

**AN OJIBWAY CULTURAL PERSPECTIVE ON THE ILLNESS CANCER AND**

**RELATED PAIN**

**BY**

**DIANA P. BARKWELL**

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for the Degree of**

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**Department of Graduate Studies  
University of Manitoba  
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**Diana P. Barkwell**

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University  
of Manitoba in partial fulfillment of the requirements of the degree  
of  
Doctor of Philosophy**

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## ABSTRACT

Due to a shift in the pattern of health and disease in First Nations populations from infectious to more chronic diseases, there is a growing pattern in the use of large urban institutions. First Nations people with culturally different backgrounds from mainstream society, are routinely treated in contemporary health institutions by health care providers whose understanding and experience of illness may have little in common with their own. Hence, differences in medical and cultural orientations on illness have the potential to compromise the provision of effective care. The aims of this research were to: 1) describe and explain how cultural beliefs framed how Ojibway people, living on a reserve community, understood the illness experience of cancer and related pain and, 2) to describe differences and/or similarities between Ojibway respondents and health professionals' explanations and perceptions of cancer and related pain. This qualitative study used a grounded theory approach to collect and analyze data, using open-ended focused interviews. Eighteen Ojibway persons and thirteen health professionals participated. The data revealed that these Ojibway participants used culturally patterned knowledge to construct their understanding and perceptions about the biomedical disease called cancer and related pain and, that this differed remarkably from that of health professionals. The core concept of blocking, emerged as the central explanatory scheme for understanding how cancer and related pain were interwoven with and epitomized that which was most painful in life. The properties and dimensions of blocking were revealed as affording protection from exposure to threat and alienation from cultural and spiritual values. Blocking was triggered within well articulated contexts. Examination of these contexts provided valuable insights into issues of cultural safety in biomedical institutions.



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## CHAPTER 1

### Introduction

#### Statement of The Problem

##### Overview

##### Nomenclature

For purposes of clarity on the subject of cultural orientation of the participants in this study, it is important to first explain some points on nomenclature with reference to the indigenous populations in Canada. This research will use the nomenclature as described by Young (1994a). This epidemiologist offers as a guide that:

In Canada, the term Native continues to be used by some Native organizations and their leaders, although Aboriginal seems to be preferred, as reflected in the official communications from the late 1980's. In constitutional negotiations over self government, three Aboriginal groups are recognized in Canada: Indians, Inuit and Metis. The word Indian, while still being used by many Indians themselves, is being replaced by First Nations (p. 6).

For purposes of identification in this research, the researcher has used the tribal name Ojibway rather than Anishinaabe in keeping with Young's (1994a) explanation that the tribal names have had long usage in anthropology and popular literature. As well, in a paper by Garro (1990b) on the interpretation of illness by Ojibway people, she noted that "the people who call themselves the Anishinaabeg are more commonly known by the names Ojibway (or Ojibwa). . . ." (p. 1). She explained that "the word Anishinaabee, and its plural Anishinaabeg, are the terms people in the community use to refer to themselves

and others who speak the same language . . . . Ojibway is used in representing the community to outsiders” (p. 447). Therefore, except in situations where excerpts of talk by a participant reflected the use of the word Anishinaabe to describe themselves, the word Ojibway was used in this study to refer to the community of people being examined. When referring to the entire group as a people, the word First Nations was used except in cases where information was taken from a document using a different nomenclature. Aboriginal will refer, as noted in the above quotation by Young (1994a), to Indians, Inuit and Metis.

First Nations people represent slightly less than 1.5 percent of Canada's population as a whole. However, in some provinces such as Manitoba and Saskatchewan, a relatively large number of First Nations people are found in the general population (Young, 1984); the most recent estimate is reported to be 11.8 percent of Manitoba's population (Province of Manitoba, 1991). The statistics on cancer rates among Aboriginal people are relatively lower than they are for the general Canadian population (Vital Statistics Canada, 1988; Young, 1994a, 1994b). However, these reports identify a clear indication that the rates of cancer among First Nations people have increased in the last five years. Further, a relatively recent twenty-year study by Gillis, Irvine, Tan, Chiu, Liu & Robson (1991) demonstrated that for female Indians in Saskatchewan, the incidence of cancer risk has equalled and may have slightly surpassed that of the general female population. As well, they found that there is good evidence to suggest that the incidence of lung cancer has significantly increased in the Indian male population.

This change appears to be in keeping with the trend identified by Young (1989,

1994b) which indicated a shift in the pattern of health and disease among First Nations people. Unlike infectious diseases of the past (which unfortunately persist), he noted that there has been an increase in the incidence of chronic diseases such as diabetes, hypertension, cardiovascular diseases and cancer. Accompanying this trend is a growing pattern of use of urban hospitals for health care by First Nations people, and the necessity for First Nations people to leave their communities to seek specialized diagnostic and treatment interventions in institutions in large urban centres (Kaufert & O'Neil, 1991; Young, 1989).

Herein lies the significance of the problem. It is in these health care institutions in urban centres which are dominated by the biomedical ethic that First Nations people with culturally different backgrounds from mainstream society, are routinely treated by health care providers whose understanding and experience of illness may have little in common with their own (Agnail, 1989; Kaufert & O'Neil, 1991). Here, "medicocentrism" [which means a world view which filters experience through medical filters in which the medical view is the only reality (Pfifferling, 1981, p. 151)] predominates as the only legitimate reality through which illness can be evaluated and understood. In this biomedical institutional setting First Nations people are isolated from their cultural context, and forced to interact with a dominant health care structure for interpreting illness which might not acknowledge their own.

Problems referred to as 'world view conflict' (Pfifferling, 1981) inevitably arise. Such conflict serves only to create greater distress for already sick individuals. In an ethnographic study by Morse and colleagues (Morse, Young & Swartz, 1991), they

charge that nurses and other health professionals pay only "lip service" to holistic care. They continually devalue the First Nation person's cultural perspective on health and illness both in their professional-patient interaction and in their provision of care.

Those who embrace the biomedical model, view pathology as central to illness and search to "fit patients' experience into objectified symptoms" (Pfifferling, 1981, p. 197). This creates a situation which demands a convergence of models and a legitimizing of models other than the biomedical model if therapeutic outcomes are to be realized in the encounter between health care provider and health care recipient. It is not surprising to note that Morse, Young and Swartz (1991) concluded that there was dissatisfaction with care approaches in health care settings by First Nations people who used these services. These authors asserted that this dissatisfaction was due to a lack of "a cultural perspective which has meaning for Native people" (p. 1365).

It therefore becomes paramount that health professionals recognize the extent to which their healing practices can be compromised when culturally framed structures for interpreting and understanding illness experiences are ignored and discounted. One constructive means of beginning to address this problem lies in exploring the extent to which First Nations people define and perceive illness experiences, given their particular cultural perspective. Another, is attempting to define and describe the particular contexts which create dissatisfaction with the existing health institutions where First Nations people seek medical and technologically advanced services for complicated medical conditions. Cancer is just such a medical condition and therefore best lends itself to the exploration of these issues.

Further, cancer is a medically defined disease which has been shown to be associated with a complex network of culturally shaped meaning which affects both how people respond and cope with this illness experience. In Italy, the discourse on cancer centres around death. A diagnosis of cancer is tantamount to a death sentence and for this reason is not disclosed to the patient (Gordon, 1990). Interestingly, despite recent social and political changes in Italy with respect to human rights and the patients' need to be informed, the beliefs around disclosure of information regarding a diagnosis of cancer by both physicians and relatives remain tantamount to a death sentence (Gordon, 1994; Gordon & Paci, 1997). It has also been noted that culturally based association of cancer with death in Japan underlies a type of conspiracy of silence with respect to disclosure of a diagnosis of cancer (Long & Long, 1982). More recently, in a review of disclosure practices around the world with respect to a diagnosis of cancer, it was observed that many non-Western cultures perceived the disclosure of a diagnosis of cancer to be a potentially harmful act and embraced the conspiracy of silence doctrine as a more ethical stance to take on this issue (Mitchell, 1998). Suffering, pain and mutilation was noted to constitute the cultural meanings associated with cancer in North American culture (Levin, Cleeland & Dar, 1985), although a shift to the heroic metaphor (Sargent, 1984) and discourse on hope now prevails in modern oncology (Saillant, 1990). A cultural model is suggested to underlie how people respond to cancer in these studies.

Further, pain continues to be the major presenting problem for patients with cancer despite major advances in pain control strategies (Foley, 1999). It has been suggested that psychological distress, spiritual, cultural and other factors are implicated in the illness

experience cancer and that the impact of these variables need to be addressed in order to arrive at a comprehensive strategy for the effective management of cancer pain (Cleeland et al., 1996; Foley, 1999). Therefore there is a need for qualitative studies that can explain the impact of such variables as culture on cancer and related pain. For this reason, cancer and its related pain represent an appropriate illness experience from which to examine how culture influences or shapes perceptions and experiences around illness.

### **Purpose of the Study and Research Questions**

The investigation in question proposed to address the issue of "culture," and how it might influence a particular First Nations community's perception and understanding of the illness experience of cancer-related pain. It was also important to determine whether there were differences between biomedical and First Nation people's cultural model of this illness experience and to explain how this could have the potential to impact care delivery. To accomplish this, it was necessary to define what is meant by "culture" in this investigation. Since there is no single universally accepted definition of culture (Helman, 1990; Hughes, Seidman & Williams, 1993), the definitions used to extrapolate the research questions are drawn from the following three sources:

- 1) "Culture refers to an organized system of knowledge and beliefs whereby a people structure their experience and perceptions, formulates acts and choose between alternatives" (Goodenough, 1961, p. 521).
- 2) "Culture refers to a system of shared ideas" (Keesing & Keesing, 1971, p. 21).
- 3) "Culture refers to a system of symbolic meanings that shape both social reality and personal experience" (Kleinman, 1978, p. 85).

Given these definitions, the objectives of this research effort were to generate information about ". . . an organized system of knowledge and beliefs" (Goodenough, 1961, p. 521), or information learned by participants in a given culture, which acts in such a way that it frames people's perceptions and experiences. Concomitantly, it was necessary that the investigation provide information on whether this framework of organized knowledge, beliefs, experiences and perceptions were "shared" (Keesing & Keesing, 1971, p. 21) and had "symbolic meaning" (Kleinman, 1978, p. 85), to the extent that it shaped people's social realities as well as their personal experience.

In order to accomplish this task with respect to cultural knowledge about a particular illness experience (cancer and its pain), it was important to also recognize that, according to Roberts (1964, p. 439), "In any culture, information is stored in the minds of its members." Since the focus of this investigation was on those in a particular culture who would have information about the bio-medically defined disease cancer and cancer pain, it was necessary to also recognize that "one of the characteristics of human society is that there is a major division of labour in who knows what" (D'Andrade, 1981, p. 180). Therefore, one could logically deduce that in a given culture, those who would most likely hold information about illness, would necessarily be those who had experienced the illness either personally or by having had close interaction with someone throughout the illness course; those who assumed the role of a healer and thereby attended to matters pertaining to health and illness and health professionals who assumed the role of providers of medical health care. It was information stored in the minds of these people (Roberts, 1964) that could provide answers to the research questions posed in this investigation.



The aims of this research were therefore to: 1) describe and explain how cultural beliefs framed how Ojibway people, living on a reserve community, understood the illness experience of cancer and related pain and, 2) to describe differences and/or similarities between Ojibway respondents and health professionals' explanations and perceptions of cancer and related pain.

