; physicians diagnose and treat 'disease'...illnesses are experiences of disvalued changes in states of being and in social function: diseases are abnormalities in the structure and function of body organs and systems. (Eisenberg, 1977: p11)

Kleinman *et al* (1978) in their study of the Taiwanese found that illness is the experiential aspects of a body disorder which is shaped by cultural factors which in turn influence perception, labelling, and explanation of experience. Kleinman (1988) describes disease as what the physician sees and diagnoses while illness is a lived experience of monitoring bodily processes and then categorizing and explaining these processes in lay terms.

White (1982) examined the notion of cultural differences in concepts of illness using a sample of Hawaiian students. Half the students were of Chinese descent and the other half were Caucasian American. What White found was that the two cultures put different conceptual emphasis on the causes of problems. The American students focused upon internal feeling states while the Chinese students emphasized external situational causation.

Eyles and Donovan (1990) are not so concerned with how lay beliefs differ as they are with the lay beliefs themselves. They argue that this is because a "belief truly held will have consequences for individual actions" (Eyles and Donovan, 1990: p19). They are concerned in their study of three communities in Britain with understanding the context from which these beliefs are derived because it is context

which shapes the nature and effect of beliefs. Cornwell (1984) agrees that it is not enough to know how health is interpreted without understanding the context from which this interpretation evolved. For example, Walters (1992) study of Canadian women found that they normalize the mental health problems that they experience. This, Walters (in press) argues, is because in Canadian society there is a lack of social reinforcement and validation of their experiences which would lead to these women perceiving stress, anxiety and depression as legitimate health problems.

Previous studies of lay perceptions have incorporated several different themes. We have seen that lay beliefs about health and illness are varied and can differ or be influenced by the biomedical model. Individual concepts can vary based on individual health experiences (Blaxter 1990; Donovan 1986, 1988). Lay concepts can also be viewed as social representations such as Herzlich and Pierret (1986) and d'Houtaud and Field (1984) discovered. Lay beliefs have their own logic which can only be understood when we examine them within their own social context. The only consistent conclusion that can be made follows that of Williams. People's perception are often contradictory and follow a logic of their own. Still, they are governed by concepts and ideas of considerable complexity and variety. Nonetheless attention to lay perceptions of health can be clinically helpful and successfully incorporated into health policy.

CHAPTER THREE

Method and Theory

3.1 Introduction

The aim of interpretive geography is to understand and explain the nature of reality. This is done by examining the definitions and perceptions which are usually taken for granted, and then trying to understand how these influence human behaviour. In revealing the nature of the social world, we come closer to understanding how people act and give meaning to their lives within a specific context or setting.

The methodology needed to study and understand lay perceptions of health and illness is one which is sensitive and flexible enough to uncover and grasp the meanings that people attach to their actions and perceptions. This particular research draws its methodology from interpretive geography, particularly symbolic interactionism. Interpretive methods are situated within a recent movement in human geography towards qualitative research. "The aim of such geography is to understand and explain the nature of (social) reality" while recognizing that we cannot possibly totally re-construct the real world just through investigation of the social world (Eyles and Smith, 1988: p1).

Central to interpretive geographic research is the process of uncovering the

nature of our social world by examining how people act and allot meaning in their lives. These meanings demonstrate the inter-subjectivity of our world and interpretive geography seeks to reconstruct social reality by examining these meanings held by individuals within a particular socially constructed and physical space. How these meanings and perceptions occur and evolve are explained by Mead's theory of symbolic interactionism.

3.2 Symbolic Interactionism

Theory must guide the researcher and be used to analyze and validate the interpretations. For this research project the theory of symbolic interactionism is used to supply such validation. Symbolic interactionist theory is one sub-group of the interpretive school (Jackson and Smith, 1984). This theory is based upon the work of G.H. Mead (1934) but the actual term was created by H. Blumer (1985).

The theory rests upon three basic premises. The first premise is that people will act towards things based upon the meaning that they have attached to the 'thing'. 'Things' can include everything which humans encounter in their everyday world. 'Things' can include physical objects, other people, categories of humans, institutions, values and ideals. The second premise is that the meanings attached to things are a result of or arise from social interactions with other people. The final premise is that these meanings are altered and negotiated through an interpretive process used by individuals in dealing with things they encounter.

The symbolic interactionist believes that the meanings that are attached to

things by people are central in their own right. To ignore meaning, and instead focus upon factors, such as patterns or habit, which are said to produce the behaviour, is neglectful of the role that meaning plays in the formation of certain behaviours. There are several other approaches (eg. phenomenology) which share the idea that people act towards things based on what things means to them. However, the one main difference between symbolic interactionist and other theories which share this first premise is about where the meaning comes from. Symbolic interactionists do not see the source of meaning as being intrinsic to the 'thing' itself. Nor do they see meaning as arising from an expression of the given psychological element which is triggered by the perception of the 'thing'. Instead meaning is seen as arising in a process of human interaction. The meaning attached to anything evolves from the ways in which other people act towards the person with regard to the thing.

The last premise also differentiates symbolic interactionism from other theories. While the meanings of things is formed through social interaction and is derived by the individual from that interaction, the use of meaning by the individual involves an interpretive process. This process is comprised of two steps. Firstly, the actor has to indicate to him/herself the 'thing' toward which s/he is acting. This is an internalized social process which the actor undertakes within him/herself. The second step involves the individual selecting, analyzing, negotiating and transforming the meanings to fit the situation in which they are placed.

Symbolic interactionism sees human society as people engaged in living. People are involved in a process of ongoing activity in which they are constantly

forming lines of action to suit the many life situations which they encounter. They are also involved in a vast process of interaction in which each person develops actions which must fit everyone else's. Interaction involves indicating to others what to do and at the same time interpreting indications made by others.

We live in a social world of 'things' and our actions are guided by the meanings we attach to these 'things'. 'Things' are formed, weakened, and transformed through our interactions with one another. This process, however, must be examined within the social context or world from which it has emerged. People, by nature, tend to cluster in specific groups. Consequently, they will approach each other differently and guide themselves by different sets of meanings. Interactionist theory includes a range of perspective descriptions of the complex and dynamic characteristics of people's lives. From this description, we can conclude that symbolic interactionist theory is able to assist the researcher in gaining a valid perspective on the intricacy of human life.

3.3 Methodology : The In-depth Interview

Much of our everyday experience is shared. To investigate, we must involve a method which will allow the researcher to observe and interact with the 'real' world. It must allow the researcher to record the happenings of everyday life and to allow people to speak of this everyday world using their own words. Interpretive methods are those which centre upon the understanding and analysis of meaning. One such qualitative method is informal or in-depth interviewing and this

method was used for this research of lay perceptions.

Interviewing methods can be divided into two categories; formal and informal. Within the formal interview, questions are asked and the responses are recorded on a standardized form. Informal or in-depth interviewing involves the researcher not working out the questions or their sequence beforehand. It involves developing a framework or a group of 'themes' which are to be introduced at appropriate moments into the conversation. The wording of each question is tailored to suit the individual and to fit naturally in the conversation. The goal is to have all the questions evoke meaning for all the respondents and to allow the interview to be structured by the informants thus merely appearing to be a conversation. This conversational style can put the informant at ease and this allows the researcher to probe into the meaning of their words and to consequently uncover new clues and to open up new perspectives of a problem. Consequently, such research a method involves a great deal of practice, and it would probably be most accurate to say that the methodology in this particular project evolved from a semi-structured interview, into a completely unstructured interview. Appendix 1 provides the checklist used to ensure that all topics relevant to the research were discussed with all informants.

Throughout the process of investigation, there is a maturing process on the part of the researcher. This particular methodology involves an empathetic listener who is a good conversationalist. But it also involves an individual who is able to link responses and meaning to a broader body of knowledge. Therefore, as the researcher interacts with each respondent, s/he becomes increasingly intuitive to the

best way to phrase a particular question and how to keep dialogue going.

3.4 The Site and The Sample

In order to conduct the research, a 'contract' which guaranteed the informant's anonymity was made. Therefore, in order to protect the identity of the informants, the name of the research site has been changed to Small Town Ontario. Small Town Ontario is located in the south-central part of Ontario and is very close to a large urban centre. This town has a population of approximately 20,000 residents but its land area is relatively small covering 24 square kilometres. Consequently, population density is high compared to the urban centres surrounding Small Town Ontario.

Small Town Ontario is considered to be a "nice place to raise a family". There is a small amount of industry in the town but most of the residents commute to the large city where they are employed. The tree lined streets in Small Town Ontario are filled with single family dwellings. Small Town Ontario can be described as middle income, suburban Ontario.

The sample is comprised of individuals from Italian, Jewish, French Canadian and British backgrounds. Eleven of the informants were women and thirteen of them were men. Their ages ranged from twenty-six to eighty years. In all cases the interviews were done in English. The majority of the informants had white collar occupations. Of the twenty-four people interviewed, one individual was unemployed, one individual worked in a factory and three were retired. Interestingly,

the one person who was unemployed had a university degree and was using his time "off" to study to become a chartered management accountant. Appendix 2 provides a brief description of each informant's name, age (in some cases their approximate age), sex, and their occupation.

3.5 Data Gathering and Analysis

In order to gain access to this community, several methods were employed. Initially, a letter asking people to participate in the study was delivered randomly to homes. This method yielded only three interviews. Due to this lack of success, the interviewer tried to approach people by going door to door This approach yielded only two more interviews. It became increasingly apparent that any attempts to just approach people were regarded with suspicion. Therefore, another method of sampling known as the 'snowball method' was employed with the involvement of social gatekeepers.

Social gatekeepers are individuals who allow the researcher to enter their social world by accessing certain people. If only one gatekeeper is employed, the sample can only involve those who are within the gatekeeper's own world. Therefore, for this particular study, five different gatekeepers were used. In three instances, after gaining access, the informants suggested other people who would participate in the research.

Each interview took place within the individual's own home. The average time for each interview was one hour but a few were as short as 35 minutes and some were as long as 90 minutes. Each interview was tape recorded and then later

transcribed verbatim. The data analysis was an ongoing process which involved the researcher keeping track of emerging themes and following up on these themes and hunches throughout the data gathering process. The actual analysis was constantly evolving, so by the time the researcher began the second phase of the analysis, much of the preliminary work was already done.

The second phase of the analysis began with reading the transcripts at least twice before coding. During these readings, notes about possible themes or links were made and then transcripts were analyzed using the traditional cut-and-paste method. It is felt that this method of analysis, while time consuming, allows for the researcher to be deeply connected with their data set, to 'know' their informants personally. Cut-and-paste methods allows for the researcher's insight and intuition to help in the interpretation the data. Seidal and Clark (in Taylor and Bogdan, 1984), creators of the computer program called THE ETHNOGRAPH admit that there is no mechanical substitute for this. During this stage of the data analysis where themes were refined, the data were cross checked in order to be certain that no data were excluded.

When writing up the findings, themes are supported by quotations from the informants. The quotations are transcribed verbatim and appear in the body of this work in this same form. Context plays a crucial role in understanding the informant's words. Often this context is described in order to provide the reader with a greater tool for understanding the meaning of the informant's words.

3.6 The Interviewer: A Brief Autobiography

Within qualitative research and the interpretive paradigm, the role of the researcher is considered to be crucial. It is a recognized fact that the researcher brings with him or herself certain prejudices and biases. Therefore, a brief autobiographic sketch is required in order to reveal the researcher's character and to explain why certain interpretations are made.

The researcher was born in Canada in 1967, and at the time of data collection she was 23 years of age. Her ethnic background is mixed, including one parent from Holland and another parent of Slovak heritage. The researcher is from a relatively large, Roman Catholic family comprised of three brothers and one sister. Presently, the researcher lives in a large city, but had spent a significant part of her childhood growing up in a very small, rural town. The researcher is from a middle class background with her father employed as a professor of electrical engineering and her mother working in the home.

The largest influence in the researcher's perceptions about health and illness stem from her grandmother who at different times in the researcher's life lived in the family home. She came to Canada in the 1950's from Holland. In Holland, this influential figure was a public health nurse and a midwife. From this individual, the researcher learned a great deal about folk medicine and early public health movements. Subsequently, this individual died alone in a Canadian hospital due to the negligence and oversight of the hospital staff.

The researcher is married to a carpenter who runs a small household repair

business. While conducting the interviews, the researcher was between two and six months pregnant. Initially, the physical discomforts were sometimes a hindrance and did influence the researcher's mood. As the pregnancy became more obvious it actually appeared to work to her benefit. The pregnancy assisted in establishing a rapport with the informants because it assisted people in viewing her as non-threatening.

3.7 Conclusions

Interpretive geography cannot rely upon traditional geographic methods used to describe the physical world. It relies instead upon the representations and constructions from the observed and the observer. The research is inductive in that generalizations are developed from particular case studies. Initial results are initially ideas which become more refined as the data are checked and re-checked. The coding and refinements of the data are complete only when the findings are consistent with the data. Theory is produced from the relationships found between the observed events.

This research draws its methodological approach and theory from a sub-set of the interpretive school: symbolic interactionism. It is felt that this methodology, borrowed from interpretive school of sociology, is able to provide a picture of how different people perceive and react to issues surrounding their health. By using in-depth interviewing methods, we are better able to achieve the goal of observing and interacting with the 'real' world.

CHAPTER FOUR

The Definition of Health

4.1 Introduction

In this chapter we will look at the different definitions of health, illness, and disease. It is how these variables are defined by the individual, which determines whether they will take action for their condition, and how and when they will do so. At the time of the interviews, all the informants professed to having a good health status despite the fact that some were suffering from back injuries, arthritis, diabetes and mental illness. Health is important to all of the informants but when asked to describe or explain the term, it proved to be a difficult task. Illness and disease are terms which they found to be easier to explain.

4.2 Definition of Health

Many people would argue that 'health' and 'healthy' are one and the same thing. But for these people, they do have different meanings. Healthy is much easier for people to describe because it is a subjective feeling not defined by any medical boundaries. The term health is obscure and in many cases very unspecific. Most people found health to be a very hard term to describe. When asked what healthiness is, they were able to give much broader definitions. People have a much

clearer understanding of the term "healthy" because it is an individual experience as opposed to being medically defined.

> Mary - " I guess there's many ways to be healthy- spirit, mind, body, well-being, feeling good about yourself."
>
> Robert - "To feel alive, feeling energetic."
>
> Sue - "capable, physically and emotionally of coping with my day-to-day life and things I have to deal with, and thus a general sense of well being..."
>
> Julie -"It means to function at a very whatever, an optimum level with a minimum of inconvenience, no [reliance] on medication, having very little use of the health system..."

Healthiness is strongly linked to the quality of living that people can experience. This may mean feeling free from aches and pains and therefore able to carry out everyday activities. Interestingly, this perception of healthiness closely fits in with how the World Health Organization's (1985) defines health.

> Max - "Freedom from illness. Freedom of discomfort. A feeling of well-being. Yes, primarily that, feeling of being well."
>
> Glen - "Getting by each day without having any kind of pain or aches or anything like that."
>
> Julie- "I think that's ...you know functioning in a manner appropriate with, with, with the age. I think that's probably my, you know my perception..."

The term 'healthy' is a socially constructed one. This allows room for people to re-negotiate its meaning so that an individual can "label" themselves as being healthy even if they are not. For example, Angus who has diabetes is able to renegotiate the meaning of his illness so that he can describe himself as being healthy.

> Angus- "I realize what diabetes can cause, and know down the line-down

> the road I might have problems but, psychologically ....I feel like I'm at peace with myself, and perhaps that's a problem. I should be thinking maybe more down the line, but, that's where I am health-wise myself. I guess I'm overweight. I guess health-wise there's a plus side."

The term 'healthy' also allows those living with physical disabilities to renegotiate its meaning to fit in with their lives. Janet is not working because of a back injury which has left her critically disabled and Terry also suffers from debilitating back problems. Yet Janet and Terry still see themselves as being healthy

> Janet -"I mean, I don't consider a physical disability makes you an unhealthy person."
>
> Terry - "It means I'm healthy...my sore back, but that doesn't count, does it?"

Elizabeth, who suffers from arthritis and bursitis, and who has had to undergo surgery for cancer, also does not see herself as being unhealthy

> Q- "Are you unwell would you say?"
> Elizabeth - "No, no, no."
> Q - "Are you unhealthy?"
> Elizabeth - "No."

The term health is more difficult to explain. People, like Aylmer, really only noticed health in its absence and therefore, it is largely taken for granted.

> Aylmer- "I must admit I've taken it for granted the longest...being basically the healthy person I am."

In order to explain the term, many of the informants relied on a medical definition of health. They refer to health as simply as freedom from physical or mental illness but do not account for quality of living.

> Steve - "Health is to be healthy in a physical way and psychologically "

> Max - "Health is the ability to do what you want to do without physical restrictions."
>
> Reta - "It's - to my life, an absence of any physical disability or mental disability "
>
> Janet - " I think of health as a day to day physical state, as far as, you know, the way your body functions and heart and lungs and those kinds of things as opposed to your ability to do certain things."

Health is an important component for day-to-day living. It involves freedom from physical and emotional discomforts and because of its ability to be re-negotiated to fit individual circumstances, it is easy to achieve. It is linked with an individual's ability to work and play

The term health can imply a state of perfection which is perceived to be difficult to explain and may be impossible to achieve. The concept of perfect health is dependent upon the individual's definition of health. For many of the informants, perfect health was more than just freedom from ill-health. In fact, perfect health can involve certain 'normal' illnesses which are seen as unavoidable.

> Aylmer - "Oh yes, I think illness or disease is part of life. It's like health as far as life. It's quite obvious, there are diseases here and they are part of life normally "
>
> Terry - "Just because you have a cold, I don't think you're not healthy If you have a cold, you're still healthy..."
>
> Mary - "I would say it's probably normal for most people to be, have some problems with health during their lifetime ...normal ailments, I guess, yes, I guess you would expect. When you think in terms of children with childhood diseases and that sort of thing, colds."

4.3 The Importance of Health

Health is important to people because without it, you are ill and cannot enjoy life. As Patrick says "the opposite is unhealthy, and I don't want to be unhealthy because unhealthy- you don't feel good." Health allows people freedom, independence and the ability to manage their lives. It is one of the most highly valued components of people's lives.

If Catherine did not have her health, then she would not be able to continue living on her own. At eighty years of age, being able to take care of herself means Catherine can keep her independence. She tells us that "I have independence when I have my health."

Health also allows people like Patti to manage life stresses and thus keep on working. Patti, who is going through a divorce, describes how having good health allows her to cope better with the stress she is experiencing.

> Patti - "If you don't feel healthy, and you don't think healthy, I just don't think you can cope...because I can't function on any level without my health, and I understand that I would not have my life- my life would be totally different -I wouldn't have a life."

Being healthy can mean you can live longer and lead a more fulfilling life as Lynn explains. On the other hand, health, as Elizabeth describes, determines how you will live your life.

> Lynn - "Because you feel better when you're healthy. You live longer. You live a more fulfilling life, I guess."
>
> Elizabeth - "Oh, of course it's important. It's the.... state of your whole life, of what you can do and what you can't do and how you function."

Health is seen as being important to these people because it allows them

to work. Steve and John see their health as being important because it contributes to their ability to work.

> Steve - "Being able to do certain things, playing lots of sports, being happy, performing well at work.."
>
> John -"It's well, partly due to my job, but just it's always been really very important in my life."

Health obviously contributes to many components of people's lifestyles, and in fact it seems to be central to their ability to carry out day-to-day activities. Yet, being healthy is equally important because it allows people to enjoy the quality of their lives. Because of its highly negotiated features, healthiness can allow people to do things which may be considered unhealthy.

4.4 Definitions of Illness and Disease

The terms illness and disease are associated with the term health but are somewhat easier for the informants to explain. Illness is perceived as being an acute, temporary dysfunction, whose cause may be unclear, but is easy to treat and recover from. Kleinman (1988) describes illness as the lived experience of monitoring one's bodily processes which involves the appraisal of the condition based upon how the people within one's social network lives with, and responds to the same symptoms.

> Steve - "Illness can be something that may not necessarily be a black and white issue. It could be kind of a vague sort of a situation..."
>
> Patrick - "An illness I would think of as something that is treatable, but something that is often temporary, like a cold or the flu, or mumps, or something like that."
>
> Janet - "An illness is - is more acute where you're suffering more acute

symptoms right now..."

Lynn - "Well, an illness you can get over, a disease you can't most of the time..."

Sue - "An illness is something I expect to get over, a disease I feel I have no control..."

As Patti points out, illnesses are not really definable. Illnesses, she says, do not involve the disease process and the term itself can cover just about any feeling of uneasiness.

Patti - "When I think of an illness, it could be, um, just feeling unwell, not necessarily some sort of...disease process, affecting the body and when I think of illness, I feel it can cover a lot..."

Illness is perceived to be not necessarily contagious and it is an expected part of life. Julie tells us that "an illness could be from within..." and the degree of illness depended upon the individual reaction to it. People did not think that illnesses are life threatening or that they are very serious so they do not necessarily need medical care. Colds and influenza were often cited as examples of illnesses.

Some of the perceptions held about disease are that it is a medically defined, chronic illness, which can be life threatening and almost always needs medical treatment.

Max - "A disease may have been identified and have a nice long name and may be bacterially or virally [sic] induced, but illness can also just be a feeling of malaise."

Catherine - "Well, a disease is germs and viruses and everything today is a virus, so I guess you could describe a disease as a virus...a disease is something like that's contagious, where an illness isn't necessarily contagious."

Steve - "A disease, to me, seems to be something that, you know, requires

more in-depth medical treatment."

People see diseases to be more serious than illnesses. Unlike illness, the informants feel that diseases are beyond the control of the individual and therefore they are not responsible for their ill-health.

> Sue - "An illness is something I expect to get over, a disease I feel I have no control."
>
> John - "A disease is something that you have to learn to live with, an illness, I think, depending on some person - if you're a hypochondriac or something like that - it's something that can be, you know..."
>
> Julie - "A disease is almost something that's imposed on you from the outside for which you're not responsible, I would say."

As we see from the following quotes, disease is seen as an invasion of the body by germs or viruses which you can 'catch'. Diseases are also perceived to be caused by genetics or by the environment.

> Max - "I think of disease as being more of a genetic thing. It isn't always, but lots of times it's more genetic."
>
> Robert - "A disease I would look upon as being an invasion of a body system from outside, so much as to - something happening in the environment..."
>
> Aylmer - "I think of it in terms of something that invades you system, you get a virus or the result of an accident, or there are congenital disease, like deficiencies in your immune system, or your make-up, that would be a disease style rather than illness."

While people have a practical knowledge about illness and disease based upon their own life experiences, one of the reasons that the two terms are easier for the informants to relate to is because they are what the doctor sees and treats (Kleinman, 1988). From this experience the informants have gained some sort of

practical knowledge of the two terms and can make a clear distinction between them.

Illnesses and disease are part of everyone's world. Because people really only notice their health when they are ill, they then focus upon the particular characteristics of the ill-health. Therefore, all individuals have created individual perceptions about the differences between illness and disease, their causes, and how they will respond to them.

4.5 Conclusions

We have examined the definition of health and how this definition can be clarified by changing the term to healthy. The term healthy illustrates how people socially re-construct the term health to suit their purposes. Healthy is perceived to be a more subjective term. It allows for everyone, including those with physical disabilities or chronic illness, to see themselves as being healthy. People are more loose in their description of healthiness than they are when defining the term health. This is likely because the term health is perceived to be a medically definable, objective, impersonal term, not subject to individual interpretation or social construction.

The concept of perfect health is defined individually by the informants to sometimes incorporate certain 'normal' illness as being part of the perfect health state. Illness is perceived to be less serious than disease and is caused by something internal. Diseases are seen as an invasion of the body which often require formal health care. The causes are perceived as being external to individual control and

therefore beyond their fault.

People perceive their health as being very important for many different reasons. Their health allows them to enjoy their lives in different ways either by allowing them to stay at home on their own or by allowing them to continue doing their jobs.

In the next chapter we find that many people see such behaviours as smoking or drinking alcohol as pleasurable and therefore are not threatening their health. Alternately, the medical perspective would view such behaviours as risk taking and health threatening. Therefore, health for the lay perspective is negotiated to include these behaviours which contribute to their quality of living. So as long as an individual is 'feeling' good and is free from physical complaints, then they are in good health despite their health behaviours or health state.

CHAPTER FIVE

Perceptions of Health Behaviours

5.1 Introduction

In 1974, the Lalonde Report which was called A New Perspective on the Health of Canadians recognized the importance of behavioral and environmental determinants of health on the health of the population. This chapter looks specifically at the perceptions people have of some of the determinants of health. While people have definite perceptions about the impact of smoking, diet, exercise, alcohol, environment and occupation upon their health, they do not perceive them to be determinants of health status.

5.2 Smoking

Smoking cigarettes is the one lifestyle behaviour that nearly everyone agreed could cause illness or death. As Patrick states "it seems pretty well accepted now that smoking causes lung cancer." The knowledge of the types of illnesses associated with smoking is very high among the informants. Some of the illnesses cited are "lung disease", "lung cancer", "throat cancer", "respiratory disease", and "heart disease". This information comes from a variety of sources, but the most

significant sources were the newspapers and television programs or advertisements.

> Glen - "I think there's lung cancer - cancer is the biggest one, lung cancer, throat cancer. It also, if you've got people smoking in the family, I think it can cause problems for the other people in the family that don't smoke."
>
> Angus - "I'm believing what I'm reading, I'm believing there's a correlation between smoking and heart attacks, there is a correlation between smoking and cancer."
>
> Patti - "It's proven that lung cancer, like almost 99%, is from smoking it [tobacco]. That is the one cancer. Like the other cancers - no they can't prove anything, but definitely lung cancer and they've proven it. Even the second hand [smoke]."

Smokers and past smokers are able to see the link between smoking and ill-health. In Sue's case, this link was enough to make her quit smoking.

> Sue - "I think - I believe what I've read. I believe what I've seen. I think it causes respiratory disease. I think it causes lung cancer. I think it causes heart disease. Yes, I do, and that's why I quit."

Sandra's words show how she feels towards her smoking habit. She hates it and speaks of the habit as being disgusting. This was enough to make her quit.

> Sandra - "I hated the thought of the stupidity - I smoked a lot. And I really did - I hated the fact. I thought it's just disgusting that it's practically the first thing I do in the morning and the last thing I do at night."

Quite often smokers are seen as responsible for their illness because it is felt that they knowingly accept the risk associated with smoking. People who do not smoke often judge individuals who do as being weak or morally deficient. Russ' words illustrate a strong perception that is held by many of the informants. Russ feels that since the risks of smoking are so obvious, those who smoke are tempting fate by continuing to do so. If anything happens to them, then it is their own fault.