### Basis for Methodological Approach

Theorists have posited that illness experiences are given meaning within the cultural context in which they are embedded and can therefore only be understood in light of this (Kleinman, 1988; Lewis, 1981). Studies have shown that cultural orientation is reflected in how pain is understood, responded to and expressed (Zborowski, 1952, 1969; Illich, 1981; Zola, 1966) and this has an effect on the appropriateness of health care responses to pain (Pilowsky, Manzap, & Bond, 1969). Further, Illich (1981) suggested that "for an experience to be pain in the full sense, it must fit into a culture" (p. 429). Therefore, failure to explore the cultural milieu from which responses to pain evolve is to neglect that which is salient to its definition. As Stein (1990) so aptly stated:

Currently, within the American culture, a social process has occurred whereby a wide gamut of problems is redefined and managed as more narrowly biomedical issues. As a result of this transmuting, matters rich in personal meaning and imbedded in social significance are denuded of their larger context (p. 8).

It is this "denuding" of the "larger context" to which Stein (1990) referred that leads our scientific inquiry further and further away from discovering a full understanding of the phenomenon of pain as a human experience. Pain has psychological, social and

cultural significance to humans and can therefore only be understood in light of this significance (Zborowski, 1969). It is this failure to address the personal meaning of the pain experience within a cultural context that seriously limits our attempts at effective pain management.

Given the research questions proposed by this investigation, it was necessary to use a methodological basis which permitted “understanding and enabled others to make sense of reality” (Morse & Field, 1995, p.16). The answers to these questions can best be captured by qualitative accounts describing the realities of a lived experience. There are well-established measurement tools for pain with proven reliability and validity such as, the McGill Pain Questionnaire (Melzack, 1975) and a host of visual analogue scales or verbal descriptive scales (Chapman, Casey, Foley, Gracely & Reading, 1985; Cleeland & Ryan, 1994) which have been used specifically in the measurement of cancer pain (Barkwell, 1991; Cleeland et al., 1996; Donovan & Dilion, 1987; Dugeon, Raubertas & Rosenthal, 1992; Foley, 1979). However, they are inadequately suited to address the research endeavour aimed at capturing the meaning of an experience and the context in which that experience occurs, from the view point of the participants having the experience.

The major issues which present problems in the measurement of pain stems from attempting to quantify the essential components of this very complex, highly perceptual experience of pain in a simplistic compartmentalized fashion. Visual analogue scales (VAS), verbal rating scales and the like, although proving ease of application in the clinical setting, require a full range of emotional responses to be collapsed into an artificially small

and linear continuum and assumes that the line marked represents the full magnitude of the patient's pain response. These measures are recommended as most useful when used to target only a single dimension of pain at a given time (McGuire, 1992), and even then, this does not represent a satisfactory solution to the problem.

In order to address the aims of the current study it was necessary to choose a methodology that had explanatory power and could yield qualitative accounts of rich description. Lincoln and Guba's (1985) explanation of how they used the term grounded theory seemed a good fit for this research. They offered that "the information that is gathered in the field situation is used by the holist to build a model which serves both to describe and explain the system" (p. 205). However, on examination of other qualitative approaches, ethnography also appeared to offer a good methodological fit for this research. According to Morse & Field (1995) "ethnography, always informed by the concept of culture, is a generalized approach to developing concepts and understanding human behaviour from the insider's point of view" (p. 23). Given that the current study was concerned with cultural issues and, that it required entry into a First Nation's reserve community to ensure this 'insiders' view, the methodological approach initially planned for this research was that of ethnography.

However, it was not long after the analysis of the initial interview, that the researcher realized that something puzzling was emerging which was beyond description of cultural beliefs and needed to be explored for properties and dimensions at a higher conceptual level. A grounded theory approach afforded a well articulated systematic approach for data collection and analysis which could yield a theoretical scheme for

illumination of an area of study in which little was known (Strauss & Corbin, 1998).

Further, Strauss and Corbin (1998) noted that their intent in using the techniques involved in grounded theory was to build theory but that this might not be or need not be the end product of every research project. They explained that “some will use our techniques to generate theory, others for the purpose of doing very useful description or conceptual ordering (classifying and elaborating)” (p. 9). The ethnographic approach was abandoned for the more appropriate fit of grounded theory to this research. This was considered the appropriate action to be taken at this point given the presenting circumstances encountered in the field. For, as Wax (1971) asserted:

Strict and rigid adherence to any method, technique or doctrine position may for the fieldworker become like confinement in a cage. . . . If he is lucky or very cautious, a fieldworker may formulate a research problem so that he will find all the answers he needs within his cage. But if he finds himself in a field situation where he is limited by a particular method, theory or technique, he will do well to slip through the bars and try to find out what is really going on (p. 10).

Therefore, grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1991, 1998) was used in this research investigation as a method of data collection and analysis. Grounded theory draws its perspective from the central tenets of symbolic interactionism, which is a perspective that focuses on the way people define their reality and the meanings constructed of that reality in its natural setting (Blumer, 1969; Morse & Field, 1995). This methodology suited the aims of this research project.

In this chapter, various methodologies were examined which were used to guide

**studies which examined the pain of cancer. The methodology planned for the current research was presented stating why it best suited this research. The following chapter deals with a review of the literature.**

## CHAPTER 2

### Review of The Literature

#### Introduction

There are contradictory positions espoused in regard to conducting a literature review when using a qualitative approach. Glaser (1978) offered the opinion that the literature should not be reviewed before conducting field work. The reason given for this was that there was the danger that this might bias and distract from the discovery process. The disadvantage of this is that time could be wasted rediscovering already established findings (Morse & Field, 1995). Others offer that all information on the topic should be reviewed and then bracketed off before initiating fieldwork. Again this posed a problem. The researcher might be biased to new discovery because of the unconscious influence of having read the already developed theories and lose control of bracketing, leading the investigator to support only those findings that were supported in the literature. As well, the literature read could also have been initially generated from a biased perspective or have been based on false assumptions which could then be misleading to any subsequent investigation based upon it. The recommended approach is that the literature should be reviewed, but that it should be evaluated for inconsistencies and used only selectively (Morse & Field, 1995).

In this investigation a literature review was carried out. The investigator chose to adopt the suggestion that “naturalists prefer to think of themselves as open-minded rather than empty-headed” (Lincoln & Guba, 1985, p. 204) and as recommended by Morse and Field (1995), used the literature selectively. Therefore the literature review examined the

literature on culture, and the various methodologies used in studies on pain and cancer pain.

### Pain: a Complex Conceptual Phenomenon

The conceptualization of pain has progressed from that of a simplistic, unidimensional, physiological sensation to that of a complex multidimensional phenomenon. In Morris' (1991) historical account of how pain is conceptualized in Western culture and literature, he proposed that it has been the medical profession that has dominated our understanding of pain since the eighteenth century. As a direct consequence of this, pain "has come to be defined . . . as a sensation associated with real or potential tissue damage involving chemical disturbances along neurological pathways" (Morris, 1991, p. 282-283). This biomedical conceptualization of pain has had a great impact in shaping the way both physicians and nurses assess and manage pain.

The "Specificity" and the "Pattern" theories of pain were early nineteenth century theoretical underpinnings which promoted this simplistic conceptualization of pain well into the early twentieth century (Howard-Ruben, McGuire & Groenwald, 1987). The 'specificity theory' proposed that a mosaic of specific sensory receptors for pain were located in the body tissue and that these had a specific pathway to a pain centre in the brain. Sets of free nerve-endings were believed to be in the peripheral nerves known as A Delta and C fibres. This theory suggested that pain was determined by impulses in a straight-through-transmission system from skin to pain centre. It advocated the view that the perception of pain was simply a sensation (Hardy, Wolff & Godell, 1952; Melzack, 1973). The 'Pattern theory' proposed by Goldscheider and described in the writings of

Melzack (1973), was a reaction to the specificity theory. This theorist offered that pain perception was based on stimulus intensity and central summation of sensory inputs at the dorsal horn cells. It was believed that excessive stimulation could result in the total sensory output exceeding a critical level and that this summation of impulses was thought to be interpreted centrally as pain. Outputs that remained below a critical level were thought to result in other non-noxious sensations such as warmth, or heat (Melzack & Wall, 1965).

These direct-transmission systems of pain perception advocated in these models indicated that pain could be eliminated or modified by removal of the pain stimulus or by blocking pain pathways. Hence, interventions such as surgical severing of neural pathways to prevent impulses from reaching the pain centre in the brain or removal of the thalamus (where it was believed that the pain centre was located), were expected to result in effective pain control. However, clinical findings did not support this. White and Sweet (1969), in a comprehensive review of surgical interventions involving procedures aimed at blocking pain pathways, found that it was not possible to predict pain relief as a necessary outcome of these interventions. Further, they noted that in many cases where relief was gained, it was proved to be only temporary. Melzack and Loeser (1978) also later observed cases of patients who had sustained total spinal resections at thoracic or lumbar levels who continued to suffer severe pain.

In the case of analgesic use for pain relief, Swerdlow (1973) advised that it was difficult to generalize about the effectiveness of analgesic drugs as they appeared to work for some patients and not for others. Further, Melzack, Ofiesch and Mount (1976) noted



that despite the use of powerful narcotic preparations such as the Brompton Mixture, it was not possible to control pain in as many as 10% of terminal patients. There was therefore good reason to believe that purely somatic treatment approaches which were an outgrowth of these unidimensional conceptualizations of pain had great limitations.

Beecher's (1956) work which resulted from clinical observations suggested that there were broader dimensions to pain. He proposed that in addition to a sensory dimension, there was a reactional/emotional component to pain. In his classic study of soldiers wounded in battle and their response to pain, Beecher (1956) argued that the setting and the significance of the wound greatly influenced the pain experience. In field observation of 215 men seriously wounded in battle, he observed that only 25% of them requested analgesic narcotics for relief of pain. However, in civilian life where patients in hospital had similar surgical wounds, more than 80% of these individuals requested narcotic analgesics for pain relief. He explained that despite the fact that the soldiers in battle were wounded they remained safe and alive and were grateful for this. In civilian life, however, surgery meant disaster and was at best an unfavourable event (Beecher, 1956). He concluded that the difference in reaction to the wounds by these men was attributed to the significance of the wound to the individual involved, rather than merely due to the size or extent of tissue damage.

Sterenbach (1968) was also influential in his contribution to the conceptualisation of pain as a more complex phenomenon. He emphasized the importance of conceptualizing pain as "a personal and private sensation of hurt" (Sterenbach, 1968, p. 12). He stated that pain signified danger and was a pattern response aimed at protecting

the organism from harm. As well, comprehensive reviews of the literature on pain (Liebeskind & Paul, 1977; Weisenberg, 1977) have all presented arguments for the conceptualisation of pain within a framework that considers the subjective or individual experience of pain and acknowledged the influence of variables such as past experience, emotional, cultural and biochemical factors.

The gate control theory proposed by Melzack and Wall (1965) emerged as a landmark breakthrough in the conceptualization of pain. It represented the culmination of the best of both the 'specificity' and 'pattern' theory and presented a new paradigm for the conceptualization of pain. Melzack and Wall (1965) proposed that pain was a complex phenomenon with sensory-discriminative, motivational affective, and cognitive-evaluative components. Pain was viewed as multidimensional and the pain experience diverse in terms of quality. It was purported by these theorists to be a category of complex experiences and not one specific sensation with variations along a unidimensional scale. Macrae, Davies and Crombie (1992) aptly noted that "many advances in the management of pain over the past three decades are consequent upon the gate control theory. . . . Further, the explanation of possible mechanisms whereby higher centres affect the perception of pain has made psychological approaches respectable" (p. 289).

However, the unidimensional models for the conceptualization of pain which emerged in the early nineteenth century, persisted into the 1960's even with the arrival of the multidimensional conceptualization of pain offered by the gate control model. Furthermore, this unidimensional conceptualization of pain is clearly evident in the way in which approaches to pain assessment and management are currently implemented in

biomedicine. Nurses and physicians continue to base their assessment and treatment of pain on outdated earlier theoretical orientations, such as the specificity theory (Walker, Tan & George, 1995). According to these authors, nurses and doctors continue to evaluate and identify the presence of pain as dependent on tissue damage. They fail to recognize the integration of the sensory dimensions of pain with the emotional, cultural, spiritual and behavioural aspects of pain. Macrae, Davis and Crombie (1992) concur with this evaluation of the biomedical conceptualization of pain. These authors, examined the impact of the gate control theory on changes in management of pain by physicians. They found that although the experts surveyed in the field of pain were knowledgeable of the changes now possible in terms of improved drug therapies and although they recognized a decline in the destructive neurosurgical techniques previously used, physicians were still treating pain inadequately. Inappropriate use of these neurosurgical procedures and hesitance in providing adequate treatment with opioids persisted. At the same time, TENS and other complementary techniques such as these were being under-utilized. These authors concluded that the provision of new knowledge to medical professionals has not proven sufficient to ensure translation into improved care for patients in pain. Further, they pointed out that there were dangers inherent in the adherence of physicians to a medical model of pain that embraced pathogenesis as its only source. They explained that this has erroneously led medical health professionals to continue to endorse useless theories and to reject efficacious therapies that did not concur with their prevailing ideas. They concluded that "the history of medicine is littered with medical models that, in retrospect, stifled progress in treatment" (Macrea et al. p. 290).

Furthermore, this conceptual oversimplification of pain by medicine also precipitated an important change in the discourse between patient and physician with respect to pain. Morris (1998) cites Michael Foucault's writings on the 'clinical gaze' as marking that critical change. He noted:

This gaze—a way of seeing indispensable to modern clinical medicine—Implies not only a new focus on empirical fact but also, in consequence, a total reorganization of medical discourse. . . . The clinical gaze redefines pain as something visible only to physicians as they peer, with the objectifying light of science, inside the human body (Morris, 1998, p.192).

He continued to explain that “these historical forces that in the nineteenth century began to transform pain into a visible object encouraged us to overlook and undervalue the life of pain beyond the clinic” (Morris, 1998, p.192). With the burgeoning technologies available today for accurate and precise inspection of the inner body for the detection and confirmation of pathology, there is little need to consider the imprecise and seemingly untidy patient's perspective in the medical encounter.

Morris (1991) writes that medicine “because of its dominant position in our culture, tends automatically to suppress or to overpower all other voices that offer us a different understanding of pain, including voices of dissent within medicine” (p. 2).

Encandela (1993) further points out the importance of listening to the patient's story about pain stating that “. . . when they have been given an opportunity to be heard, (patients) tell the story about pain that differs significantly from the traditional medical account and that points out the limits of medical treatment” (p. 786).

It is clear that the theoretical conceptualization of pain throughout the years has had a powerful impact on the understanding of pain. Conceptual oversimplification has resulted in limitations in how health professionals assess and treat pain and in the quality of the clinical encounter between those in pain and their care givers. Current research continues to demonstrate that despite the advances in technology and the use worldwide of powerful opioids and other drugs in pain control, 50%-80% of patients dying in hospital experience moderate to severe pain in their final weeks (Bruera & Lawlor; 1997; Foley, 1999; SUPPORT principal investigators, 1995; WHO Expert Committee, 1990). Obviously, according to Morris (1998, p. 195 ) “other forces are at work, cultural forces, to give our undertreated pain its distinctive local history.”

#### Cultural Variation in the Response and Expression of Pain

The complex issue of pain and its expression began to be examined from an ethno-cultural perspective by anthropologists in the 1950's. This marked the introduction of a social/anthropological perspective into biomedical research practice. Research on pain and culture first looked at qualitative accounts comparing different cultural and ethnic groups. The much cited landmark study by Zborowski (1952) is said to have offered the first explicit scientific explanation for cultural differences noted in the human pain response (Wolff, 1985). Zborowski (1952) demonstrated that indeed there was ethno-cultural variation in pain behaviour and the expression of pain when he compared “Old Americans,” individuals of Anglo-Saxon ancestry, with Italian Americans and American Jews. In this investigation all the subjects were male and patients in a Veterans Administration hospital in the Bronx, New York. Marked differences in attitude and

response to pain were noted between the various groups examined. "Old Americans" in this study were found to be more stoic and tended to withdraw from social contacts when in pain. The other two groups were found to complain more and to vocalize their pain more, although they also differed from each other in terms of their underlying attitudes about the pain. The Italian patients were distressed by the immediate pain experience and loudly demanded help which, when given medication, seemed to alleviate their concern. The Jewish patients however, were most concerned about what the pain meant with respect to a pathology and future threat to health, their personal well-being, and that of their families. Zborowski (1952) concluded that Italians were more 'present-oriented' and the Jewish participants were more 'future-oriented.'

Zola (1966) conducted a study which examined reactions to pain and the behavioural response of people of different ethnic backgrounds. The 196 males and females interviewed were of Italian Catholic, Anglo-Saxon Protestant and Irish origin. With the use of some objective measures along with an open-ended interview format, this investigator found that the Irish patients were noted to deny the presence of pain and to be concerned primarily with symptoms which related to a specific location and specific physical impairment. The Italian patients reported no specific location to symptoms but thought pain was an important aspect of their presenting problem. They also had more diffuse complaints and generally reported more symptoms to the doctor. They were also more demonstrative and vocal in their reporting of symptoms. Anglo-Saxon patients' responses in the majority of cases were more similar to the Irish relative to responses and perception of symptoms.

In both of these early studies comparisons of pain response and behaviours were made across different ethnic groups in order to determine whether culture influenced pain behaviour, attitudes toward pain (Zborwoski, 1952) and the expression and reaction to pain (Zola, 1966). They both demonstrated that pain was not a simple neurophysiological response but was also a cultural response. They also demonstrated that pain expression, response and tolerance were learned in the cultures in which people were socialized. Moreover, these studies demonstrated that there was significant ethnic variation in the response to pain. However, they also had the potential to provide empirical evidence which supported stereotyping of certain ethnic groups and inadvertently perpetuated ethnocentrism.

A later study by Lipton and Marbach (1984) examined the response, attitudes and descriptions of the pain experience of Black, Irish, Italian, Jewish and Puerto Rican patients with facial pain. Ethnicity was determined by the place of birth of the patient and religious upbringing. Random sampling and an objective measurement tool were used to gather the data which was subjected to quantitative research methodology as opposed to qualitative measures used in the two previously cited studies. The results of this study revealed that the reported behavioural and attitudinal responses to pain were similar among all five of the ethnic groups examined. However, each group was different relative to the factors that influenced their response to the pain: for Blacks, the degree of assimilation and medical acculturation was most influential; for Irish, degree of social assimilation (friendship and solidarity); for Italians, duration of pain was most influential; for Jewish patients, level of psychological distress was most influential; and for Puerto

Rican, assimilation and acculturation and duration of pain was most influential. Despite the restriction of forced answers afforded by the use of only a Likert-scale measure to capture the patients' descriptions of their pain, there were still differences identified in the pain experience relative to cultural orientation.

A number of studies examining the effect of cultural background on responses to pain used different ethnic and racial groups as subjects and employed experimentally induced pain to compare pain tolerance and pain thresholds. Sternbach and Tursky (1965) used electrical stimulation to test pain tolerance based on Zborowski's (1952) hypothesis of 'present' and 'future' orientation to pain by patients of different ethnic groups. The subjects were middle class housewives of different ethnic background. Significant differences were found between groups for pain tolerance. Yankees were found to have the highest tolerance for pain, then the Jews, the Irish and the Italians. Lambert, Libman and Poser (1960) also carried out studies on experimentally induced pain but examined groups of people of different religious affiliation for tolerance and sensitivity to pain. These researchers found that when one group (Jews) were informed that the other (Christians/Protestants) could endure more pain, they increased their pain tolerance significantly and vice versa. Neither of the control groups when given the same information showed any difference in tolerance to pain. The researchers concluded that even a variable such as difference in religion could lead to a demonstration of different responses to pain.

Zatzick and Dimsdale (1990) did an extensive literature review of the thirty studies available on exploring cultural differences in laboratory induced pain during the 1960's and



1970's. There were multiple ethnic and racial groups, as well as gender factors examined in these studies aimed at testing tolerance to pain. According to the authors, these studies showed that pain tolerance was influenced by culture. It was more difficult to draw conclusions about the quality of the experience of pain with any degree of confidence from these studies. The difficulties with these studies were that they had little applicability to clinical experience in the context of a known or unknown illness state or injury. Every participant was aware that the pain was temporary and that it was controlled and hence the reality of the dimensions of the pain experience is difficult to capture in a laboratory. As well, Hughes, Seidman and Williams (1993) suggested that investigators of non-mainstream cultural groups make assumptions about the commonality of values, beliefs and behaviours within and across groups. This appeared for the most part, to be the basis on which cultural groups were defined in these laboratory studies. Hughes et al. (1993) stated that many of these studies often incorrectly used demographic and setting variables or proxy variables such as race or nationality to define cultural groups and paid little attention to group boundaries and the within group variations that exist among cultural groups.

Studies on pain and culture were also conducted to examine a single culture rather than making comparisons across cultures as noted in earlier studies. These qualitative studies offered dramatic examples of what should constitute to the most open-minded observer a point of disbelief. They are observed in the practices of initiation rites and rites of passage observed by some societies such as: young Egyptian boys circumcised without a single sign of pain (Ammar, 1954) and love trysts in Truk society which involve the

burning of a man's arm by the woman without a sign of discomfort shown on the part of the male (Gladwin & Sarason, 1953). These are all accounts of situations where stimuli typically assumed in Western culture to be extremely painful, evoked no evidence of pain expression.

The complexity of the issue of pain becomes even more puzzling as one examines the interplay of cultural context and social sanction on the expression and response to pain. In a fascinating study Sargent (1984) described the seemingly unresponsive reaction of the Bariba people to intensely painful situations. This author presented the perspectives of 120 Bariba women and other key informants on the pain experience associated with delivery and information on how other painful experiences were handled in this society. She noted that the majority of Bariba women of Benin endured labour without any expression of experiencing pain and performed their own delivery except for the cutting of the umbilical cord, without help. She was also informed when interviewing various Barika informants that such practices as clitoridectomy, circumcision and other mutilations of body parts (e.g., a man holding his penis in fire and one who broke a misaligned leg without aid of anaesthetic) were tolerated with no expression of pain. The most interesting thing to be revealed in this study about pain, was that the lack of observable behavioural and vocal expression of pain did not necessarily mean that pain was not being experienced. A Bariba woman offered, in describing the experience of a clitoridectomy, that "nothing in life is as excruciating as that experience." The man referred to earlier, who has his misaligned leg re-broken, when asked about that experience replied that "the experience was painful but could not be avoided; expressing pain, therefore, was not

productive." This author noted that many women when asked about their pain experience during delivery stated, "will the pain diminish if you complain?" (Sargent, 1984, p. 1302).

The culturally dictated sanctions of shame and dishonour were revealed to be the factors influencing this remarkable stoicism in the face of intense pain. As Sargent explained, ". . . courage, as demonstrated by absence of manifest behaviour in response to pain and honour, accrued via appropriate behaviour, are signalled as intrinsic dimensions of Bariba ethnicity" (1984, p. 1303). Thus the connection between cultural orientation and pain is arguably defensible in light of these findings and underscores the complexity of the phenomenon of pain and the measurement challenge it poses.