If they need health care then they should have to pay for it. Russ feels that he should not have to pay for their self-indulgence.

> Russ - "If you smoke, then fine, you should pay more. I don't see that I should have to pay for somebody else who, thirty years down the road goes 'Oh shoot', you know, 'I've got lung cancer, I shouldn't have smoked.' Oh great, so I get to pay for that through our health system!"

Elizabeth, a past smoker, also saw herself as self-indulgent and her words reflect Russ's moral attitude towards smoking behaviour. While she smoked, Elizabeth also saw herself as lacking 'moral fibre'.

> Elizabeth - "Yes, but I was self-indulgent and I smoked. I mean, I believe that, I - I tried to quit smoking several times and I eventually did..."

Smoking is recognized as a coping mechanism for dealing with stress or other mental and physical problems. Lynn's words show us that people do recognize that smokers need a cigarette for coping with things like workplace stress.

> Lynn - "They're starting to work us a little too hard now. A lot of people have stopped smoking in there. People need their cigarettes, a lot of people. And now they can't go out and have their cigarettes...that's stressing a lot of them."

Elizabeth describes how she needed to smoke in order to suppress her appetite and stay slim. When she tried to stop smoking it resulted in weight gain so she would start up smoking. When Elizabeth's slim appearance was no longer important to her, she was able to trade-off health risks in order to stop smoking.

> Elizabeth - "...whenever I'd give up smoking I'd put on weight and when I was younger it was important to me to be thin and now the last time I gave up smoking, I just put on weight, no way in my work I could control my weight."

Although people are sympathetic about the difficulties associated with

quitting smoking, they still perceive those who do smoke as being irresponsible. The informants strongly believe that smoking is linked with all sorts of illnesses, and that if you smoke you accept these risks.

While smoking is seen as having a strong impact upon one's health it is, however, is not perceived as a factor which will determine your health. From the following perceptions, we find that fate plays a large role in whether you will become ill or not. Smoking merely shapes the type of illness you will suffer, while luck determines whether you will 'get it'. This fatalistic attitude allows smokers to cope with or negotiate the risk they are taking when they continue to smoke.

> Catherine - "I don't think smoking is good for you. I never smoked. But, you see some people smoke all their lives and nothing happens."
>
> Sue - "I've known so many people who have had bronchitis and never smoked a cigarette, so I didn't think of that at the time."
>
> Angus - "And I - as a defense mechanism, when you're smoking, you think, well, wait a minute, my father smoked for all his life, he worked - he worked in a coke oven area. These are all situations where he was exposed to toxic fumes, and he smoked, and he never had cancer."

5.3 Diet

All the informants recognized that the foods they ate certainly could affect their health. Cholesterol or 'fatty foods' are seen as the element in people's diets which is of greatest concern. Diet is largely perceived by the informants as the ability to control one's caloric intake as opposed to following nutritional guidelines. In this way, health behaviour is practised only to improve personal image, not to improve health status. For informants like Sandra, diet is mainly an appearance

concern, not a health concern.

> Sandra - "I think I was slim for a very brief period in my life and I'm not going to be slim, but I do try to eat properly."

Very few of the informants admitted to following any particular diet or even worrying about the things they eat. They were unclear about how diet contributed to any particular illness so they did not pay it much attention. If they were following a diet, such as in Angus' case, it is because they have an existing health problem. The rest took 'care' in selecting certain foods but most of them felt they had pretty good diets without making any conscious effort. Diet is a health behaviour which is perceived as being easy to control. It does not involve major changes over an extended periods of time to alleviate any negligence.

> Catherine - "I never stick to any complete diet. I eat what I want to eat. I eat when I'm hungry and it's bad, I eat it."

> Patrick - "I'm not militaristic. I don't think about any aspect of my diet - I'm not vegetarian or anything. But I try not to eat too much fatty food, or foods that are high in cholesterol."

> Mary - "I try to be [careful], you know. We try to watch that we don't, you know, the way we cook and just try to watch it. It's not always a success."

> Terry - "I don't like to eat a lot of deep fried foods and stuff like that, but I'm not going to start eating lettuce all the time."

From the informants' comments it appears that while they are aware of nutrition and diet, they are relatively unconcerned about following nutritional guidelines. Perhaps this is because in this social group, people are more likely to be able to afford a variety of foods due to the wide selection available in supermarkets. The informants are not particularly convinced that diet can contribute to any

particular disease and therefore do not treat it as a determinant of their health. It appears that the lay perception is that diet affects each individual differently and you cannot follow generalized nutritional guidelines.

> Max - "You know, it depends on the individual. Some people who diet very stringently don't necessarily prolong their life span. It depends on the propensity of the individual to cholesterol and cancers and so forth..."
>
> Robert - " A friend of mine who has enormous problems with heart disease and cholesterol- he eats virtually no fats whatsoever and yet his cholesterol level is far higher than mine simply because his physiology is such that his body manufactures cholesterol at a horrible rate."

5.4 Exercise

Exercise is perceived to be another controllable health variable for the informants. For some informants, it is an important part of their lives but not always for health reasons. The perceptions is that while exercise is good for you, this does not necessarily mean that you are healthier.

Movement is seen as very important to many of the informants for mental or specific physiological reasons. It can act as a way to deal with mental stress. Joyce discusses how just picking up the vacuum cleaner and moving about can mentally refresh her. We find that for Steve, exercise actually helps to motivate him.

> Joyce - "I know if you're doing exercise, then over time you start to feel better and I know days when I'd felt sort of blah and I've been at home, sometimes I just take the vacuum cleaner and start working, and before long I start to feel better."
>
> Steve - "Just I feel better. I feel I'm more motivated. I just feel more motivated."
>
> Exercise is also used to off-set poor dieting or to control weight. In most

cases, exercise and weight loss are not performed for health reasons but for improving physical appearance. Patty tells us that she likes to ride her bike when he feels that she has eaten too much junk food. Sandra uses exercise to help her lose extra weight.

> Patty - "I generally try and get as much exercise as I can riding my bike to school and getting out as much as possible. Again, like eating junk food, if I haven't exercised much for a while, I feel - even if I don't, you know, haven't actually gained weight or anything - I feel like I'm being a slob."

> Sandra - "Well, I've always had a weight problem, you could say I've always had a weight problem, so...exercise!"

Some of the informants do not think of exercise in its conventional form. For many, movement or activity is the phraseology used. Without this movement, people feel that their bodies would stiffen up or existing conditions would worsen.

> Sue - "I believe it's [the body] like a piece of equipment. If it doesn't get moved, it will likely seize up, or have more chance of seizing up."

> Elizabeth - "At least moving all your limbs so you don't stiffen up. I have to do that because I have bursitis in both my shoulders and if I don't keep my muscles moving..."

> Joyce - "I'm having some problems with my neck and it does some exercises like this where you move you head back and forth and that sort of thing...I think I want to try and do more of that, because I'm having trouble with a stiff neck and I think it needs some more exercise."

Sandra tells us how she uses exercise as a means of delaying or off-setting illnesses she feels she is likely to inherit.

> Sandra - "I purposely exercise because I think I'm going to have osteoporosis. I think it's in the family, and I have neck problems...and the arthritis and all that's in the family. So this is my defense to fight, to protect, to fight myself."

Exercise is not generally viewed as a determinant of health because the

informants tell us that whether you do it or not will not affect how long you will live. Exercise is seen as a means by which people can improve the quality of their lives either by preventing or helping them cope with existing health problems or by just giving personal pleasure.

5.5 Alcohol

Alcohol is not regarded as something that is particularly unhealthy. The informants, like Robert, Catherine, and Max, understand that alcohol in excess can cause alcoholism and family problems.

> Robert - "Well, certainly contributes to alcoholism..."
>
> Catherine - "Alcohol can cause a lot of problems..well, it can cause trouble in the family. It also can have a lot to do with your health if your addicted."
>
> Max - "Alcohol can have all kinds of detrimental problems to the extent of intoxication and inability to function, then [alcohol] affects the individual's family...it's a problem because if I'm intoxicated constantly, then I can't function and therefore my family will suffer."

Alcohol itself is not viewed as a source of health problems. The effects of consuming alcohol in large quantities over a long period of time is seen as a possible health threat. Steve made the only other link between immediate health effects and drinking.

> Steve - "I can just tell that, you know, if you drink too much and have a hangover, that doesn't - a clear indication that your body's saying this isn't good. But, other than that, you know, I'd say alcoholism, how that creates all kinds of health problems."

Unless the informants saw themselves as alcoholics, they did not feel that

the amount of alcohol they consumed could have any effect on their health.

> Patti - "I enjoy it, so I guess it's sort of my one vice that I'm still partaking in. I guess the problem is...is how you decide whether you're drinking too much or, obviously, the best thing to do would be not to drink at all, but you know, I enjoy it so I do it and I don't feel that it's affecting my job. It's not affecting my home life, so I guess I feel I'm -I'm okay, in the amount that I drink."

In several cases, the informants feel that alcohol, in limited amounts, could actually benefit their health. Max and Patrick describe how they perceive alcohol to contribute to better health.

> Max - "I think alcohol does have a detrimental effect upon one's health, you know, again, to excess. I understand there are studies which have indicated that a small quantity of alcohol is not detrimental and may indeed have beneficial effects."

> Patrick - "I think in medium to large quantities, maybe, I don't even know, if maybe small quantities...although I've heard that having very small parties, for instance, one glass of wine a day or something like that, is better for you than not drinking at all."

From these statements, there appears to be a strong positive social attitude towards alcohol unlike that against cigarettes. While everyone, including previous smokers agree that smoking in any amount is bad for your health, the relationship between variable alcohol consumption and health is not clear for informants. For them, the consumption of alcohol is either perceived to be harmless in small amounts or in some cases a health benefit.

5.6 Occupation

The informants were asked how they felt their occupation affected their health. Their responses do not reflect the wider picture of the relationship between

income and health status. Instead, the informants responded to this question with health risks they perceived to be job related. The informants words reflect a strong awareness of the relationship between work and health. These links, states Walters (1988) are established based upon their own observations and experiences. The primary occupational health risk for this particular sample is cited as being stress. Stress is perceived by the informants to be the significant cause of both physical and mental complaints.

The experience of stress is very individualistic and has been connected to such features as an individual's lack of authority in the workplace, to low degrees of decision making, and to job satisfaction (Jenkins, 1971; House, 1986). Whatever the reason, people do link occupational stress to specific changes in their health status.

> Aylmer (Minister)- "I had a round of colitis and that's stress related. And it occurred at a time of change from one parish to another parish..."
>
> Robert (Minister)- "There would be situations within the job situation which I could see as being related to, being - my immune system not being able to fight off the disease, at that particular point."

Stress is an accepted health risk associated with work. It is seen as a normal or an expected occurrence. Sometimes work related stress can cause people to partake in behaviours which are otherwise perceived to be dangerous to health. Cigarette smoking is one example of a health behaviour used to help deal with this stress. Lynn relates to us how her job as an assembly line worker and the pressure by management to increase production is having a detrimental effect on her peers. They are unable to take longer breaks and have a cigarette therefore they are having a harder time coping with workplace stress.

> Lynn - (Factory worker)"It's starting to get now, because they're starting to tighten up the job so much now, that people don't have a lot of free time and you need a little bit of free time in between. Just...they're starting to work us a little too hard now. A lot of people have stopped smoking in there. People need their cigarettes. A lot of people. And now they can't go out and have their cigarettes."

People feel that they are individually responsible for managing their stress. If they fail to manage the levels of stress that they are experiencing then their resistance can break down and they are then making themselves vulnerable to illness.

The informants accepted stress-related illnesses much more readily than physical injuries from work. Again, we must keep in mind that very few of the informants actually did or had done physical labour where there is a risk of such injury. Among the informants, however, there is a high level of faith in the governments's ability to protect people from physical harm.

> Tony - (Fireman)"Yes, they were pushing the safety glasses all the time and take your shows and safety work habits, and I thought they were a little ridiculous you know."

Since these safety guidelines are perceived to be so obvious, any work-related injury is viewed sceptically. Reta views some work injuries/illness as people taking advantage of the system.

> Reta - (Housewife) "My husband deals a lot with occupational health,...and he's very conscious, not that he's on the side of the management, but he's very conscious of employees who abuse the system, because being ill, they can be recompensed, so it's very easy to take time off and dwell and nurse a minor illness."

Angus discusses how it is sometimes difficult to relate a particular illness or injury to the workplace because not everyone becomes ill or there may be several years before the illness or injury reveals itself to its full extent. Quite often these

factors result in the informants not perceiving a particular illness to be work related.

> Angus - (Engineer)"I know people who have, for years have worked when we had PCB's, in particular in our transformer cooling modules, where - well...they used to work up to their armpits in PCB's. And nothing happened to them, not yet. So they have difficulty rationalizing what they have been told about it based on their own experience."

Work gives people a strong sense of identity. So some people feel that they must always work. For many, being a workaholic is not seen as a psycho-behavioral disorder similar to other addictive behaviours. Instead, it is often perceived as a positive behaviour or an individual strength. Aylmer discusses his work addiction with pride.

> Aylmer -(Minister)"I have been more or less a workaholic, you might say, so in this kind of work [ministry], a lot of it public, your work's never done. There's always more to be done. You can't just walk away at 5 o'clock and they won't let you do anymore..."

Some of the older informants mentioned that to not be working could be potentially hazardous to a person's health. They spoke of staying healthy so that they can continue to work and support their family. Aylmer talks about how he has seen several of his friends die shortly after retiring.