#### Variation in Culture and Language of Pain

Local cultural orientations influence how the ordinary person understands and copes with illness (Kleinman, 1988), and how she or he views the illness reality as it is rooted in experiences of everyday life (Blumhagen, 1980). Further, meanings ascribed to illness terms are often taken from the cultural definitions of everyday language to interpret experience and structure behaviour (Good, 1977; Blumhagen, 1982).

Intrinsic to the evolution of culture is the evolution of language and as Fabrega and Tyma noted, "the language systems of man are as varied as his cultures" (1976, p. 351). Semantics, which is noted to be the unit of grammar which is primarily concerned with conveying meaning (Fodor, Bever & Garret, 1974), seems to be the level at which culture and language is most intimately intertwined. Semantic units express how people classify phenomena through language and is realized in subtle ways through which meaning is expressed in language (Fabrega & Tyma, 1976).

Pain is a highly subjective experience which can only be discovered as it is revealed by the person experiencing it. It is through language and behaviour that pain can be communicated and its meaning and significance portrayed (Fabrega & Tyma, 1976). In a review of the literature on the language of pain, Garro (1990a) noted that language differs considerably in terms of how people talk about pain. Diller (1980) noted a marked difference between the Thai language which has basic pain terms exceeding a dozen in number as contrasted with the Japanese which has a single all-encompassing term for pain (Fabrega & Tyma, 1976). Further, Garro (1990a) explained that the Thai speaker may use a basic pain term to designate location of pain. In contrast to the English language which treats pain as an object which one experiences (e.g., "I have a pain"), the Thai language treats pain terms as verbs (e.g., "to suffer focussed abdominal pain") indicating perception of sensation (Garro, 1990a, p. 34-35). As well, in English, various pain terms can be drawn upon which allows the speaker to describe the pain experience so that "a version or a model of what pain is or stands for in English is revealed" (Fabrega & Tyma, 1976, p. 364). The Thai speaker on the other hand, appears to have no equivalent descriptive terms of the pain experience (Fabrega & Tyma, 1976) thus highlighting the difficulty in capturing the meaning expressed through language of the perceptual experience of pain.

Even as the origin of the word 'pain' in the English language was examined, it was found that of the four primary pain terms identified (i.e., pain, hurt, sore and ache), 'pain' was the only term not "purely Germanic in origin" (Fabrega & Tyma, 1976, p. 355). These authors revealed that the term pain was actually derived from the Greek word 'poine' meaning tax, and the Latin word 'poena' meaning punishment, penalty, fine and tax. From

its very inception the word pain was ascribed the connotation of wrong doing, victimization and other negative associates. However, at no time historically can a relationship be drawn semantically in English between the pain terms and the quality of the pain experience, to injury, emotional state or behaviour. Description of the pain experience through the use of the English language necessitates the use of words having wide meaning in this language, but which refer to what the perception of pain is being likened to (e.g., cutting, jabbing, etc.). The ways in which these secondary pain terms are constructed in language therefore represent the perceived features of pain (Fabrega & Tyma, 1976).

The measurement of pain using clusters of descriptive words proposed by Melzack and Torgerson (1971) to embody the language of pain is the most comprehensive attempt at capturing the multidimensional aspects of pain to date. However, due to the intricacies of the meaning as dictated by culture, translation of the semantics of pain across varying cultures using the McGill Pain Questionnaire (MPQ) format has been difficult (De Benedittis, Massei, Nobili & Pieri, 1988; Harrison, 1988; Ketovuori & Pontinen, 1981). De Benedittis and colleagues (1988) noted that one category of the English MPQ had to be completely renamed because the semantics of pain in the particular Italian culture being studied was completely different in meaning than that intended in the English version of the questionnaire. In yet another study, the classification of words to describe pain into sensory, evaluative and affective categories in the Arabic language resulted in completely different categorizations of the words than that outlined in the English MPQ version (Harrison, 1988).

Patients necessarily use language to communicate a personal experience such as

pain. Yet, given the culturally shaped semantic structure of language around the phenomenon of pain, it is highly possible that translation across cultures could fail to capture the pain reality for the pain sufferer. Variation in the semantics of pain from different cultural orientations presents as a major challenge in both understanding and accurately measuring pain.

### The Pain of Cancer and Its Meaning

A report by the World Health Organization in 1986 declared that the enormity of the problem of cancer pain was staggering. Pain was reported to be the major symptom in as many as 70% of patients with advanced cancer and in 50% of patients still undergoing anti-cancer treatment (World Health Organization, 1986). Due to the prevalence of pain in cancer and the poor management and treatment of it in many countries, pain was declared a world health problem (World Health Organization, 1986). Since that time, efforts to control cancer pain through the appropriate use of opioid analgesics, coupled with progress in the understanding of anatomy, physiology and psychology of pain perception, has led to some improvement in the treatments available for the control of cancer pain (Foley, 1999).

However, studies have shown that the prevalence of pain in adults with cancer remains comparable to earlier findings (Bonica, 1990; Coyle, Adelhardt, Foley & Portenoy, 1990; Morris et al., 1986; World Health Organization, 1986). Foley (1999) noted that significant pain was experienced by one third of the patients receiving active therapy and by two thirds of the patients with advanced cancer. Further, she pointed out that pain associated with tumor involvement continues to be the most common cause of

cancer pain for upwards to 85% of patients on inpatient services and 65% of patients in outpatient clinics. Moreover, in a comprehensive international study of 1840 cancer patients, it was noted that the prevalence of moderate to severe pain was observed in 51% of all patients, with a range from 43% in stomach cancer to 80% in gynecological cancer (Vainio, Auvinen & Symptom Prevalence Group, 1996, p. 8).

Clearly, pain remains a major problem for people with cancer, especially in the advanced stages of the disease. Despite better use and availability of opioid and non-opioid analgesics world wide and guidelines available for appropriate treatment of cancer pain, it is still reported to be experienced in 80% or more patients with cancer before their death (Bruera & Lawlor, 1997). These authors suggested that cancer pain should continue to be addressed as a public health problem because it continues to be poorly managed. They argue that the challenge in appropriate management of cancer pain lies in appropriate multidimensional assessment initiated as a necessary precursor to treatment intervention.

A whole new set of problems related to opioid toxicities have arisen as a result of merely escalating the dosages of medications without first recognizing that medications do not adequately control pain in all patients (Bruera & Lawlor, 1997). Moreover, given the complexity of the pain experience, as demonstrated in seminal work by Melzack and Wall (1982), critical variables such as cultural, social, spiritual and other issues can have a profound influence on the pain experience. Careful assessment and attention to these factors are often neglected in favour of using only analgesic techniques for the alleviation of cancer pain (Bruera & Lawlor, 1997; Foley, 1997; Vainio et al., 1996). It is therefore not surprising to find that even in recent studies conducted worldwide, that the conclusion

with respect to cancer pain continues to be that “pain is the most common, most feared and most investigated symptom of advanced cancer” (Vainio et al., 1996, p.8).

Unfortunately, literature on cancer-related pain has attested to variability in response to this illness experience. There is evidence in early studies of metastatic disease that even in the absence of identifiable progression of pathology, people reported pain (Speigel & Bloom, 1983; Ahles, Blanchard & Ruckdeschel 1983; Twycross & Fairfield, 1982), and the pain experience was found to be more disruptive and intense for those who thought it to be related to cancer (Daut & Cleeland, 1982). Further, even in the presence of identical neoplastic processes, the degree of pain reported can differ across subjects (Twycross, 1982). Obviously the distressing experience of pain in the context of cancer goes far beyond the biochemical and pathophysiological characteristics of the disease.

Increases in the knowledge about common pain syndromes in cancer and developments of analgesic and other treatment protocols for pain control in cancer have not been matched by research aimed at explaining the discrepancies in response to pain or how psychosocial, cultural and other variables influence cancer pain. However, conclusion statements of reports on quantitative studies of cancer pain continue to hint at the possibility that variables such as culture, economic status and other psychosocial variables may be responsible for the differences noted in pain response (Bruera & Lawlor, 1997; Foley, 1997; Ger, Ho, Wang, & Cherng, 1998). These authors endorse consideration of these factors in facilitating effective, comprehensive management of cancer pain.

However, quantitative studies currently predominate what is published in this area.



A recent quantitative study by Ger et al. (1998) presents a good example of a study which demonstrated evidence that cultural/ethnic background and socioeconomic status are in some way implicated in the reporting of the presence and severity of pain. However, we have no information about how, what or why these factors were found to be implicated in the prevalence of pain for cancer patients in this study. In this study the investigators (Ger et al., 1998) noted that cancer was a leading cause of death in Taiwan and that cancer pain relief was poorly controlled in that country. The relatively large sample of 296 patients with cancer pain consisted of the different ethnic groups that accessed the major health institution in Taiwan: mainlanders, Fukienese, Hakka or Aborigine. Interestingly, ethnicity correlated with prevalence of cancer pain and other variables under study. However, an assumption rather than a research finding was used to explain why, for example, more Mainlander patients visited the hospital than did the Fukienese, Hakka or Aborigine. This is not to negate the appropriateness of the methodology used to address the problem outlined in these authors' study, but it does speak to the paucity of qualitative studies which could elucidate important cultural issues that contributed to these findings. There is need for qualitative studies which could make a contribution to enlightening perspectives in this area.

The meaning associated with cancer and its pain is also an important consideration noted in the literature. A landmark study by Lipowski (1970) noted that the manner in which people cope with illness is directly related to the personal meaning and the attitude toward the illness. This author offered that in our culture, the subjective meaning of illness for each individual plays an important role in how one is able to deal with illness and

disability. He suggested that the meanings attributed to illness reflect past experiences, knowledge, cultural background and beliefs about sick people. Lipowski (1970) proposed that the given meaning of any particular disease "functions as a cognitive nucleus which influences emotional and motivational responses to illness and thus the coping strategies" (p. 98). He postulated eight major categories of meaning which he views as prevalent in our North American mainstream culture: illness as a challenge, an enemy, a punishment, a weakness, a relief, a strategy, an irreparable loss and a value. In exploring the meanings linked to the disease cancer there is certainly no lack of negative associations across various cultures.

Golub (1981) graphically described the perceived horror of having the disease cancer in the following way: "the cancer victim, host to a parasite gone wild in its development, is yoked to machine for detection and treatment and provokes in us our deepest dread and our darkest dreams" (p. 730). Gordon (1990) offered that "the tremendously strong association of cancer with death, suffering and hopelessness still exists in much of Italy, coupled with the tremendous power attributed to naming and 'sentencing'. . . . It is the social reality here, such that informing a patient of cancer can be tantamount to social death" (p. 276). Gordon's (1997) most recent work suggested that these culturally constructed meanings persists and endure over time despite social and political legislation imposed to change them.

Thus, powerful negative connotations and ascribed meaning exist in relation to cancer and they appear to be well rooted in culture. Stein (1990) posited diseases as powerful organizing metaphors within a culture, noting that some diseases are more

symbolically burdened than others. Cancer is just such an illness and is seen in American culture today to conjure "an unending Orwellian nightmare of foreign intrusion, unsuspected terror that overruns, controls, consumes, and destroys all with the compliance of the host whose very machinery is used for its own self-destruction" (Sontag, 1978, p. 350). Since, these powerfully negative connotations have the potential to influence the patient's, health care professionals' and society's perceptions around the disease, it is important to uncover these meanings if we are to fully understand the patient's suffering (Stein, 1990; Cassel, 1982).

Moreover, pain in the context of cancer may have a great impact on the individual's emotional well-being inasmuch as the fear that the presence or increase in pain could indicate disease progression. However, there is no direct relationship between variability in disease progression and variability in the pain experience in cancer. Therefore a disparity may exist between the significance of the pain as interpreted by the pain sufferer and the actual physical deterioration (Ahles, Blanchard & Ruckdeschel, 1983). It has been noted in a study of patients diagnosed with cancer (Woodforde & Fielding, 1975) that the patients who were experiencing pain and had the disease were more emotionally distressed than other patients who also had the disease but were not experiencing pain. These investigators concluded that the combination of pain and depression were indicative of a helplessness and inability to cope with the potential threat to life that the pain indicated.

There is a suggestion in much of the literature that the meaning of pain to the patient suffering from cancer, may play a role in the intensity of the pain being reported.

Cassel (1982) cited a case in his treatise on the nature of suffering which offers support for this point. He noted that a patient reported that she believed the pain in her leg to be the pain of sciatica and could control it with small amounts of codeine. However, when she was told that the pain was due to metastatic spread she required greater amounts of medication for relief. The fundamental point that Cassel (1982) made in this paper is significant to the underlying thesis to be explored in the present research project being proposed. He concluded that "what something signifies and how important it is to the whole array of a person's concerns contribute to its personal meaning. Personal meaning is a fundamental dimension of personhood, and there can be no understanding of human illness or suffering without taking this into account" (Cassel, 1982, p. 641).

That meaning is ascribed to cancer-related pain, and can have an effect on the patient's well-being and ability to cope with the situation, has been borne out in research. In a study by Ahles, Blanchard and Ruckdeschel (1983) they found that 61 percent of the patients with cancer stated they feared that the pain they were experiencing was indicative of a deterioration of their condition. Thirty-nine percent of this group admitted to no such beliefs about their pain. Interestingly, an analysis of these two groups revealed that the patients who believed that pain was indicative of disease progression showed significant elevation in anxiety and depression. The meaning of pain in the context of cancer may well be responsible for the emotional distress experienced, and in turn the intensity of the pain experience.

Kremer, Atkinson and Ignalzi (1982) in a study of the affective dimension of a cancer pain population obtained similar results. In the second part of a two-part

experiment, these authors found that the patients suffering from the pain of cancer reported a reliably greater affective component to their pain than did those patients who reported the same sensory intensity, but whose pain was related to benign etiology. These authors concluded that "it is likely that this greater affective loading reflects the differential meaning of cancer pain versus benign pain" (Kremer, Atkinson & Ignalzi, 1982, p. 161). Moreover, the pain of cancer was noted to be described differently than pain associated with benign conditions in a study by Dubuisson and Melzack (1976). Multiple discriminant analysis was used to investigate whether diagnosis of various types of pain could be identified according to pathological condition by specific clusters of pain descriptors using the McGill Pain Questionnaire. In a clinical study of 95 patients suffering from various painful conditions such as rheumatoid/osteoarthritis, toothache, phantom limb pain, and metastatic carcinoma, the investigators attempted to distinguish among these eight clinical categories on the basis of pain descriptors. It was determined that there was a reliably different cluster of pain descriptors for each of the eight categories of conditions, and these findings were statistically significant. The researchers demonstrated that patients with cancer used a unique cluster of pain descriptors for their pain experience when compared to other pain syndromes.

Speigel and Bloom (1983) systematically examined 86 women suffering from metastatic cancer of the breast and reported on the pain experience of these women. These investigators also explored the relationship between factors such as pain and psychosocial factors, coping response and the meaning attributed to pain. They found that there was statistically a significant relationship between the pain experienced and psychosocial

variables. The patients' belief that the pain was indicative of the worsening of their condition was found to be statistically related to more pain and to disturbance in mood.

Not only is there evidence of a predominantly negative cancer metaphor but Gordon (1990) alerted us to the fact that in the United States as well as in Italy, the associates of death and helplessness is changing to "... a heroic metaphor." A good example is easily found in the popular literature portraying cancer patients who manage to survive the odds through pulling on inner resources as "exceptional patients" (Siegal, 1987) and "more and more the illness is being confronted as a challenge that can be 'beat' with a 'fighting spirit'" (p. 277). Saillant (1990) also noted that there is a "new discourse on cancer." This discourse is centred on survival rather than death and articulates themes of maintaining hope and morale ... is embodied in the slogan 'we can beat cancer' (p. 82). Good, Good, Schaffer and Lind (1990) echoed this and posited the notion that "oncological practice draws on distinctive cultural meanings associated with 'hope' and is infused with popular notions about the relationship between psyche and soma, the progressive efficacy of biotechnical interventions, truth telling and the nature of the physician-patient relationship" (p. 60). Gordon (1990) explained that in Italy there was a similar trend toward this perspective on cancer. She noted that a variety of popular books such as those by Simonton, Simonton and Creighton (1978), Siegal (1987) and Cousins (1979), which depicted the courageous victor over the disease rather than the helpless victim, were all now translated into Italian and were thought to "disseminate this new and popular North American approach to cancer and survival" (Gordon, 1990, p. 277).

Interestingly, in a study conducted by the author of the current study (Barkwell,

1991) in Canada (Winnipeg, Manitoba), it was noted that the cancer metaphor of both helpless victim and survivor was evident in the meaning people attributed to cancer and its related pain experience. Using both quantitative measures (McGill Pain Questionnaire, Cognitive Coping Strategies Questionnaire, Centre for Epidemiological Studies: Depression Scale) and qualitative accounts of meaning ascribed to pain as categorized by Lipowski's (1970) eight categories of meaning, this investigation was conducted on 100 patients with metastatic cancer who were experiencing pain. What was particularly noteworthy was that there were three categories of meaning which were chosen to describe the meaning attributed to pain by this group of patients (Lipowski, 1970). ANOVA revealed that patients who choose a meaning category of challenge had significantly lower pain scores, lower depression scores and higher coping scores than those who choose the categories of enemy or punishment. Qualitative findings revealed the challenged persons to be actively mobilizing efforts to gain control over the pain. In complete contrast were the statements given by those who choose 'enemy'. Their statements were characterized by a sense of helplessness and resignation to circumstances that had robbed them of their satisfaction with life. Finally, those who chose 'punishment' made statements which were characterized by an external force, mainly God, meting out punishment for unknown transgression.

This discussion of the literature on meanings associated with cancer reflects the complexity of the human being's reaction to a given illness reality. It also suggests that culturally shaped meanings influence the discourse and conceptualization around the illness experience of cancer. The review of the literature highlights the highly complex

nature of an illness experience especially as it pertains to one that is as metaphorically laden as cancer is and as ubiquitous and multidimensional as pain is.

However, it is clear that cultural factors play an important role in defining the meaning of the illness experience and shaping the response to it. Investigation into the meaning and coping behaviour of patients who embrace a culturally different context, could provide a valuable breadth of clinically relevant knowledge in understanding and managing cancer and the pain of cancer. For as Pfifferling (1981) so aptly explained, "If the meaning of illness is known, then communication and treatment plans will be more congruent between patient and provider. Each should feel more understanding, more actively involved in the therapeutic process, and the caring relationship will be self evident" (p. 198).

#### Theoretical Frameworks Used to Guide Investigations on Culture and Illness

##### Explanatory Models

The Explanatory Model (EM) is a theoretical framework proposed by Kleinman (1980), which proposed that individuals have culturally constructed meanings that are significant in helping them make sense of illness experiences. Explanatory Models focus on five central issues which individuals, regardless of cultural orientation, seek explanation when faced with illness: 1) the cause or etiology; 2) time and mode of onset; 3) pathophysiology; 4) course including both the degree of illness and sick role; and 5) treatment (Kleinman, 1980, p. 105). Knowledge structures and beliefs which incorporate these features to the degree that they are formulated and used in understanding and coping with specific illness experiences are called Explanatory Models. The potential to discover



**the influence of culture and personal experience on the response to biomedical disease makes this a useful framework for eliciting an explanatory model of illness experience.**

**This framework proposed by Kleinman (1978) was an attempt to provide a method whereby health, illness and healing could be understood from a social and cultural perspective. It is based on the premise that the lay person and the medical practitioner's views of clinical reality and evaluations of efficacy of treatment outcomes are fundamentally different. These differences are thought to exist because the cultural construction of the illness experience is tied to specific systems of knowledge and values in the lay, folk, and medical professional contexts. That is, "professionals talk about sickness in a sector-specific language of biological functions and behaviour, whereas patients and families, even when they incorporate terms from the former, talk about sickness in a culture-wide language of experience" (Kleinman, 1978, p. 88). Discerning the equally legitimate perspective of illness held by folk and lay persons were deemed by Kleinman to require a new research methodology for analysing the different clinical realities of illness. The EM model is "a model of cognitive transactions in health care" (Kleinman, 1978, p. 89). Explanatory Models, therefore, are thought to represent how people think about illness: the common sense representation of illness and health which provide explanations about beliefs on illness, sick roles and practitioner roles, experience of illness and choices of treatment approaches. They are anchored in a particular social and cultural context and "are not easily reduced to technical questions which can be answered with simple biological explanations" (Kleinman & Sung, 1979, p. 7).**

**This model, evolving from field research which spanned five years, demonstrated**

content validity in its use in studying the phenomenology of depression in a Chinese society (Kleinman, 1982), practitioner-patient transactions (Kleinman, 1975) and the efficacy of Shamans and indigenous healers in Taiwan (Kleinman & Sung, 1979). The EM format, according to Kleinman (1978) offers “. . . an alternative social and cultural model to challenge the egregious distorting biological reductionism of the biomedical model in research and teaching” (p. 90). This model has potential for use in guiding qualitative accounts on culture and disease. It was used successfully to frame questions in a study of cultural knowledge of blood-pressure in Ojibway people (Garro, 1988).

#### The Cultural Hermeneutic Model For Clinical Practice

Central to the conceptual orientation of the cultural hermeneutic model for clinical practice proposed by Good and Good (1981) is the “clinical importance of the meaning of symptoms” (p.169). These authors offer that the major underpinnings of this meaning-centred approach is that it:

Recognizes all illnesses to be fundamentally semantic. Whatever the biological correlates or grounds for disease , sickness becomes a human experience and an object of therapeutic attention as it is made meaningful. . . . All illness realities are meaningfully constituted (Good & Good, 1981, 167).

Their second most important point is that:

A meaning-centred approach recognizes all clinical transactions to be fundamentally hermeneutic or interpretive. Thus “. . .the culture or meaningful character of symptoms and the clinical task of understanding and interpreting those symptoms are central issues” (Good & Good, 1981, p.167).

These authors proposed that a particular expression of distress is rooted in its cultural context thus affording people culturally appropriate ways for articulating distress. They further pointed out that notwithstanding the presence of pathology in disease, illness constitutes an even wider dimension of the human response. Illness is thought that to consist of “a unique semantic network [which] condenses a unique configuration of meaning” (Good & Good, 1981, p. 176). These authors proposed that this unique configuration of meaning around illness, including such things as fears and expectations about illness, personal trauma, life stresses, social reactions of friends and authorities, and experiences with therapeutic intervention, all create a unique illness reality that is grounded in and shaped by a particular cultural context. Therefore, this model conceptualizes illness as a meaningful experience that is culturally shaped.

Good’s (1977) study of ‘heart disease,’ a category of illness in Iran, revealed that illness categories can be understood as a “net of words, situations, symptoms and feelings which are associated with illness and give meaning to the sufferer” (p. 40). In this study the author discovered that the label given to what is understood in biomedical terms as a discrete pathological condition, can be categorized differently or can have culturally varied causal explanations and hence differing individual experiences from one society to another.