> Aylmer - "I've watched people die within 46 days of having quit their job. I've seen them die the day after the retirement party..."

The informants in this study did not make any link between occupation, income, and health. Instead they focused upon how work directly affects their own health. For many people, work can provide a level of life satisfaction which actually contributes to a healthier and longer life (Palmore, 1969; Palmore and Jeffers, 1971). Excessive levels of work are not perceived to be unhealthy. While job satisfaction

can be health producing, people do not really perceive their occupation as determining their level of health. How an individual's work affects their health is largely up to the individual. Job satisfaction is seen as being 'lucky' and for those who simply can not cope, they must have something wrong. Should an injury occur, then the individual is mostly responsible.

5.6 Environment

The link between the environment and a particular illness or disease is often very difficult to prove except in the case of extreme environmental contamination. For the informants, the link between their environment and their health is a difficult one to establish. The informants have a fairly narrow definition of environment. When they spoke of the environment, they were referring largely to the physical environment or the 'outdoors' The relationship between the environment and health problems existed primarily in terms of air and water quality and their effect on people's health.

> Russ - "I think our environment has so much to do with - you know, heavy pollution really affects my eyes. They water like crazy "
>
> Aylmer - "Oh there's a relationship. I don't think there's any question around respiratory infections, I'm sure."

The informants indicated that they did not think that the environment determined their health. In fact, very few felt compelled to discuss it because "it doesn't really affect us here." This may be because of the lack of evidence or a lack of awareness of the potential health impacts of physical environments. Those who

did comment on it expressed concern only in terms of air quality. Robert and Patrick's words leave us with the conclusion that informants do not perceive the environment to be a determinant of their health. Instead the environment seems to only be a nuisance when it aggravates existing problems.

> Robert - "Well, I think people with such respiratory problems...it's conceivable that probably the environment contributes to that disease to some extent."

> Patrick - "I used to have asthma when I was young and I still very occasionally get short of breath and wheezing. I start wheezing and so on, especially - sometimes you can notice if it's very humid and the air feels kind of heavy and you can smell the pollution, and you can feel -I can feel it in my lungs."

5.8 Conclusions

In this chapter, we have looked at a few of the determinants of health - smoking, diet, exercise, alcohol consumption, occupation and environment. After examining people's perceptions of these determinants of health, we can conclude that only smoking is perceived to be strongly linked to illness. The rest of the factors are perceived to shape healthiness but they are not seen to be determinants of health. The informants suggest that there are other variables which must factor in with these behaviours in order to determine whether you will become ill or not. In the following chapter, we will look more closely at these perceived determinants and how they contribute to people's health status.

CHAPTER SIX

The Determinants of Health

6.1 Introduction

Increasingly, health promotion programs have focused upon the lifestyle behaviours which the epidemiological data have indicated are affecting the health status of the population. In the previous chapter, we looked at some of these behaviours and also at occupation and environment, to see if people perceive them to be the determinants of their health. In this chapter we look more closely at three factors the informants feel contribute to whether they will be ill or not. Through their words we find that the causes are social and personal constructions based upon individual experiences and feelings. Angus' statement illustrates this relationship:

> Angus - "I think many of the health situations or attitudes towards health are based on, as I said, from personal experiences and perhaps until we've had that experience, it's happening to somebody else, it's not really happening- it's can't happen to me."

Angus' words describe why the causes of ill-health are not clear for every individual. Determining cause is often difficult until the individual experiences that illness. Then they must gather information and rationalize what has contributed to their illness. Perceived cause gives meaning to the illness and the causes are part of lay understanding and explanation for illness. From the informant's words, we find that

fate, fault and family, are perceived to be the factors which determine whether an individual will experience illness.

6.2 Fate

Certain illnesses are accepted by the informants as controlled by fate and therefore impossible for them to prevent. Various elements such as germs and viruses are viewed as being external to the individual's control and thus the blame for becoming ill is removed from the individual. The following excerpts illustrate this point.

> Sue - "The other thing I think that causes illness is straight fate -something that's just in the cards, that just happens."
>
> Lynn - "Everybody's going to get a cold or the flu every once in a while. You can't get around it, so, your immunities, well, you know you're going to get it anyway."
>
> Tony - "It's all there. All the other illnesses and diseases are out there. The causes are out there all the time. You can stay away from them as long as you can, but they're going to find you and you're going to get it sooner or later."
>
> Terry - "There's no way of getting around that. It's be nice if you could, but it's not likely. I just don't think it's possible..."
>
> Sandra - "I think it [illness] has to happen to everybody at one time or another."

These expressions of the role of fate made by the informants may be linked to the fact that they often do not know what the causes of many illnesses are and this makes people feel defenceless. While fate is not seen as an isolated cause of illness, it is one of the factors which can determine an individual's chances of getting sick

or of staying healthy.

6.3 Family

Closely related to fate, but still seen as a separate determinant of health, is the concept of heredity. Some health problems or the propensity for becoming ill are seen as being inherited. Since some illnesses are perceived to be part of an individual's biological make-up, the individual is also seen a powerless over controlling their health status. Steve, Janet, and John present some of the common perceptions about how some people are genetically more vulnerable to illness than others or they have inherited a gene that results in a specific disease. Family history or background is perceived to play a significant role in determining an individual's health.

> Steve - "There's always history - family history of disease and what-have-you that can be a factor."
>
> Janet - "Because some diseases are hereditary, then I guess you're lucky if you don't inherit one. For a lot of people, if it's in your genes, that you're more susceptible to some illnesses and diseases than others."
>
> John - "Well, some things are hereditary, you can't really do too much about them. You're born with them, it's in your genes."

6.4 Fault

The last perceived determinant of health is that of individual fault which may also be seen as blame. Here the cause of illness is seen to be internal because the individual is mentally or physically weak. It involves a strong moral element because individuals who cause their own illness are not seen a 'strong' people who

can resist such poor behaviour. Kleinman (1988) rationalizes that culture can shape illness to be a sign of moral distress. People often rely upon a moral perspective to explain or anchor the disturbing aspects of our world. In this case, people cannot comprehend why someone would engage in a behaviour which could cause illness and therefore interpret this behaviour from a moral perspective. People can tolerate illness when it is felt that the cause of the illness is beyond the control of the individual. If the cause is seen to be rooted in the individual attitude or behaviour then tolerance is much lower. Robert tells us that he feels that illness can be a result of poor mental attitude. Aylmer and Sandra feel that some individuals are physically weak and this makes them more easily overcome by illness. Sue feels that when behaviours contribute to your poor health then it is your own fault.

> Robert - "I think a lot has to do with one's mental attitude. I think living with illness, I know I think even with mental attitude and one's lifestyle has a lot to do with contributing to healthy living and lack of disease."
>
> Aylmer - "I think in terms of causes there are weaknesses in physical, my physical make-up. There are people who are, by nature, maybe have depressive parts of their make-up and they can make a great deal out of that one...there are other people who have the same kind of thing and get with life."
>
> Sandra - "I see some of my friends having hysterectomies, okay, now one person is just, I mean, for months they're out of it, they can't cope with [it], they can't move. You know, and it takes them such a long time to recover. Another person in three or four weeks is functioning and out and going..."
>
> Sue - "I really do firmly believe if you drink two quarts of liquor a day, or smoke two packages of cigarettes a day, you are likely contributing to it."

The perceptions that illness is due to personal fault is a prevalent one among the sample. Individual lack of control over personal actions is seen to have a crucial role

in shaping a person's health. Unlike fate and family, an individual is seen to have control over whether they wish to take a risk by participating in particular unhealthy behaviours.

6.5 Conclusions

In this chapter the lay perceptions of the causes of illness have been examined. Fate is seen as the individual not having any control over whether or not they become ill. Family is seen as having the cause of your illness rooted within the individual but once again it is beyond their control because fate determines which genes you will inherit. Fault is individual blame. It is perceived that people do have choices over certain lifestyle issues. If an individual decides to partake of the particularly unhealthy ones such as smoking, then they are accepting responsibility for illnesses that may result. The ability to avoid unhealthy behaviours is seen as a physical and mental control that only some people have. The overall conclusion from this chapter is that fate, fault, and family are the perceived determinants of whether an individual will become ill or not.

CHAPTER SEVEN

Illness Behaviour

7.1 Introduction

Illness goes beyond the physical body by affecting our self image, our behaviour, and how others perceive us. While the social aspects of illness are linked to the biophysical, they are at the same time separate from them. We find that the process of defining a symptom as an illness has social consequences for the individual.

Illness behaviour is described by Mechanic (1978) as "any condition that causes or might cause an individual to concern himself [sic] with his symptoms and to seek help" (Mechanic, 1978: p249). This includes how people perceive, evaluate, and respond to symptoms. The use of lay perspectives of illness behaviour is an indispensable way of trying to understand what goes on before an individual seeks medical attention. In this component of the study, the research goal is to understand how the informants know when they are becoming sick and how they respond. From this knowledge, we find that it is necessary to remove illness behaviour from the perspective that all proper responses to symptoms involve the health care system. Surprisingly, seeking medical care is perceived by the group as something to be done

only when the symptoms do not meet specific expectations.

7.2 Signs and Responses to Illness

Symptoms are differentially perceived, evaluated, and responded to, depending upon the social structure in which the individual is immersed. The most common initial symptom the informants described is unusual tiredness or fatigue. For Aylmer it means that this tiredness does not allow him to work at his regular pace. Lynn describes how she feels 'sluggish' before the illness becomes evident. Joyce experiences a deviation in her normal routine due to the fatigue she experiences before a particular illness.

> Aylmer- "Just a little lack of energy - I can't work 16 hours."
>
> Lynn- "I usually get sluggish, just slow down a little bit. That's usually a good sign."
>
> Joyce - "Well, I'm a person who wakes up early and gets up early, and if I sleep in, I often feel there's a cold coming on. I'm just more sluggish..."

For others, pain can signify that something is wrong. This pain can vary from headaches such as Russ experiences, to a sore throat or a generally 'achy' feeling.

> Russ - "Oh, something's coming up? Probably a headache -severe headaches."
>
> Mary - "Usually a sort of achy, headachy, type of thing. Just a - I'd have to go along with that, just sort of an achy feeling."
>
> Steve - "Normally, it's, you know, a temperature - a high temperature or a sore throat."

People know when they are not well. They have either experienced this feeling before and then it developed into a more serious illness, or they appraise

these bodily feelings against the experiences of their friends and family. From this information, each individual develops a perception of what is 'normal' for them and any deviation causes them to consider that all may not be well inside their bodies.

In responding to a symptom, the informants had a very clear idea of what to do when they developed a specific symptom. For some, the response was to seek some sort of treatment. This may have involved self-medication, or in getting more rest. Others recognized that the illness was an inevitable process and they chose to simply carry on and ignore the symptoms until they worsened or went away.

> Patrick - "I generally just sit it out..."
>
> Joyce - "Just suffer. Well, if it's a cold or something like that, there's not much you can do, other than drink lots of liquids and take aspirins and vitamins."
>
> Mary - "Yes, I just try and sort of carry on and hopefully it doesn't turn into anything, you know, but - and headachy and that, I guess, you can take something for the aches..."
>
> Sue - "If I have a headache, I take Tylenol. If that doesn't work, then I decide I might have my sinuses plugged up; I'll take a Sinutab. Although I'm not a pill taker. I don't get headaches often. But, I'll try and solve a headache with a common remedy that everybody uses - a pill- the Tylenol, a sinus pill, whatever. If I have diarrhoea, I use Dr. Fowler's Wild Strawberry...I try to - yes, I try to take care of myself, I do not go to a doctor until I've tried a few things."

7.3 Seeking Medical Care

It appears that people have many ways of coping or dealing with illness in its initial stages. What we realize is that managing illness involves recognizing that something is physically or mentally wrong and being sensitive to what these changes might imply. Use of the health care system is not an automatic response for the

informants. All of the informants felt that they only sought medical attention after they tried to deal with the problem themselves or when they had 'proper cause' (Eyles and Donovan, 1990).

> Lynn - "I'd have to be deathly ill before I would ever call the doctor."
>
> Joyce - "No, no, I'm not one to go to the doctor, really. I don't go that often."

So we may wonder at what point do people feel that they must seek medical care. Again, to determine this, the individual will draw upon past illness experiences. They may consult with others to determine what they think about their symptoms. They may draw upon knowledge which they have heard or read at some time or other. Usually, at this point, several things have changed regarding the illness state. Their normal functioning has been disrupted; they no longer recognize the signs or symptoms; the illness has lasted too long; or the symptoms have worsened and do not respond to treatment.

> Catherine - "It has to be something pretty severe, because I don't believe in pampering myself, or calling a doctor for a headache or a stomachache. It has to be something persistent, something really - something I couldn't explain to myself and it seemed out of the ordinary."
>
> Ken - "I do try to look after myself in terms of getting a bit more sleep at those times or whatever and generally they, like, they'll go away in a few days or whatever. I have gone to the doctor if it's persistent for a few weeks or something like that...yes, I would say it has to be something that has to be unusual before I'd go to the doctor."
>
> Glen - "Like I said, if I thought it would go away on its own, like a twisted ankle, or just a sore back, or something like that, even though a doctor might speed the recovery, I probably wouldn't go to one- again, but it'd have to be something where I would need - I knew I needed some kind or medication or treatment, that I couldn't do myself..."

The informants are under the impression that they have tried to heal themselves before they seek medical attention. Initially, when the symptoms emerge, they are particular to that individual. Hence, the sick person is able to define this symptom, categorize it as a 'abnormal' and proceed to 'treat' the symptom.