The findings in this study suggested that the label given to a particular illness must therefore be acknowledged within a socio-cultural context. Therefore, the understandings and meanings associated with that illness label can only be fully understood if information is garnered from the perspective of the individual in the context of that individual’s cultural orientation. This model has implications for measurement of a perceptual

experience such as pain in a population where the cultural orientation is other than that of the mainstream English speaking majority population. It offers a framework which has the potential to capture the complexities of the cultural variation in perceptions and experience.

Frameworks for examining the knowledge structures that are used by the individual to make sense of illness reflect culturally patterned knowledge. However, research approaches have also been directed towards examining shared cultural knowledge on illness. Blumhagen's (1980) study of hypertension presented a fascinating but convoluted design to explore the extent to which individual models of an illness are shared within a general cultural model. He developed a shared cultural model representing what he called the 'cognitive domain' of the illness. He admitted being unable to estimate with any degree of certainty the extent to which individual models were culturally shared models. The consensus theory of culture and informant accuracy (Romney, Weller & Batchelder, 1986) offers a methodology for making such distinctions when carrying out research on intracultural variation.

#### The Consensus Theory of Culture and Informant Accuracy

The Consensus Theory of Culture and Informant Accuracy (Romney, Weller & Batchelder, 1986) offers another perspective from which to examine the cultural knowledge which shapes how people understand and respond to illness. This model defines culture as that which has to be learned as opposed to biological heritage. Hence, the aspect of culture that this model attempts to account for is that which is shared and learned (Weller & Batchelder, 1986). The model proposes that the amount and

distribution of cultural knowledge can be systematically measured. Given that there is such a large size to the pool of cultural information available on a given culturally constituted reality, it is deduced that knowledge would have to be distributed and shared. Since we can only access a small segment of the total information pool constituting cultural knowledge the model suggests a focus on the "systematic cultural patterns" which are "subsystems of knowledge that tend to cohere and persist as a unit limited to one aspect of culture" (Romney, et al., p. 314). The consensus of agreement among informants on a systematic cultural pattern can be used to make inferences about how they differ with respect to the shared knowledge which constitutes the cultural pool.

This model therefore measures what is believed and understood to be true on a certain cultural domain and the extent to which there is a consensus among informants on what is understood to be true. This method has the potential to yield data which reveal what the actual cultural beliefs are around a given subject. Further, it has the potential to show, through mathematical analysis, whether or not these beliefs are shared. The validity of this methodology in measuring estimates of cultural competence was demonstrated by Boster (1986) and by Garro (1988) in a study using two methodologies, to ascertain beliefs about high blood pressure in an Ojibway community.

This theory shows great potential for use in a study combining two methodologies. It proposes a mathematical formula for arriving at an index which indicates the degree to which culture is shared. Although intriguing, it would not provide any more information about the dynamic and complex nature of the experience of pain or the complexity of the culturally constructed meanings attributed to cancer, than would any other well established

reliable quantitative measure. Further, this methodology would be useful only if one made the assumption that all members of a minority culture were the same in terms of beliefs and practices and, that knowledge of this consensus of cultural beliefs could serve some useful purpose. Unfortunately this search for consensus of beliefs and practices among all members of a specific cultural or ethnic group often feeds into perpetuating stereotypical ideas about specific groups of people who may be as diverse in their attitudes and cultural practices within their community as the dominant society (Ramsdem, 1993). The aims of this current research were to describe and explain culturally constructed meanings and understanding around cancer and its pain, not simply to identify differences in beliefs. Therefore, a qualitative approach was the preferred methodology.

In this chapter, a literature review highlighted studies on pain and the impact of culture on meaning and responses to the pain of cancer. Both qualitative and quantitative approaches have been used to address this issue. Conceptual frameworks which have been used to examine cultural models of illness and shared cultural knowledge was also examined for possible use to answer research questions such as the ones proposed in this study. There are however, no studies found which examine cultural understanding of cancer pain in an Ojibway First Nations community. In the following chapter, the qualitative approach to data collection and analysis will be discussed. The underpinnings of the grounded theory will be presented for its suitability of use in this research.

## CHAPTER 3

### Qualitative Methodology

#### Introduction

This research used a qualitative approach for data collection and analysis because the questions posed required answers which described the experience of cancer and related pain and the cultural information that framed how people understood this illness. A grounded theory approach using constant comparison of theoretical data was used, employing a conversational interview guided with open-ended questions.

Qualitative research is said to “go beyond numbers into the realm of conceptual manipulation. The symbols we work with are words rather than numbers” (Stern, 1989, 137). Unlike quantitative studies, the aim of qualitative research is to build theory rather than to test them. Qualitative research is concerned with using rich description, data synthesis and abstractions in the development of theory (Morse & Field, 1995). The results upon completion of a qualitative work are based on providing a maximum of information on the subject of enquiry, rather than generalizations based on statistical findings. As well, redundancy or saturations (as it is commonly referred to) of categories signal the point at which data collection should end, as opposed to a statistical confidence level (Lincoln & Guba, 1985).

#### Sampling in Qualitative Research

The sampling strategies in qualitative research are distinctly different to that of the quantitative research. In quantitative research, the purpose of the sampling effort requires that it be representative of a given population for the purposes of generalization.

Theoretical sampling used in the qualitative paradigm is concerned with all the possible variations and possible information that is part of the context being studied. According to Lincoln and Guba (1985), “the purpose of maximum variation is best achieved by selecting each unit of a sample only after the previous unit has been tapped and analysed” (p. 201). In so doing “each successive unit can be chosen to extend information already obtained, to obtain other information that contrasts with it, or to fill in gaps in the information obtained so far. . . .” (Lincoln & Guba, 1985, p. 201). The purpose of this sampling is to ensure comprehensiveness and relevance of the theory. Theoretical sampling evolves during the process of the research endeavour. It is not selected in an a priori fashion. It “is based on concepts that emerged from analysis and that appear to have relevance to the evolving theory” (Strauss & Corbin, 1998, p. 202).

### Analysis of Qualitative Data

Qualitative research yields rich descriptive data which must be systematically and logically analysed. Sampling and analysis, according to Strauss and Corbin (1998, p. 203), “must occur sequentially with analysis guiding data collection.” The process of analysis consists first of the units, which are small pieces of information which can be interpreted on their own merit without needing additional information, and which would make no sense if any part of it were removed. Therefore, a word, sentence or paragraph can be a unit which is found in the interview transcripts or any other notations or nonverbal behaviour (Lincoln & Guba, 1985). Coding is the means whereby “raw data are systematically transformed and aggregated into units which permit precise description” (Holsti, 1969, p. 94) of all that is relevant. Eventually these units form the basis for



defining categories. Those sets of units that relate to the same content are linked together to form categories. Incidents are compared which are applicable to each category. Coding of incidents for categories is carried out. This involves also comparing them to previous incidents in the same and different groups, coded in the same category (Glaser & Strauss, 1967).

Constant comparison generates properties and categories. The dimensions and properties, contexts, consequences and relations to other categories are derived by thinking at a conceptual level about the codified data. Categories resulting from this analysis and respondents' words, become more descriptive and explanatory. Multiple memo writing is said to provide a more comprehensible definition of the category. A return to comparing new and previous incidents to properties and previously established categories, affords definition and redefinition of categories at a higher conceptual level. With analysis guiding new data collection, categories become well developed and more integrated. As categories become fully defined, "saturation" is said to have been accomplished (Glaser & Strauss, 1967; Lincoln & Guba, 1985). This means according to Strauss and Corbin (1998) that " (a) no new or relevant data seem to emerge regarding a category, (b) the category is well developed in terms of its properties and dimensions demonstrating variation, and (c) the relationships among categories are well established and validated" (p. 212).

### The Interview

The interview in qualitative research, unlike quantitative research, is usually

unstructured. It involves having the interviewee shape the focus of the interview, and permitting that person, rather than the researcher, to introduce what is important and relevant information. This does not mean, however, that the researcher does not have at least a tentative focus which s/he brings to the inquiry. The interview structure in qualitative research can be unstructured or semi-structured. Unstructured interviews are carried out with little to no guidance to the flow of conversation because the goal is to ensure that there is no preconceived focus by the investigator on the interview process. The semi-structured interview is organized loosely around the topic of interest yet permitting flexibility in the direction and scope of the discussion (Polit & Hungler, 1987).

Due to the fact that too much structure is not productive in the early period of the investigation, "early interviews may look much more like 'guided conversation' and may be appropriately called interactive interviews" (May, 1991, p.192). As the study proceeds the investigator attempts to focus on areas of interest emerging from the data, looking for differences and similarities. The interviewer then directs questions to the topic area being focussed upon. As data analysis proceeds, questions in the interview become more focussed to address gaps in the questions arising from the analysis. The challenge becomes one of permitting flexibility in the structure of the interview as well as maintaining consistency in questions asked, to allow for comparisons to be made within and between interviews. It is suggested that systematic review and preparation for each interview will help eliminate this problem (May 1991). This author suggests that given the unstructured format of qualitative interviews, it is important to use an indirect approach to the area of

interest by using rather nonspecific language and open-ended questions (such as, tell me about your life with diabetes) . . . then framing questions using language that reflects the informant's language . . . (what do you mean when you say 'out of control')" (p.196).

Interviewing in qualitative research is a challenge. It is costly and time consuming. It requires skill to understand the vagaries that are often presented and to discern the possible inroads to in-depth description. It involves negotiating how to get the story, while making judgements about what information is relevant what is not (Appleton, 1995; Hedges, 1985).

The types of sources where information might be best gathered for the project are identified by Lincoln and Guba (1985, p. 261) as: "the existing literature and experienced and knowledgeable experts." However, according to these authors, caution should be taken not to be biased by these sources as one enters the field. Literature can be used to:

Stimulate theoretical sensitivity, as a secondary source of data, it can stimulate questions, . . . direct theoretical samples . . . give you ideas about where you might go to uncover phenomena important to your theory and it can be used as supplementary validation . . . of the accuracy of your findings (Strauss & Corbin, 1991, p. 51-53).

### Rigour in Qualitative Research

Questions of validity and reliability, as espoused by the quantitative paradigm, are critical elements in evaluating rigour in the research endeavour. It is also important in a qualitative research to address issues of rigour. Glaser and Strauss (1967) suggested that

on completion of qualitative research it should have “credibility, plausibility, and trustworthiness” (p. 223). Similar criteria were offered by Lincoln and Guba (1985) which are essentially addressing the same issues. They suggested that a qualitative study should have “trustworthiness.” The first criterion for this is suggested to be “truth value,” which means that the study should be evaluated on whether it is credible. They argued that since the qualitative approach assumes there are multiple realities which are constructed in the minds of humans, it must be shown in the qualitative endeavour that those multiple realities were adequately represented by the data that was collected. The argument is that the reconstruction of those multiple realities should therefore be credible. Taking the reconstructed data back to the source for their approval of whether or not these realities were credibly reconstructed is the test upon which qualitative research trustworthiness should be judged. If persons having the experience under study are able to recognize the researcher’s reconstruction and interpretation as fitting their own, then there is support for the truth value in the research effort (Lincoln & Guba, 1985; Sandelowski, 1986).

By implementing the criterion of credibility the qualitative researcher will have introduced an appropriate measure of evaluation to the research effort. Credibility in qualitative research is the counterpart to internal validity in quantitative research and aims to inform on the issues of validity. Applicability is the criterion used in qualitative research to evaluate what is referred to as external validity in quantitative research. The descriptive interpretations made in qualitative research take into account all contextual effects as a critical aspect of capturing all the possible variables that constitute the

phenomenon under study. In order to evaluate applicability in qualitative research, one has to ask a question about transferability from one context to another. The question of generalization (its counterpart in quantitative research) is an inappropriate criterion for evaluating external validity in qualitative studies. It requires that two contexts being investigated be compared "on those factors that define them. In order to be sure of one's inference, one will need to know about both sending and receiving contexts. . . .

Transferability inferences cannot be made by an investigator who knows only one sending context" (Lincoln & Guba, 1985, p. 297). The burden of proof of transferability lies with the person who wishes to apply the findings elsewhere. The original investigator needs only provide sufficient descriptive evidence to make sure that judgements about similarity in contexts are possible (Lincoln & Guba, 1985).

Consistency (which speaks to reliability in quantitative research) is another criterion on which to judge the credibility of qualitative research. Dependability is the operational word used in qualitative studies. Reliability is demonstrated by replication in quantitative studies. Lincoln and Guba (1985) questioned the notion that any circumstance in the real world which is subject to constant change and history, could ever be replicated. Replication is therefore not acknowledged as an appropriate criterion for the evaluation of the reliability of qualitative research. Qualitative studies look for dependability as a counterpart to replication. Dependability means "taking into account both factors of instability and factors of the phenomenal or design induced change" (Lincoln & Guba, 1985, p. 299).

Neutrality, refers to ensuring against bias in the approaches one takes in the research effort. In qualitative research, the issue of neutrality addresses the issue of objectivity in research. From the qualitative research perspective, the emphasis of objectivity is not placed on the investigator, but on the data. The question then becomes one of whether the findings are confirmable.

“The four terms ‘credibility,’ ‘transferability,’ ‘dependability,’ and ‘confirmability’ are then the naturalist’s equivalents for the conventional terms ‘internal validity,’ ‘external validity,’ ‘reliability,’ and ‘objectivity.’” (Lincoln & Guba, 1985, p. 300). There are strategies suggested to enable the operationalization of these terms in qualitative research. The following are ways to ensure credibility, transferability, dependability and confirmability as dictated by Lincoln and Guba (1985).

**Credibility:** This is achieved by spending a prolonged period of time in the setting.

Understanding the contexts in which behaviour and events take place is imperative in order to detect nuances and distortions that might be in the data collected. As well, the investigator requires time to establish and build trust and therefore increase the possibility that respondents will be comfortable enough to provide answers to the inquiry, that the investigator will decrease the possibility of distortions, recognize atypical events in the data and thoroughly understand the context in which the inquiry is taking place. Things such as personal bias and assumptions on the part of the investigator must be examined. A reflective journal may be helpful. Anonymity and freedom to volunteer participation without pressure must be ensured and will maximize the possibility of getting candid

answers to questions posed. The use of triangulation of sources and different methods are also ways of ensuring the credibility of the findings.

The peer debriefing process is also a way to establish credibility of the findings. It involves having an opportunity to have peers who have no vested interest in the investigator or her/his research, to question and explore the investigator's personal biases and the basis for interpretations made. It also provides an opportunity for the researcher to discuss and clarify emerging themes, to vent feelings and to acquire important feedback about the next step one takes in the inquiry.

Negative case analysis "is a 'process of revising hypothesis in hindsight'" (Lincoln & Guba, 1985, p. 309). This process involves checking and rechecking interviews against previous interviews to identify instances of exceptions or outliers and revising hypothesis to include the different information. It also reduces the number of negative cases and therefore makes data more credible.

Member checks and peer review are thought to be the most critical approach for ensuring credibility of the findings (Lincoln & Guba, 1985; Strauss & Corbin, 1998). This involves reporting the interpretations, conceptualizations and conclusions drawn to the original participants in the inquiry to ascertain whether they recognize the representation of their own realities as portrayed by the investigator. A member check represents a judgement of the entire research enterprise in terms of its credibility.

**Transferability:** In qualitative research, establishment of transferability in the conventional sense is impossible. The purpose of a qualitative inquiry is to produce rich description and

working hypotheses derived in a particular context and time. It is impossible to know whether these same hypotheses and descriptions would hold true in another context or at another time unless the degree of similarity of the other context is also known. Therefore, providing description with the widest range of information from the context examined is the extent to which qualitative findings can contribute to transferability (Lincoln & Guba, 1985).

**Dependability and Confirmability:** These criterion for establishing rigour is related to finding consistency in the findings. According to Lincoln and Guba (1989), dependability and confirmability are related criteria for checking rigour as they both address the issue of ascertaining whether the findings are grounded in the data. They represent checks to ensure that the research process and the results are free from bias. Thus the research product should be examined to ensure that the results shown are supported by the data. This involves examination of the data, the findings, interpretations and recommendations, and these should to be supported by data. In order to accomplish both dependability and confirmability, it is necessary to have an "audit trail" (Lincoln & Guba, 1985, p. 319) which consists of the raw data, the field notes and other ways of showing the way concepts were linked and thought through (memos), as well as notes about how the trustworthiness of the enterprise was established. The main purpose therefore is to examine whether the findings were grounded in data and whether another researcher, following the logic used at arriving at the findings, would agree with the results (or at least not arrive at contradictory conclusions).



**Strauss and Corbin (1998) suggested that 'reproducibility' is also a way of establishing confirmability and rigour in qualitative research. They argued that two studies of the same social phenomenon cannot be expected to produce the precise results. However, they pointed out that "given the same perspective of the original researcher, following the general rules for data gathering and analysis, and assuming a similar set of conditions, other researchers should be able to come up with the same or very similar theoretical explanations for the phenomenon under investigation" (p. 267). They added that in their studies of chronic illness, other qualitative studies on the same topic have demonstrated findings consistent with theirs despite the fact that their emphasis on a specific aspect of the topic area might have been different, or alternative conditions may have existed in the specific study.**

**Grounded theory, they explain, should also have explanatory power. This, along with the other aspects of trustworthiness previously addressed, is recommended as a criteria upon which grounded theory should be evaluated. Therefore in writing the theoretical formulations evolving from a study, the conditions that give rise to the phenomenon should be specified. That is "problems, issues, the use of strategies or actions/interactions to manage these problems or issues and explanations of what consequences occur as a result of those action/interactions" (Strauss & Corbin, 1998, p. 267).**

**Hence, the final requirement of the trustworthiness of a qualitative study is that "researchers consider the plausibility of their evidence in the context of other research and**

theory” (Avis, 1995, p. 1208).

### Grounded Theory

Grounded theory was first introduced by Glaser and Strauss (1967) as a qualitative approach to data analysis as opposed to quantitative approaches. Grounded theory is said to be a particular way of collecting and analysing qualitative data. The goals of the authors were to “produce research that would be of value to professional and lay audiences and to develop solid theory that fit that reality” (Morse & Field, 1995, p. 157). All of the above processes outlined in qualitative research, represent the underpinnings of grounded theory. Morse and Fields (1985) pointed out the specifics of the grounded theory requirements:

When using a grounded theory approach, the researcher must consider several factors. The setting itself influences the way in which behaviour is evidenced, and so it must be taken into consideration in data analysis. There must be adequate range of participants to provide a full range of variation in a phenomenon, so that definitions and meanings are grounded in the data. If participants are restricted to a homogeneous group, this fact must be made clear. The descriptions of social behaviours should be described as they occur in their natural settings which means that in interviews the researcher must ask questions that identify the “what” and the “where” of the described situation. All behaviour must be understood from the participant’s perspective (p. 157-158) .

The current study has used the guidelines for grounded theory outlined by Strauss and Corbin (1998). In so doing the emerging theory was derived from the data following

**systematic gathering and analysis of data. The research process involves description of events or phenomena with further analysis that explains and interprets the data.**

**Description is said to be basic to both theory building and conceptual ordering.**

**Conceptual ordering, according to Strauss and Corbin (1998), is “organizing data according to their properties and dimensions and then using description to elucidate those categories” (p. 19). These authors see conceptual ordering as a precursor to theorizing.**

**Theorizing does not stop at depicting various actors’ perspective and explicitly ordering these into well developed themes. Theorizing goes further. It is the “act of constructing (we emphasize this verb as well) from data an explanatory scheme that systematically integrates concepts through statements of relationships” (Strauss & Corbin, 1998, p. 25).**

**Using the operations previously outlined for the implementation of qualitative methodology, a grounded theory approach was used to collect and analyse the data. The following Chapter details the steps taken to construct theory which is grounded in data.**

## CHAPTER 4

### Methodology

#### Introduction

A qualitative approach, using a grounded theory methodology for data collection and analysis, was used in this investigation to discover whether culturally patterned knowledge framed the way in which Ojibway people from a reserve in Eastern Manitoba understand, experience and deal with cancer and related pain. The aims of this research were to: 1) describe and explain how cultural beliefs framed how Ojibway people, living on a reserve community, understood the illness experience of cancer and related pain and, 2) to describe differences and/or similarities between Ojibway respondents and health professionals' explanations and perceptions of cancer and related pain. The information gathered from this investigation could contribute to the theoretical basis of cultural models in framing of illness.

#### Population, Sample and Inclusion Criteria

Although in using a grounded theory approach one does not focus on the selection of a randomized sample, it is necessary to focus on appropriateness and adequacy of the methods used to select participants for the study. Data appropriateness, according to Morse and Field (1995, p. 189) "refers to the process of selecting participants who could best inform the research." Data adequacy means "the amount of data obtained and whether or not saturation occurred." Both of these are important considerations to be

made in sample selection. In the current study, participants were of the Ojibway cultural orientation, and they were people who were believed to have information on the subject being addressed by the research. Hence, the participants who constituted the sample from the reserve community setting were Ojibway, and they were believed to have gained knowledge of the disease cancer and related pain through having had the illness experience as patients, having been a care-giver for someone throughout the course of the disease, or having dealt with the disease in the role of healer (traditional healer). The participants from the biomedical hospital setting were physicians and nurses who were potential providers of health care for residents of the adjacent reserve. It was believed that various perspectives would yield data that provided greater breadth of understanding and a wider perspective from which to conduct theoretical sampling.

Theoretical sampling guided the selection of the final sample accrued in the study. The data collection process in grounded theory suggests that sampling is grounded in theory. Therefore, the process used in collecting data involves concurrently collecting and analysing data in order to develop the emerging theory. Data collection therefore influenced the analysis process throughout, based on insights gained from previous interviews. The number of participants were selected as the analysis process was emerging rather than before it began, as is required in quantitative methodology.

### Sample and Setting

The target population consisted of adults in an Ojibway reserve community in Eastern Manitoba. The name of the community is withheld in order to maintain anonymity

as agreed to in the proposal. This community consists of a population of approximately 4,000 to 5,000 people. The selection of this community was based on the fact that, according to a prominent community member, a number of the people who constitute the population are bilingual (i.e., Ojibway and English language), but do adhere to "the old ways". Rogers (1962), who wrote about the Ojibway people noted that, in contemporary times, despite the fact that more faith was being placed in biomedical practitioners, "much of the old remains, especially in terms of attitudes, beliefs, and values of the people" (p. A25). Since the present research is designed to explore cultural influences in framing illness experiences, an attempt was made to ensure that the population to be studied was one which demonstrated some degree of adherence to a distinctive cultural orientation.

Eighteen Ojibway participants and thirteen health professionals participated in the study, for a total of thirty-one participants in the study (see Table 1). The Ojibway group consisted of patients with various types of cancer, caregiver relatives and healers. There were ten women and eight men which constituted the sample. They ranged in age from 37 to 72 years.