> Russ - "I'd have to be flat out, down for a day or two, and if it was something I felt was unusual like, - if I've got the flu, I don't call him [doctor] because I know I've got the flu. What has he ever been able to do? Nothing, you know, rest and take some more of those Tylenol things..."

If the symptom changes or persists and does not respond to treatment, then the individual no longer 'trusts' his or her ability to judge the technical qualifications of the illness. Then he or she will seek medical care to diagnose and treat the symptoms.

Parsons (1951) argues that when the sick person adopts the 'sick role', there is an implied bargain that they will seek and co-operate with 'expert' advice. From these accounts, however, seeking medical advice is not an automatic response. People rely on lay referral or sometimes prefer ignoring the problem instead of seeking a doctor's opinion. Even seeking medical care does not guarantee that the patient will co-operate with the doctors advice.

> Joyce - "He [doctor] prescribed something - an anti-inflammatory something - and I took it for about a day and it really bothered my stomach and I didn't take it anymore, just let the finger heal itself- which it did- and it probably would have done anyhow, without the prescription...and they were expensive too."

> Glen - "- the most I've had to use a doctor is for sports injuries, and through experience, if you just go to a family doctor--I end up, through just from experience, I knew probably more what to do that they did..."

The informants perceive themselves as only using the health care system when they really need to and only after they have tried to deal with the problem themselves. In many cases the informants after seeking a medical opinion, they would not comply with the treatment.

7.4 Conclusions

Talcott Parsons (1951) theorized that there is a shared cultural norm regarding the 'sick role'. He argues that the sick person has a dependent relationship with his family and friends. In exchange for this temporary freedom from social responsibilities and blame, the sick person gives up control. He describes the sick person as helpless and in need of help (Parsons, 1951). The help implied here is medical care.

Indeed, a person who is sick certainly has an unusual status in our society. But Parsons' theory does not seem to apply completely to this study of middle class perceptions of health. Being sick is not always perceived as a reason from freeing oneself from social obligations. These informants tell us that sometimes they must continue going to work, even when they are unwell.

> Steve - "Normally I'll come in if I'm not too sick, you know."
>
> Joyce - "I usually drag myself in until I really get...even if I'm not feeling that great..."

While this attempt to look at the critical work of Parsons' does not dismiss his theory, it does raise questions regarding its applicability. It appears that there is an elaborate lay system upon which this study only touches. Arguably, Parsons'

theory fails to consider the subjective or "inside" perspective of what people do when they are sick. The study of illness behaviour must be moved beyond the objective realm. As Conrad and Kern (1986) state, it is when we understand and view illness as a subjective, as well as an objective experience, that people will no longer be treated as deviant, but as humans who are sick. From this, a more humane health care system will arise.

CHAPTER EIGHT

Perceptions Of Physicians and Hospitals

8.1 Introduction

In this chapter, we look at people's perceptions of their family doctor and of health care facilities such as the hospital and emergency services. When people seek medical attention, the family physician is usually their first contact with the formal health care system. Seeking medical advice is usually for the purpose of seeking relief from pain, regaining a lost function, or having a symptom validated. As stated in the previous chapter, the informants will go to considerable lengths to avoid using the formal health care system.

A patient has an understanding of what the role of a medical doctor is, and how it is to be performed. This perception is a reflection of the experiences the individual has had with doctors and of what they have gained from family and friends experiences (Fitzpatrick *et al*, 1984). It is this frame of reference used by the patient to determine whether the doctor is 'good' or not (Mechanic, 1978).

The quality of the doctor is not determined by his/her technical skill because the lay person is usually not qualified to determine this. Instead, the doctor's ability is evaluated upon how nice they are, how interested they are in the patient, how much time they spend with the patient, and how willing they are to

listen. If these expectations are fulfilled, then the doctor is judged as competent by the patient and the doctor-patient relationship is more likely to be successful (Mechanic 1978).

While the majority of people appear to be satisfied with their present family doctor, we find that satisfaction with health care delivery is variable. Those with little or no personal experience with hospitals or emergency services feel that they have no complaints with regards to the treatment. However, it appears that those who have had extensive experience, either through their own treatment or through a family members, do have some serious complaints.

8.2 Perceptions of Doctors

All but two of the informants have regular family doctors. When asked what they liked about their particular family doctor, people were very complimentary and exhibited a strong degree of loyalty towards their doctor. People are hesitant to be openly critical of their doctor and it often required probing to find out what features people did not like about some doctors.

The informants said that they like to be told about their health problems but in a way that they can understand. We know that if the doctor cannot communicate well with the patient and s/he fails to meet the patients expectations, then the doctor's ability is questioned and treatment may not be followed (Kincey, *et al*, 1975; Fitzpatrick and Hopkins, 1983).

> Lynn - "Like, she tells me everything that's going on. She's very straightforward."

> Patti - "Um, she is always straightforward with me. I like the fact that she explains to me that she won't push anything...she doesn't push pills on me that I don't need."
>
> Russ - " The ability to speak in terms that you understand and to explain what's happening and why he thinks this..."
>
> Catherine - "Treat them [patients] kindly and patiently, but on the overall, I think they should listen to you and be honest, don't beat around the bush."

As Catherine points out, it is important to the patient that the doctor listens carefully to them. Listening to a patient involves taking the time to hear what they have to say. Sometimes, the doctor's ability to listen is viewed as a reflection of his or her competency. Because Sue's doctor listens to her, and then prescribes treatment, she feels that he is very competent as a doctor. Sandra relates a story that her brother, a family practitioner, told her about how he felt an increase in the time to listen to patients could actually reduce the number of prescriptions he gives out.

> Sue - "My doctor is a listener - he listens. He doesn't rush you out of the office. He listens. He takes action. He is not judgmental, and I just think he just generally is a competent doctor."
>
> Sandra - "I really - I feel that you've got to listen to people. I have a brother who's a doctor and, he's a family - he's a family practitioner, this family medicine, and he says to me -he said if he could spend an hour sometime with some of these people, he would give out half the pills that he could give out. That he could have the time to talk to people and talk through some of their problems. That so much - they're giving people pills when you don't have to."

Withholding information from the patient with regards to their particular health problem is seen as very aggravating by the patient. Russ suspects that the lack of communication is because some doctors think that the patient is stupid. In

addition to it being very insulting to the patient, a lack of communication can also be potentially very dangerous. Elizabeth, after having surgery on her foot to remove a lump, was frustrated by the lack of information she received from her surgeon. She assumed that this lack of information meant that everything was all right. Instead, Elizabeth finds later on that the lump was in fact a malignant tumour.

> Russ - "They want to keep you in the dark and my - the feeling that I get is 'ssh, this is family, they're complete idiots. Just stay out of our way will you'."

> Elizabeth - "A lot of my problem, I think, is when I had this cancer removed from my foot and some muscles severed and so on, and I'm never able to get answers out of the doctors about what I should do...well, I come in and I said, well, I think I said 'I assume it's all right because nobody's been in touch with me.' And he [doctor] said 'No, it's a sarcoma'."

The informants felt that it is important that the doctor care about them and be empathetic towards their problem. Physicians who lack a certain degree of empathy towards their patients are not seen as being good doctors. As Max states, a doctor without empathy for his or her patients will not 'get' anywhere with the patient.

> Max - "...I don't think any doctor is going to get anywhere with any patient unless that doctor can indicate a concern for that patient. You know, I think the answer to your question is just empathy. Sure."

The ability to make the patient believe that he or she is important can be demonstrated by the doctor in many different ways. Russ' wife had to have an emergency caesarean section and their family doctor stayed with her throughout the procedure. When Patti was going through a marriage break-up, the fact that her doctor supported her showed that the doctor cared for her and thus strengthened

their doctor-patient relationship. Catherine's doctor is sensitive to her inability to get about so he comes to her home. As we see from Sandra's comment, having concern for the patient can be more important than having great technical skill.

> Russ - "He was very good for all our family, even when my wife had my four year old, he was with her all through the pregnancy, and then at the very, very last they had to give her a caesarean, and he stayed there and had someone else give the caesarean, he could have gone home, he was good, he's really good. Excellent doctor."
>
> Patti - "The other thing I asked her about was, again with my split-up, was someone to see mentally. I asked her if I could talk to someone and she helped me out there, too. That's why I like her, because she offered me some assistance there. She actually let me sort of sit and cry on her shoulder, so she's a nice lady."
>
> Catherine - "Well, he's very considerate. He's never in a big hurry. He answers all your questions...and he makes house calls."
>
> Sandra - "I don't know whether he was the best doctor in the whole world or not. I don't know, but he made us feel that we were important."

The informants felt that a sign of a 'good' doctor is his or her ability to recognize when they cannot handle a particular problem and refer the patient to a specialist. As we see from Mary's comment, this shows the patient that the doctor is 'sensible' and cares about their well-being.

> Mary - "He's always seemed to us to have a very sensible, you know, approach and if he's had any doubts, you know, he's always sent us to whoever he thought that, you know, was necessary..."
>
> Aylmer - "I think that a physician - a general practitioner- should be willing to refer, although I don't think that should be his first thing to do, hand it off to somebody else."

Some of the informants, like Julie and Aylmer, liked the fact that their doctor did not always rely on medications to treat them. These two were part of a

group of five informants who felt that medication was not always the right choice. Their doctor's ability to respect their philosophy showed the patients that they were respected. By trying the least harmful treatment first and by not putting the patient at any risk is seen as being a considerate practice by the doctor.

> Julie - "She doesn't rely on, on medicines and all kinds of things, she tries simple sort of natural things first. She likes the way things are when, you know, that's my philosophy too."
>
> Aylmer - "They have sort of a holistic view. They're willing to recommend counselling if you are in stress."

As we have discussed, patient's complaints about a doctor may not necessarily be a reflection of the doctor's competence. Complaints are usually an indication of the doctor's inability to fulfil the patient's expectations in some significant way. On one hand the doctor may be criticized for 'pushing pills', on the other the same doctor may be criticized for not 'treating' the problem with a prescription. Mechanic (1978) argues that the success of the doctor-patient relationship hinges upon the extent to which the doctor and the patient share a common frame of reference.

We find that quite often the patient expects to be treated in a certain way and does not receive this particular treatment. Max and Catherine both sought treatment but felt that the doctor did not believe their pain or discomfort. When such a situation arises, the doctor is viewed sceptically and the trust relationship is broken.

> Max - " When I had had some surgery and I was in considerable amount of pain and I went to seek relief, basically asking for, you know relief- I was turned away with absolutely nothing. I was very angry with that

person."

Catherine - "I wasn't very happy with what went on - I mean, they made me feel as if I wasn't - as if I was putting on -I wasn't sick as I thought I was, yet I was running a temperature, and I was so sick I couldn't hardly hold my head up. But I got a feeling that I wasn't important. I don't like to have a lot of people make a big fuss over me, and I don't expect it. But, I like to feel as if I'm not lying, and when I say I was sick, I was sick."

In some cases, when the patient goes to the doctor to have a symptom diagnosed they feel that they are not believed. This can be traumatic for the patient. Sandra's daughter was experiencing severe pain in her abdomen. The doctor's response was to suggest that the pain was not real and that perhaps Sandra's daughter was suppressing a psychological problem. From the following excerpt of her interview, you can get a strong sense of how emotionally disturbing it was for Sandra to see her daughter's pain doubted by the physician.

Sandra - "....the last time I brought her in, this time it didn't stop - I - she's bowed over in pain. I mean, she was really in pain, okay, it was a bowel block, so you can imagine the pain, the stuff, okay?"

A- "Yes."

Sandra - "Okay. And he's [doctor] telling me - I don't know, I think we'd better get a social worker. I mean, this - not the time, look at this kid suffering, okay? And I think we'd better start to get a social worker and all- I-even if they are psychosomatic, when you're going through the pain, you've got to get past that and then deal with it."

A - "Right."

Sandra - " Anyhow, he [doctor] was really questioning her pain...it was terrible. She went in on Wednesday and she had surgery on Friday and the pain never stopped from then..."

Sometimes people perceive the attitude or the approach of the physician

to be wrong. People want their doctor to be interested in their well-being, and to let them be involved in their own care. Sometimes the doctor is either too busy or not concerned about his or her patient. This makes does not make the patient feel valued. The doctor does not see the patient, only the disease.

> Steve - "Just a lack of concern from a previous physician, and simply everything was run by the clock, so it was more of a money-making process than you know, health care....yes, just a- and a poor attitude."
>
> Lynn - "She can be cold fish at times."
>
> Glen - " Well, he shouldn't - talk to you about it - point out - give you some options and tell you what's going to happen - and he didn't do any of that. He was more just go straight ahead, this is what you do, this is what you do in the future and that's it."
>
> Elizabeth - "I really resent that they - that the orthopaedic surgeons and the cancer doctor didn't give me that kind of advice, or that my general practitioner was unable to give me that kind of advice. The can treat dis[ease] - you know, threatening diseases, but they - they don't seem to be able to come to terms with helping. And also, I resent that I was treated by the medical profession where your viewed - I mean, you know, you're just sort of an appointment."

Doctors are perceived as making a lot of money, and indeed they do make up part of the highest income bracket in Canada. Therefore, should a doctor complain about how much they earn or extra-bill, they are immediately criticised. People like Terry who feel that a doctor appears profit orientated by having an overload of patients, or spends as little time as possible with each patient, is not committed to their initial purpose of healing and helping people. Patrick initially had a physician who extra-billed him. He did not like this because he feels that the Ontario Health Insurance Plan already pays them enough.

> Terry - "Well, you're sitting there having an interview with the doctor and

> he's complaining about how he works too much and he does this too much and doesn't get paid enough and if that's all, he doesn't have the heart in what they're doing."
>
> Patrick - "I was turned off by doctors who extra billed. I mean, who am I to say, but you figure they're making enough on whatever OHIP pays them, why should they charge more..."

Finally, some of the female informants discussed how their doctors came across as sexist in that they do not know how to treat women or that they treat men better than women. Elizabeth was experiencing 'full feelings' and gas so she sought a doctor's advice. She says that no doctor was willing to address her problem or even diagnose it. Elizabeth later discover through reading the newspaper that what she was experiencing was a hormonal change due to menopause.

> Elizabeth - "Well I think that, for instance, with - with the menopause, I think I started to have all kinds of complaints, generalized complaints about full feelings and gas and that kind of thing. Now, these I have subsequently found out they're menopausal complaints, but at the time I didn't know and no doctor came and called it."

She complains that her doctor "doesn't know how to treat women and I think that is one of my most serious complaints." Like Catherine, Janet is presently very annoyed with her family doctor because "he's not great with women. He is great with men." She says this is because he just isn't comfortable treating women which causes Janet to have to force her issue or 'bully' the doctor.

> Janet - "Well, he is just more comfortable talking to men and treating men and dealing with men and I just don't take - if I need something, I make sure I get it from him because I'll just go to him and pursue it and pursue it, where a lot of women won't.'

8.3 Perceptions of Hospital Care

Most people have experienced some form of hospital treatment either as an in-patient, an out-patient or through family members who were hospitalized. It is from these experiences that people determine how good the institution is. While a few of the informants have had very dramatic experiences, generally the informants felt that the care in hospitals is good despite the budget constraints under which hospitals were operating.

People hold expectations about the type of treatment they should get in hospitals. And as it is for physicians, if the hospital does not meet this expectation, then people complain about the treatment. Steve talks about how he went to emergency to get stitches and ended up with a student doctor.

> Steve - "You know, having a cut sutured with the wrong suture material and having to have it cut and replaced, you know...because the doctor wasn't sure what he was doing..."

Janet's story about the emergency services quite clearly illustrates how failure to meet her expectations brought open criticism of the hospital. Her husband was suffering from kidney stones and was in a great deal of pain. When they went to emergency, the problem was quickly diagnosed but then they were left to cope on their own. Janet, who is disabled with a severe back injury, felt it was wrong that she had to stay in order to take care of her husband.

> Janet - "There was just nobody there. Like, he was really thirsty- there was no way that he could get a glass of water - there was nobody there to get it for him. There was no on-going patient care."

Although the lack of care is upsetting to Janet, she is still able to accept

it. She does not feel that it is neglect. She perceives the lack of care to be related to financial constraints which limit the hiring of more nursing care.

> Janet - "I thought that, that was, for him, that was going to at least make his night a bit easier, so the - the immediate acute care is fine, the on-going, hourly stuff isn't fine and I know why. I know it's because there is no money. It's not because they're not good nurses."
>
> A - "Right."
>
> Janet - "It is just because it's not possible. And because they don't hire health care aides in a hospital to make it possible."

It is interesting to discover that people do not always blame the hospital if the care they experience is not good. They are often unwilling to point the blame at the hospital staff. Instead they recognize the fallibility of the institution and change their expectations.

> Catherine - "I have really no complaints. I know there are things that they can't help and that I can accept."
>
> Glen - "It's a hospital, what you'd expect at a hospital, you know, your - food that doesn't taste real good, you don't really see anybody until you have something actually wrong, and hit the buzzer. It's not - no, it's not a hotel really, it's a hospital."

While people are willing to make allowances for certain things, there are situations like Sandra's and Elizabeth's which resulted in the patient feeling that the hospital care was neglectful. While the informants were hesitant to suggest that all people may not be treated equally when they had to use hospital services, these two accounts suggest that it may very well be true.

When Elizabeth went to the hospital to have a tumour removed from her foot she had an experience which caused her to question the amount of

communication that went on. When Elizabeth was waiting to go in for her surgery, her husband, out of boredom, decided to read her chart. It was fortunate that Elizabeth's husband did this because they discovered that the surgery was going to be done on the wrong foot.

> Elizabeth - " When I went in for my surgery, while I was waiting for the doctor, my husband happened to notice that they had actually put the wrong foot down on my chart. You know, there wasn't a lump on the foot so it's not that the doctors would have know which one, but still, that kind of thing went on right through my experience with the [Hospital C]."

Sandra's elderly mother was very ill and had to be hospitalized. When Sandra went to visit her mother, she was shocked to find that she was unable to recognize her.

> Sandra - "And they were keeping my mother so drugged that this women didn't - at time didn't - was so out of it, she didn't recognize who we were."

Sandra found a nurse and tried to find out how much sedative her mother was receiving. She subsequently discovered that they were giving her mother three times the amount that her mother had required previously.

> Sandra - "She needed half or a third of what they were giving her to keep her in the calmer state that they wanted everybody to be in."

In addition to the over-sedation, Sandra discovered that the hospital had administered penicillin to her mother who is allergic to this drug.

> Sandra - "They were also neglectful. She is allergic to penicillin- and this was at the first hospital. It's written on her wrist. It was written on the bed. It was written in the charts and it was hanging on the wall and they gave her penicillin for a - for a urine infection."

Sandra was asked what she thought could have caused such a thing to happen. All she could say was that it may be because her mother is elderly, is often

absent-minded, and because she is unable to speak out for herself.

> Sandra - "She's an older woman. She happens not to look- she didn't. She's a little bit..[Sandra points to her head]."

Sandra, and other informants, feel that certain groups who required a lot of care, like the elderly, are often overlooked or not treated very well.

> Glen - "...maybe they do discriminate against older people, because they do require- they do think they require... treatment, and maybe they don't and maybe they do, I don't know first hand."

> Aylmer - " I think some people coming back chronically don't get treated as well as they maybe did the first time...I don't know."

Joyce also experienced a problem with her mother's care. Her mother has arthritis in her ankles and was experiencing a great deal of pain so she went to her family doctor who sent her to a specialist. The specialist decided to hospitalize Joyce's mother. The hospital stay lasted for two months at which time Joyce's mother's muscles had severely atrophied. Joyce feels that the lack of attention to her mother may be due to her age.

> Joyce - "I also have a feeling that because she is older, she doesn't get the same kind of attention as, say, a young athlete who went in with the ankle problem. They'd [doctors] say 'This is a young person who has their life ahead of them, or their career, or whatever. Maybe it's a bit of an aging thing that you get to 75 or 80."

Joyce was asked if she really though that the treatment her mother received was linked to her age. She felt that it was ageism but for the purpose of saving the system some money.

> Joyce - "I think there is ageism there. It may not be a conscious this, but I think it is there, and if the health care system is under a lot of pressures and it is now, maybe they have to make decisions."

Angus, Sandra, and Aylmer feel that differential treatment can also be linked to who you know in the hospital, by how much money you have, or by your social status. In Sandra's case, the treatment of her mother greatly changed when her brother who happens to be a physician got involved with her care. She concluded that " it sure helps when you know someone."

> Angus - "I think- I still think, perhaps, there are certain treatment where it's related to the ability to pay."
>
> Sandra - "If you don't know someone- if you don't have a friend or if you don't know someone that's there, yes...if there's someone who knows you, then you're going to get that little bit of extra, you're going to get that."
>
> Aylmer - "I don't think anybody treats out to treat anybody unfairly, but there are ways that some of us can get access and the same has been true when it came time to give treatment to some people that I was counselling and taking care of. I could phone and get a referral and get into an emergency situation, where the person couldn't get anywhere."

8.4 Conclusions

Medical doctors are in a difficult position in our society. The structure of the helping potential they can provide to their patients is far more limited than the lay person's expectations. Lay expectations of treatment are not constrained by the boundaries enforced by the medical community. Physicians are not often taught how to 'care' or show 'concern' in medical schools. Their medical role is restricted not only by our laws, but by professional ethics, politics, and time constraints. Physicians are expected to be both professional and personal with each patient. Failure to do so would bring forth criticism of their skill from both the medical community and from their patients.

People have clear expectations of the physicians that must be fulfilled in order for the doctor to be able to treat that patient. People want their doctors to be patient, and to have time to listen to them. They want to be treated as adults and have information provided to them in a straightforward and open fashion. Lastly, it is very important that the doctor proves to the patient that he or she really cares. Concern or empathy for the patient can be demonstrated in many different ways.

On the other hand, people know what they do not like in some physicians and will purposely avoid those who possess traits such as sexism or a lack of concern. If the physician does not spend enough time with each patient, they are seen as being money oriented. One of the most damaging things a doctor can do to a patient next to actually harming them, is to not believe their pain.

Perceptions about hospital care appears to be variable among the informants. Many of the informants felt that they did not have enough experience with hospitals to pass any judgments about the care. The informants who did have problems seem to have very dramatic experiences. We can conclude that there probably is differential treatment in our hospitals. While it can be very distressing when it is a family member, many seem to view this as part of the nature of the health care system.

CHAPTER NINE

Perceptions of Health Expenditure

9.1 Introduction

In Ontario, the health care system is publicly funded for universal services. Presently, however, the future of this system of health care is in peril. Throughout the eighties, Ontario invested a large amount of its resources into maintaining this system. In 1980, universal health care in Ontario cost the tax payer $4.9 billion. In 1990, this figure has tripled to 15.3 billion. In the supplementary paper of the 1992 Ontario Budget, Managing Health Care Resources (May 1992), it is expected that health care expenditure will reach 17.2 billion in 1992.

Presented in this chapter are the perceptions of the informants about the health care system and health care expenditure in Ontario. With the delivery of universal health care greatly threatened by increasing costs, it becomes important to understand how people perceive this threat and to examine some of their ideas about how to change the system.

9.2 Perceptions of the Health Care System: "The Best System in the World!"

The health care system is one of the fundamental features which characterizes Canada. Despite the daily newspaper spelling out criticisms of the

Canadian health care system, amongst all of the informants there is a great deal of pride about the delivery of health care. It is felt that Canada has one of the best health care systems in the world. When Lynn, Robert, and Terry were asked if they liked the present day health care system, they were very enthusiastic in their responses. Sue tells us that other countries are actually jealous of the way health services are provided in Ontario. Joyce values the system and recognizes that certain sacrifices may have to be made in order to preserve it.

> Lynn - "I think our health care system is great!"
>
> Robert - "I think the medical care in Canada is good and I think we should try and maintain it."
>
> Terry - "It's one of the best systems in the world!"
>
> Sue - "I feel, extremely privileged and fortunate to live in a country where, I feel, we have the best level of health care in the world. I think this OHIP thing is fantastic. Other countries,- have envied it - but, how much longer can we afford it? It's expensive, but I do think we're very, very fortunate and I don't take it for granted."
>
> Joyce - "I'm really thankful I live in a country that has a universal health care. That's really important to me. And, so I hate to see cutbacks that are going on. I don't really [think] they can afford it."

People do value Ontario's system for delivering health care. The informants recognize that the present system for delivering health is expensive, but they feel that it is much better to endure this expense than to not have universal health care. People like Patrick and Terry appear to be very proud of the Canadian health care system because they have both had experiences with the American health care system.

> Patrick - "Yes, I'm very happy with it, especially after visiting in the U.S."

> Terry - "It's not so bad here in Canada as it is in [the] States. In the States it's terrible. They have a terrible health care system. It could break a family - oh, we have a thousand times better system than the States. I'm pretty much happy."

Aylmer and Steve recognize that the health care system in Ontario has many problems. Despite the apparent shortcomings, however, they argue that the delivery of health care in Canada is very good and that it should continue to be delivered in the same way as it has previously been although in order to do so, improvements would have to be made.

> Aylmer - "I think there's a lot that could be done to improve it, but you're always going to be in that position, I think of having to ask yourself whether it's attaining what was intended to attain. I think in terms of our health care system, we have one of the finest and have a vision of providing it for everyone and we keep working at that."

> Steve - "I think it's a great benefit, but, you know, if you're looking at it from a cost stand point, there are certainly problems in it which can result in the system being.....but the benefits are obviously, you know, terrific."

9.3 Health Expenditure

In Canada, we spend more per capita on health care than any other industrialized country with a universal health care plan. The informants were asked if they thought too many tax dollars were being spent in order to maintain the system. One strong perception that surfaced from the interviews is that we do not necessarily spend too much, we just spend tax dollars incorrectly. They argued that resources were not being allocated correctly.

Steve and Catherine suggest that if cutbacks are to be made, that we should not make them in areas that they regard are really necessary. To them, basic health

care delivering is an extremely necessary item and to make cutbacks in this area is irresponsible.

> Steve - "Certain areas, I think, are ignored, and certain areas that it's spent - they waste a lot of money, it's just - its not well managed, but it's a difficult task, you know. It's a very difficult task to run smooth."

> Catherine - "I could open a hornet's nest right here. I think we spend too much in the wrong places. I think where it's needed the most, we neglect. And where it's not absolutely necessary, we spend."

One of the areas where the informants feel that money is poorly spent is in the health technology and research. Angus tells us that "the technological society is robbing us blind, and you no sooner get the computer in place, with a computer program and then you change it." Angus says that " that's even why we have some of the cost burdens that we do, as well, because a lot of the technology is not cheap." On the other hand, Glen describes how our health care system is in need of specific technology and can not afford it.

> Glen - "People are either generally sick and need something, like somebody needs a kidney machine and someone tells them they can't have it just because there's not enough money, I don't really agree with that."

People feel that there are management problems within the health care system. It is perceived that a great deal of health care funding is wasted on poor management. Russ feels that better management might actually reduce health care costs. Russ tells us that the health care system has "got to be better management of what they have and better management of what they have is making doctors more fiscally responsible."

The informants were asked where they would like to see funding directed.

One of the most common responses was that the informants feel that more funding should be allocated towards preventative health measures such as health education. Traditionally, health education has been viewed as a inexpensive means to reform the health of the population. The informants tend to agree with this but they feel that more money has to be spent teaching people how to maintain their health.

Some of the informants like Reta, Aylmer, and Sue feel that health education should begin in grade schools.

> Reta - "On health care and how to look after your body and what are the symptoms of illness and what you can deal with. And it should be started in high school for sure."
>
> Aylmer - "I think we could do a lot more eduction wise in our schools. I think there's a lot you could do with some good health care teaching."
>
> Sue - "I think there's a lot of - I think we need to have more education at a very basic level of first aid. There's too much, particularly of young parents, running to the doctor."

It is clear from these informants' words that they are not speaking in terms of the traditional health education directives. What they are implying is that they would like to see health education take a more functional approach in educating the public. Reta feels that health education should teach people how to determine when health care is needed. Sue suggests a basic level of first aid so that people can treat themselves to a certain extent. By focusing efforts upon more health education, Aylmer feels that "we could probably drop our hospital populations by a third." Preventative medicine is perceived by the informants as a more practical allocation of funding and also "more useful than just opening up more beds." As Catherine says "an ounce of prevention is worth a pound of cure, yes, I think prevention would

be one step."

The informants want the health care system to be more accountable to the public. Patti tells us that she "just wonder[s] sometimes if the money is going in all the right places, but I'm not sure where it's going." Mary tells us that she is distrustful of the government and if the health care is in some sort of crisis, they had better explain why to the general public.

> Mary - "You know, like, I don't know, I guess we're always distrustful of governments and as to what they're saying. Is it the truth? Are we getting all the facts? I guess, you know, if we're paying into it, then we should be certainly well informed as to where the money is going and what it is for and why and that - and not be a sort of a closed book."

Robert also asks whether the tax payers money is being spent on 'unnecessary health care' and agrees with Mary and other informants that we should be better informed or that the information should be made more accessible to the public. He has "some question as to how much money is wasted in providing unnecessary health care."

9.4 "The Conspicuous Consumer"

It is surprising to discover that the consumer holds themselves almost completely responsible to the high cost of health care. The ratio of informants who believed that patients were the main abusers of the health care system is 3:1. At the same time, not one of the informants saw their use of health care as unwarranted. Sue tells us that she has "no qualm with the system, [but] I have a qualm with the people that use it."

There is a great deal of blame directed at individuals who either see the

doctor for 'minor complaints' and at people who like to are perceived to "dwell on their illnesses" [Catherine]. Sue describes how abuse of the system stems from a lack of practical health care knowledge. Russ describes how some people fail to take good care of themselves and then have to see the doctor.

> Sue - There are some things - first aid- that should be common sense. By all means, use the system when needed. But, I think a lot of people have a common cold and go running to a doctor, and I think that's an abuse of the system and I see a lot of that."
>
> Russ - "I think it's overused. I think that if people tried to work out some of their stuff themselves. I mean when you really look at that - a lot of the self-help stuff. I don't mean natural path stuff [naturopath], but I mean, just taking care of yourself and making sure that your health is good."

Steve tells us that most of the patients go to see their doctor either because they are lonely or want sympathy. Sandra suggest that those who seek their doctor's opinion do so because they lack a support system at home.

> Steve - "You know where 60% of the patients that are in the doctor's office, don't require health care. They just need the doctor to hold their hand, or tell them that their sore throat will be fine in two days, and rest and drink fluids, and our - we're spending billions of dollars on!"
>
> Sandra - "A lot of people who seem to me to run to the doctor are probably people that don't have - I'm only guessing- that maybe don't have support system at home or don't have anybody who can give them that pat on the back and...[Sandra shrugs her shoulders] "

Reta, Lynn, and Steve describe why they feel that there is so much abuse by patients. They suggest that accessibility is far too high and it is this feature which allows for patient abuse. Ironically, one of the health goals adopted by the Premier's Council on Health Strategy (1988) is to provide accessible, affordable, and appropriate health services.

> Reta - "Well, because it's, free. I - this really, it might sound very strong to you, but I think for people who have other frustrations in life, they can just afford to dwell on their illnesses."
>
> Lynn - "I don't think half of the people would go to the doctor's as much as they do if they had to pay for it."
>
> Steve - "I think access is too easy, as far as, you know, a larger percentage of people want to see their family physician just for hand-holding or for colds."

Angus tells us that patient abuse of the system is likely linked to the increasing awareness they have with regards to different illnesses and coupled with that a decreasing tolerance of illness on the part of the patient and the public.

> Angus - " I probably think that people are probably more aware of their illnesses or health problems than they were in the past. I think they're less tolerant of them. I think - In that sense, you could say 'well is that patient abuse?' I don't know. My father wouldn't even go to a doctor. I mean, I've seen him have cuts that really should have gone to a hospital with and he didn't. Wash it, plaster it up and that kind of thing. I don't think people nowadays - I think they're probably more aware of what could happen and they try to prevent that and therefore they would be more likely to contact some health authority or something like that. So, that will put a pressure on the system."

The Supplementary Paper to the 1992 Provincial budget tells us that the number of physicians in Ontario has exceeded population growth by three times. This document also tells us that the majority of physicians in Ontario are paid fee-for-service which in fact encourages large volumes of service.

Zola (1986) argues that medicalization is a means by which physicians in an increasingly competitive market the past have created a market for health care services. Medicalization is the process where previously non-medical life situations are put under the jurisdiction of a physician's care. Perhaps the delivery of health

care is not a simple economic equation of supply and demand. Zola suggest that the demand is sometimes created by those who supply the service.

Yet somehow the blame for the 'demand' is placed by the public onto the patient. Reta tells us that patient abuse of health care is because we lack limits as to what we can have. The question which rises from this is, who in fact has created this standard?

> Reta - "I guess I feel strongly, it's almost a conspicuous consumption, you know. In health - abuses of the health care system, is people who need a lot of material things for comfort."
>
> A - "What do you mean by conspicuous consumption?"
>
> Reta - "Well, people who need possession of everything they see, and I think that their doctor available, well why not use him as much as you can. He's there."

9.5 "Somebody will have to almost act God": Suggestions for Change.

With so many financial pressures upon the health care system, it is becoming increasingly apparent that some major changes will have to be made to our publicly funded universal health care system. One of the most popular changes suggested by the informants is the installation of a user's fee. No other suggestion is as consistent among the informants. Other suggestions were far more particular to the individual.

The informants felt that a user's fee would reduce patient abuse of health care services. Their suggestion of a user's fee is not for the purpose of blocking people from receiving good health care. The purpose as they perceive it to be is to

force people to use it far more discriminately. Reta's suggestion is to have a small fee ranging from 1 to 5 dollars which would make patients really think about how necessary it is for them to see the doctor. Lynn feels that a small user's fee would make a big difference. Russ thinks that there should be a ceiling put on the number of visits you can make a year. After that, you must pay for your own care.

> Reta - "I think there should be a user's fee, just so you'd have to discriminate a little bit whether that little finger will get better by tomorrow, so not a dramatic user's fee."
>
> Lynn - "I think you're going to have to see, like, a small payment when you go in for your doctor's visits and all that."
>
> A - "Like twenty dollars or something?"
>
> Lynn - "Oh, no. Probably only be about five or so, and that would probably make a lot of difference."
>
> Russ - "Put some sort of user fee on, not from the first visit, but user fee Not per family, but per individual, obviously....but something free to begin with. So, for instance, if you see the doctor eight times, maybe four were free, and then after that you start to get billed."

The informants feel that information about how expensive health care is may discourage people from over-using the system. Patti feels that after your hospital stay, patients should receive a statement which tells them how much their care costs the government. Janet also agrees with Patti. She feels that consumers should receive a bill at the end of the year.

> Patti - "Maybe they need to have - maybe when they go in the hospitals, not really a bill, but something that says here's what your hospital stay costs. It's not that we're billing you, we just want to make you aware of how expensive it is and - I don't know whether that would bother people or not."
>
> Janet - "Quite possibly people need to get a bill at the end of the year to

> say 'This is the amount of money that was expended at you through OHIP'. I don't know how much more that would cost us, but it would be interesting for everybody to know what it costs the health service."

Another area the informants feel that changes have to be made is in the area of health education. Most of them feel that we need a more practical knowledge of health care. One informant liked the ideas of a 'health hotline' which they could call when they needed help either treating a symptom or determining if they should see a doctor. Reta feels that this sort of system could teach us "what you can expect - what health you need to function naturally and not."

Some of the other suggestions for changes were about ethical issues. Robert feels that there should be some change in terms of limits to treatment and that we "develop a way of euthanasia." Patti also feels that perhaps we should allow treatment of terminal patients to stop at a certain point and " maybe he should spend his last few days at home if there's any way." This, she concludes is "a nicer place to be anyway." Russ would like to see privatization of chronic care facilities. And finally, John would like to see a policing of the health care system where those who are caught abusing the system - physician or patient - are penalized.

> John - "I'd like to see some kind of a policing of the system, where that the anybody who's found to abuse the system would be fined or penalized some way."

9.6 Conclusions

The publicly funded, universal health care system is a popular feature of this country. All the informants like it and feel that we should keep it. They

recognize the crisis in the health care system and they feel that a large part of this crisis is due to patient abuse or overuse of health care facilities. The other problem with the system, they feel, is with the distribution of public funds.

The public has many ideas as to how to change the health care system which is obviously deeply valued. While some of the changes may not appear to be fundamentally correct, they are extremely practical. The informants are well aware of the situation which health care in Ontario is facing in the future. However, our health care is a very successful system. But it is a system which has forced the public to make some decisions they would prefer not to or which previously nature would do for us. Angus words summarize the perceptions of the informants very well. He tells us that choices will have to be made. Sometimes these choices are very difficult, but due to limited resources someone will eventually have to decide.

> Angus - " I think this is a question that's going to become more and more of an issue as the health resources, you say, now strain one third of our economy. Choices will have to be made, unless there is a bit of control on those prices. But the choice is - it sounds somewhat harsh, but you may - you may have to start looking at the quadruple bypass for somebody who's 75, or the long term. like, situation for the very, very young, who would quite naturally die. It sounds a very hard position to take, but if it impacts on the general well-being of the people you can really do something for, and if you've got limited resources, these are questions that will have to be asked and, I know, it's acting God is some cases. Somebody will have to almost act God..."

CHAPTER TEN

Conclusions

10.1 Summary

This thesis has dealt with some of the perceptions that a group of 24 people hold about health and health care. The research goal was to uncover and describe a set of lay perceptions as well as illustrate how they might add an additional dimension to the investigation of the delivery of health care services in Ontario. The following paragraphs are devoted to summarizing the conclusions found in this study.

In chapter 4, the lay definitions of health, illness, and disease were examined. We find that the definition of health is broadened and easier to describe when the term is modified to healthy. Health is an objective, medical term which describes physical state. Health is taken for granted, and it is usually noted only in its absence. It is also a very difficult thing to define. Healthy, on the other hand, allows for the personal or subjective feeling that people have to be incorporated. It becomes easier to define because its meaning is socially constructed. Health is important for day to day functioning while feeling healthy allows you to enjoy your life. Health is a fixed term while the term healthy can be re-negotiated to suit

individual situations. In this chapter we find health also involves particular 'normal' illnesses. Illness is perceived to be an acute, temporary dysfunction which is easy to treat while a disease is seen as a chronic disability which usually requires a doctor's intervention.

The focus in chapter 5 was on some of the determinants of health. Smoking is seen as hazardous to your health but the informants do not see it as a determinant because not all smokers get sick. Diet and exercise are negotiable activities which are usually linked to individual appearance. Neither are seen as a factor which will determine whether you will live longer or not. Alcohol is seen to be hazardous only when people go beyond 'moderation'. It is perceived to be harmless and in some cases even beneficial to your health. Occupational stress is perceived to be a major health hazard in the workplace and is linked with certain illness such as colds or stomach problems. There is a high level of faith in the government's ability to protect the worker and work place injury is perceived to either be exaggerated or the individual's own fault. Lastly, the lay definition of the environment was limited to the physical environment. The physical environment is perceived to only be a problem if it exacerbates an existing health problem. What can be concluded from these perceptions is that while these factors may certainly determine the type of illness that a person may suffer, they do not determine how long they will live or whether or not they make you healthier.

Chapter 6 deals with the issue of what lay people think are the causes or the determinants of health. Fate is one factor which is seen to affect health but it

perceived to be beyond the control of the individual. The concept of family or heredity as a determinant of health is linked to the biological or genetic backgrounds of some individuals which makes them more susceptible not only to illness but to certain diseases. The last determinant of health is that of individual blame or personal fault. It is perceived that some people are either mentally, physically, or even morally weak and this causes them to engage in behaviours which make them more susceptible to illness. It this way, people are at fault for causing certain illnesses.

In chapter 7, the focus is upon how people determine that they are ill and at what point they seek medical help. People define any deviation from their normal state as a possible symptom of illness. The informants cited fatigue and pain as common first signs. When this occurs, people state that they will take non-prescription medicine or get more rest instead of calling their doctor. The symptom must persist or get worse before the informants will seek medical attention. Going to the doctor is not an automatic response to illness and most of the informants felt that they only sought medical attention when it is absolutely necessary.

Chapter 8 looks at the lay perceptions of the family practitioner and of health care delivery. People feel they go to considerable extent to avoid visiting their family doctor by either consulting their lay referral system or by self-treating the illness. People have certain expectations about how their family doctor should behave. If the doctor does not meet these expectations, then treatment can be seriously interrupted. The informants stated that they want their doctor to be kind,

patient, straightforward, competent, honest, concerned, empathetic, and a good listener. If a doctor is seen meet the lay expectation, then great technical skill is not necessarily important.

This chapter also looks at the delivery of health care. Most people can accept that hospitals are constrained by staff shortages and by their budgets. Their level of tolerance decreases when they feel that the level of their health care has been affected. The informants discussed whether the health care system treated everyone equally. While few of the informants experienced blatant discrimination, they did discuss the fact that some doctors appeared to be sexist and that there also appears to be ageism within the health care system.

Finally, in chapter 9 lay perceptions of health expenditure are presented. Most importantly, the informants felt that the system for the delivery of health care in Canada is one of the best systems in the world and they are very proud of it. Cutbacks in the delivery of basic health care is viewed by the informants as being irresponsible. What the informants did want was greater knowledge of where tax dollars are going and how they are being spent. A user's fee and preventative health care are seen as answers to reducing the level of patient abuse of the health care system. As well, the informants had many other suggestions about how to reduce the burden on the system. This overview of many of the conclusions drawn from this research provides a picture of how informative lay perceptions are especially helpful for future health planning. Many of these are discussed in the following section of suggestions for future health policies.

10.2 Methodological Implications

The methodology used for this research is taken from the interpretive paradigm which calls for a sensitive method in order to uncover meaning in our social world. The emphasis in using this methodology has been upon trying to gain access to and understand the perceptions of health and health care held by the informants. The research has focused on people as case studies so that their perceptions can be viewed within the context of their own lives.

The methodology chosen for this research was in-depth interviewing because of its ability to allow the perceptions and experiences of the informants to be narrated in their own words. Data gathered in such a fashion allow the informants to essentially guide the interview but it also allows for the researcher to change the order and presentation of themes to suit the flow of the conversation. This method allows for the interview to progress in a conversation-like pattern with the emphasis put upon the dialogue as well as on their responses. This methodology is not a sequential process involving the creation of a problem statement, the systematic collection of data, the analysis and then the explanation of results. Like life itself, the method is a continuous process. Scientific constructs are derived from and informed by everyday life.

During the course of this study, several problems have emerged because of the nature of the methodology. One is the access to the data set. People tend to weary of revealing personal thoughts and ideas to a total stranger. Consequently, the

snowball method of obtaining access to individuals had to be employed. One could argue that this is not a representative way for gathering data. One way to overcome this is to employ the help of several social gatekeepers. In that way, the sample is socially broader than if only one gatekeeper was used.

Another problem which can emerge because of the nature of the methodology is during data analysis. There is always the possibility of the researcher unconsciously suppressing or underplaying data which may not precisely fit. This requires the researcher to be constantly vigilant by checking and re-checking the data. The emphasis of this methodology is on being faithful to the subject being studied. The researcher is responsible for providing readers with information about the social setting from which her biases and effects might emerge.

The value of using qualitative methods for examining lay perspectives comes through unquestionably. This methodology allows the researcher to investigate face responses by probing the informants for deeper explanations. This allowed for such things as how the term 'health' is elaborated by changing it to 'healthy'. Probing also allowed for such issues as the perceived sexual discrimination and ageism among some family doctors to be revealed.

The focus of this methodology is to re-create the wholeness and uniqueness of individual's experiences (Donovan, 1986). The perceptions and attitudes of the informants are emphasized while at the same time the effect of the researcher upon the informants has been taken into consideration. It is felt that the interpretive paradigm lends itself very well to this study of lay perceptions of health and health

care and that any other method would not be able to achieve the same degree of wholeness or understanding.

10.3 Theoretical Implications

From the beginning of this research project, we have stated that the theory must be used to analyze and validate the research findings. In this case the theory of symbolic interactionism, a sub-group of the interpretive school, has been used to provide this guide. The theory rests upon three basic premises. The first premise that people will act towards things based upon the meaning that these things have for them provides insight to one particular research conclusion. People do not perceive many lifestyle behaviours to be the root or the cause of ill-health. In their minds they have determined that there are some causes of illness which are beyond their own control. Certain behaviours, such as diet, exercise, or drinking alcohol are not viewed as determinants of their health. This allows people to continue engaging in these lifestyle practices. The meanings that the lay person has attached to certain behaviours is considerably different from the meaning that proponents of the biomedical perspective have.

The second premise of meaning being attached to things as a result of interacting with friends and family is illustrated in the labelling of a condition as an illness. We all go through a process of discussing these feelings with our friends and family. Someone may tell us that we are ill and that these feelings are symptoms of an illness. In that case we go to the doctor to have these symptoms confirmed or

diagnosed or we may continue to consult the lay referral system in order to find a solution other than seeking health care. These meanings are social products formed in and through the defining activities of people as they interact.

The final premise of symbolic interactionist theory is that meanings are constantly going through an interpretive process to suit individual situations or things. Interpretation becomes a formative process in which meanings are used and negotiated in order to form and guide action. One example of this negotiation process is the informant who has chronic diabetes but is still able to perceive himself as being healthy. This individual has had to re-negotiate the meaning of his illness in order to carry on with his every day life and to not have to adopt the sick role.

These are just a few examples of where symbolic interactionist theory has guided the interpretation of the perceptions of the informants. Symbolic interactionist theory not only guides the research but also aids in the interpretation of the research findings. It is hoped that this thesis has clearly explained how the material is derived from and set against theoretical concepts in order to achieve the research goal of understanding and explanation.

10.4 Suggestions for Policy

At the present time, with national health care costs rising to consume over 60 billion dollars annually, public health policy has become a political hot potato. As costs grow, the benefits of good public health are lost in the confusion. The public health movement is viewed as a means of reducing the demand and need for

health care by preventing illness. This has policy makers scrambling to create initiatives which will have an impact on the health of the people.

Health policy has largely focused upon individual behaviour as one of the causes of ill health. This focus on the individual allows for policy to deny the social constraints which influence people's behaviour (Naidoo, 1986). Many argue that constraints such as income, housing, education, occupational setting, are beyond individual control and actually fall in the political realm (Donovan, 1986; Naidoo, 1986; Eyles and Donovan, 1990). The information from this study indicates that this political focus has been adopted by the public causing them to feel largely responsible for their own health.

The focus upon individualism does not give policy licence to continue to attribute poor health status upon the individual alone. Health policy should consider this information a reflection of the power it has on the public perceptions. While perceptions are formed through a complex process of information gathering, sorting, and evolution, the source of much of health information is through public health initiatives.

The lay perspective and the biomedical perspective regarding the causes of illness begin from two different points. Certainly, no one can deny what the epidemiologic data show that the causes of illness are primarily centred around lifestyle behaviours and that this needs considerable regard. However, frameworks such as the Determinants of Health Framework created by the Premier's Council on Health Strategy (1992), need to broaden the concept of determinants of health to

incorporate lay ideas about the causes of illness. In this way, the biomedical and the lay perspective are united in the effort to create healthy public policy.

This research suggest that health policy needs to become more sensitive to lay experiences. This is strongly reflected in the focus of health promotion initiatives upon lifestyles behaviours. This study indicates that public health policy has been relatively successful in educating the public about lifestyle behaviours primarily the dangers of smoking. But to believe that educating people is sufficient to convince individuals to change is unrealistic. Knowledge of this type may or may not have any effect upon people's health. Action depends upon how well the information fits the individuals own perceptions about what causes illness. As we have seen, there appears to be a discrepancy and thus health promotion remains a problematic issue.

This study also supports the view that lay concepts of health may have significance in the way that health is measured. Usually epidemiologic indexes of health status include measures of morbidity and mortality which are based upon the idea that health is simply the absence of illness. However, we have found that health is a multidimensional concept which can be negotiated to allow people who are chronically disabled or ill to view themselves as being healthy. Because of this, Williams (1983) suggests that functional measures based upon an individual's level of activity rather than upon pathology may be a useful and indicator of health status.

People also want to know more about the health care system. Our health care system is perceived to be one of the best ways for delivering health in the world. People are willing to make adjustments but they are not willing to accept a lower

standard of care. The public is willing to accept a certain amount of responsibility, but they do not see themselves as totally accountable for the crisis. The informants is this study suggested that a user's fee may deter patient abuse of the system. They suggested that a small user's-fee of two to five dollars may reduce heedless use. At the same time, however, the public want more accountability from hospitals and from the Ministry of Health. Policy should consider allowing the public information about how much things costs. Informants in this study feel that keeping track of costs may also induce people to think about using the health care system.

The informants suggest that making the system more user friendly may reduce costly mistakes. Programs on television or the radio about calling the doctor before going to emergency, and about available health information allows people to be more prepared before they seek medical attention. At the same time, while the informants know that behaviour can affect their health, they need practical advice on how to use this information. They suggest more and broader use of public health nursing to provide this practical information.

10.5 Conclusions

This research indicates that much more research of this type and topic is needed. This thesis represents one of a small number of academic studies done on lay perceptions of health and health care in Canada. In order for this research to be most valuable to the policy maker, a much larger sample is needed. There are some specific questions that arise from this research which need attention. One is

the concept of determinants of health. With so much money and energy resting upon health promotion campaigns which focus upon lifestyle behaviours, it would be profitable to further examine the lay concept of the causes of illness to determine how or if policy can have any effect.

More research is needed on lay referral systems and how these work. In increasing our understanding of lay referral systems, we will gain better knowledge of why and when people use the health care system and be able to broaden existing models of health seeking behaviour Essentially, research of this type brings forth the perspective of the consumers of the system Based upon her study of Canadian women's perceptions of their health concerns, Walters (1992) found that people often identify different health priorities than do health experts or other key informants. From research of this type could develop a more economical and satisfactory system for the delivery of health care.

This research supports the view that lay perceptions are under-represented in the planning and the delivery of health care. Increasingly becoming valued, lay perceptions provide pictures of the social reality behind the Ontario health care system. Lay perceptions and experiences of health and health care are one step on the journey towards health for all.

APPENDIX 1

CHECKLIST OF TOPICS

THEME: DEFINING HEALTH, ILLNESS, AND DISEASE

1. Do you see yourself as a healthy person?
2. Can someone be perfectly healthy? What does it mean to be perfectly healthy?
3. How would you define health?
4. Is your health important to you?
5. How would you define illness?
6. What is a disease?
7. Are illnesses different from diseases?
8. What causes illness? What causes disease?
9. Should we expect to be ill at some point in our lives?

THEME: DETERMINANTS OF HEALTH

1. What do you think has an affect on your health?
2. What is your occupation? Do you feel that your work has any effect on your health?
3. Have you ever experienced any illness which you felt were linked to your work?
4. Does your health affect your work?
5. Do you think that living around here affects your health? How?
6. Do you presently smoke or have you ever smoked? Do you think that smoking has an affect on people's health?
7. Is your diet important to you? Do you think that your diet affect your health?
8. Is exercise important to you? So you feel it has an affect on your health?
9. Do you drink alcohol? Do you feel that alcohol has an affect on your health?

THEME: ILLNESS BEHAVIOUR

1. What is the first sign that you are not well?
2. What do you usually do?
3. At what point will you call or see the doctor?
4. Do you always call the doctor when you feel unwell?
5. Do you seek advice from other sources?

THEME: PHYSICIANS AND HEALTH CARE

1. Do you have a family doctor?
2. Does your doctor take good care of you?
3. What do you like/dislike about your family doctor?
4. Do you always follow the doctors advice?
5. Have you ever been in the hospital as an outpatient or as an inpatient?
6. How was the care? Have you ever experienced problems in getting good health care either for yourself or for family members?
7. What did you like/dislike about the care you or your family member received?
8. Do you feel that everyone gets good health care in our system?

THEME: HEALTH CARE COSTS

1. Do you like our health care system? Why?
2. Do you think we spend too much on health care?
3. Do you think that our tax dollars are spent poorly?
4. Do you think our health care system should change? How?
5. Do you think we should spend health care dollars differently?

APPENDIX 2

DESCRIPTION OF INFORMANTS

NAME	SEX	AGE	OCCUPATION
Joyce	female	50 yrs.	office worker
Robert	male	66 yrs.	retired minister
Catherine	female	80 yrs.	retired store clerk
Aylmer	male	65 yrs.	minister
Patrick	male	26 yrs.	student
Glen	male	25 yrs.	unemployed
Russ	male	late 30's	salesman
Sue	female	early 40's	secretary
Terry	male	33 yrs.	salesman
Steve	male	34 yrs.	insurance adjuster
Angus	male	55 yrs.	engineer
Mary	female	early 50's	housewife
Lynn	female	30 yrs.	factory worker
Tony	male	36 yrs.	fireman
Max	male	early 50's	teacher
Daniel	male	mid 50's	teacher
John	male	31 yrs.	policeman
Elizabeth	female	early 60's	volunteer
Sandra	female	54 yrs.	volunteer
Reta	female	late 50's	volunteer
Janet	female	early 40's	not working/ill
Patti	female	31 yrs.	nurse
Julie	female	late 40's	student
Ken	male	26 yrs.	engineer

Total number of informants: 24

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