Table 1

**Characteristics of Ojibway Participants**

Age range	35-50 Years	51-65Years	66+Years	Average
Male	3	3	2	56.6
Female	5	4	1	51.9
Total	8	7	3	54

The number of years of education ranged from 0 to 17 years ( see Table 2). All participants offered Ojibway as their first language. This type of demographic information is said by Glaser (1978) to be of significance in qualitative data only if it has earned its way into the emerging data. A case could be made for that in this study.

Table 2

Years of Education Completed

Education	< Grade 6	Grade 6 - 12	Post Secondary	Average Years
Men	2	6	0	8
Women	0	9	1	10.5
Total	2	15	1	9.4

One of the striking observations noted in the demographics was that of education. Since this research was an endeavour to understand the knowledge people in this community had about an illness experience, it was assumed that “education” equated with knowledge as is the case from our Western cultural perspective. The participant’s level of education was therefore seen as an important observation to consider. One of the most enlightening observations to be made by the researcher when examining the data was that the number of years of education did not necessarily imply knowledge: It did not imply the level of knowing within a culture. It was surprising to note that the participant with the lowest level of education was also the one who spoke most clearly and eloquently about the detailed changes in nature he had observed that indicated the level of pollutants that were contaminating their rivers and possibly causing cancer. It was also this respondent

who spoke of the importance of the “cohesiveness” of their community. When asked to elaborate, he explained how important it was for family members to be close and supportive during times of illness. He seemed to possess a wisdom that could not have been acquired through any number of years of education. Hence, the quantification of knowledge by the number of years of education spent in school as shown in the table 2, does not necessarily reflect the level of knowledge this participant had about the biomedical disease being discussed. This insight might well have been missed if purely quantitative methodology and statistical relationships were used. The participants who were health professionals were qualified physicians and nurses who worked at a hospital adjacent to the reserve.

#### Gaining Access

The sampling frame for accessing participants was through word-of-mouth and the use of an intermediary person from the Health Centre to gain access to the reserve. A Meeting with key elders in the community was arranged. This formal meeting with the elders of this community took place in a sacred lodge and involved smudging with tobacco and a drum ceremony. The researcher was previously instructed by the intermediary person as to the type of dress and gift of tobacco to offer at this meeting. After the drum ceremony, the chief elder spoke at length of the oppression and difficulty his people faced. The importance of the Creator and spirituality was also a central theme. Each person spoke. The researcher then presented the research project for approval which was granted. The project was presented to the Band Chief by one of the elders in the group who was



also the researcher's intermediary person. Following a lengthy wait, the formal approval was given for the project and access to the community by way of a formal letter from the reserve community. A meeting with the Director of the hospital adjacent to this community was arranged. After she submitted the project for Board approval a formal letter of approval was sent to the researcher (see Appendix B).

It was initially intended to gain access to patients with cancer through attaining permission from the appropriate persons in charge of such matters at the health institution. Physicians and nurses would then be approached and asked to inform patients with cancer of the research project and invite them to contact the researcher if interested in participating. In this way only patients with a confirmed medical diagnosis of cancer, as indicated on their medical record, would be recruited into the study.

Interestingly, gaining access to records did not present the usual ethical issue of confidentiality as was anticipated, but another unanticipated one arose on this subject. That the investigator thought it necessary to confirm the presence of a disease such as cancer through confirmation by a biomedical diagnosis became the issue of contention. This was interpreted as discounting the word of the patients themselves and their ability to identify their own diagnosis as provided to them by their physician. The investigator was informed that this would be interpreted as an insult to their community members. Suggesting a need to confirm the diagnosis from records implied that they (the records) were the only legitimate records of this disease, not the lived experience of these persons who had the disease. It was decided that, in keeping with the methodological approach

being used in this study, patients or family members would inform the researcher of the diagnosis they were given by their doctor. The staff at the Health Unit agreed to draw the study to the attention of anyone whom they knew would meet the written criteria (Appendix C). No medical records were accessed by the researcher. Ethical concerns and respect for cultural norms were managed in this way in order to gain access to participants.

### **Instrumentation**

An open-ended, face-to-face interview format was used in this study which was developed by the investigator and was loosely guided by Kleinman's (1978) explanatory model, which as discussed earlier, suggests that lay people have their own perspectives and understanding of illness; the causes, the course of disease and treatment. Interview questions focussed on getting descriptive data which could explain what cultural knowledge people held about cancer and the pain of cancer, what cultural beliefs supported their understanding of cancer and its pain and what the pain of cancer meant to them. In the case of patients, they were asked to describe the pain experience in terms of intensity, duration and nature of the experience as it pertained to what it meant and the impact it had on their lives. In the case of relatives, they were asked to make the same descriptions of the pain and its meaning but were also asked to describe what it was like for them when their relative was in pain.

The following is an excerpt from an interview with a patient demonstrating the kinds of questions asked when the investigator addressed cancer pain:

**I: Do you get pain with this cancer?**

**P: Yes, I do have pains like, when the pains come up, I've got to go back to the hospital to get treatments because I can't deal with the pain.**

**I: You can't deal with the pain, can you describe what that pain is like?**

**P: They're just, burning. . . like it's a little ball and it burns and then it moves and it moves fast, like it travels. That's why they uh, that's why they can't get rid of it I guess, because it moves to one area and then comes to another area.**

**I: Then it moves all over. . . I notice you are pointing all over your body.**

**P: Yeah**

**I: Um, when you get the pain, what do you think that means?**

**P: I don't know why the pain comes back. I do so good, like I pick up so good and all of a sudden, bang, and then I'm sick again, like, and I, I don't know why that pain comes back, I guess.**

**I: So when you get the pain it sort of signals that you're getting sicker? Is that what you're saying?**

**P: Yeah, uh huh.**

**I: Okay, so usually, as you said, you have to then go back to the hospital because of the pain.**

**P: Yeah, that's what it usually takes**

**I: How long does it usually last?**

**P: Well it, it lasts long. . . yeah.**

**I: What does that feel like? Describe it for me**

**P: Ah, it's pretty severe and . . . ah, like I can't stand it, I've got to have pain killers right away simply to be comfortable**

**I: Yes, I see, okay. Um, what's it like living with this? Can you tell me what this experience has been like for you?**

**P: Well it's hard. Like uh, I want to live my life. I want my life back . . . [voice tremors]**

**This patient continued to explain how cancer pain took his life away. All participants were also asked about what they thought caused cancer and related pain and what approaches to treatment and/or healing were taken. They were also asked to identify what was or could have been more helpful as they went through or (were currently going through) this experience. An example of an initial interview guide with the patients is shown in Appendix F. The open-ended format of the interview facilitated addressing further questions arising as a result of responses of informants. As well, probes were often made relative to patient responses and not according to the script. The original interview format changed with theoretical sampling and emerging analysis.**

**As well, a short demographic questionnaire was used to gain specific data with respect to age, gender education, occupation and language. The open-ended questionnaire provided descriptive and interpretive data of the perceptions and meanings of the illness experience of cancer and related pain from the perspective of the patient, relative or healer/elder.**

### **Interviews**

The interviews were conducted by the researcher. All participants were informed of the length of the interview and the location and time of interview was mutually agreed upon by the participant and the researcher. Before each interview, the description of the study as outlined in the consent form was read and patients were instructed to sign the consent form as an indication of their agreement to participate in the interview (see Appendix D). The interviews lasted approximately one hour. Interviews with health professionals were shorter, approximately one-half to three-quarter hours. An Ojibway interpreter was available for those who preferred to speak in their Ojibway language. No one took this option.

The interviews were unstructured. Broad questions were posed by the researcher. The purpose of the unstructured interview in qualitative research is to ensure that the interviewee's definition of the situation is captured. As specified by Lincoln and Guba (1985), the unstructured interview encourages "the interviewee to structure the account of the situation; and [lets] the interviewee introduce to a considerable extent his notions of what he regards as relevant, instead of relying upon the investigator's notion of relevance" (p. 168).

### **Trustworthiness of the Data**

The truth value of the study according to Lincoln and Guba (1985), is necessary to show that the analyst's interpretations and reconstructions of multiple realities reflected in the findings "are credible to the original constructors of the original multiple realities" (p.

296). The participants' feedback with respect to the accuracy of the researcher's interpretation of the data is a measure of the credibility of the findings. In order to evaluate the truth value of the study the researcher returned to the community setting and shared the findings with a group of three community members (one of whom was a healer) and as well, two individual meetings were carried out with individual participants in the study in their home. It was remarkable as well as gratifying to receive feedback from these people which confirmed the researchers' interpretation of the findings. There was one change proposed by a participant. When discussing the property of blocking categorized as "lack of talk," the researcher offered the conceptual label of silencing on the subject of cancer, noting that in some countries such as Japan there was a "conspiracy of silence" with respect to cancer. The researcher shared that she had seen no evidence of conspiracy in the data gathered in this Ojibway community, but that there was certainly evidence of silence on the topic. The participant agreed stating "its more a respectful silence." This word was incorporated into the data.

Coded data, transcripts and the process of the conduct of the research followed those outlined in Glaser and Strauss (1967). At the onset of the interview coded manuscript were shared with a colleague with expertise in qualitative research (she taught qualitative methods in research) for her feedback in terms of the investigator's interpretation of the data. There was agreement. Later on in the process when data collection was becoming more focussed, an interview was submitted for an informal peer review to ascertain whether their interpretations were different from those of the

investigator or whether the reviewers arrived at the same conclusions. The group consisted of twelve people from various disciplines, from all over the world, who were all taking a short course in Qualitative research from J. Corbin who co-wrote with A. Strauss, the 1990 and 1998 text on qualitative research. It was initially intimidating to submit one's work for a review but the feedback was encouraging and validating. Dr. Corbin guided the review and each member of the group provided helpful feedback. Valuable feedback was gained in this process as there was confirmation on the core concept which was emerging which matched that of the investigator's.

Dependability and confirmability are also criteria for checking rigour as they both address the issue of ascertaining whether the findings are grounded in the data. There are strategies which are recommended for increasing the possibility that the findings resulting from the research effort are credible and that they can be confirmed in the data (Lincoln & Guba, 1985). Hence, the process used in this study to arrive at the findings are outlined.

The interviews were transcribed using Word Perfect Corel 8. A computer software package called Qualpro was initially used to help with coding. It became too complicated to use and cost more in time than the benefit it was supposed to provide. The computer Word Perfect Corel 8 was used for line numbering and creating margins, highlighting and copying significant passages from the interviews and creating files where similar strips of data were stored under categories. Each line of the interviews were initially completely read and a descriptive code name was written to represent concepts arising from the data. Categories were coded manually using colour codes for ease of

identification of emerging categories and tracing concepts within and across interviews when making constant comparisons for theoretical sampling.

Qualitative analysis was employed using the constant comparison process, comparing each piece of data within and across interviews. This first stage of the research therefore provided descriptive data based on the informant's personal experiences and meaning attributed to their illness experiences. These qualitative data were analysed line-by-line on a continuous basis as the study progressed, using open codes to identify salient themes emerging from the data. Open coding was manually written in the margin, of words or phrases that captured dimensions and properties of emerging categories. Analysis involved noting the similarities and differences in the data and abstracting core concepts that were significant by nature of their repeated appearance or obvious absence when comparing each aspect of the data.

Ideas and conceptualizations about the relationships between categories and emerging concepts were documented in Memos. According to Morse and Field (1995), Memos serve to “help the researcher obtain insight into tacit, guiding assumptions. . . . increase the conceptual level of the research. . . . capture speculations about the properties of the categories, relationships of the categories or possible criteria for selection of additional participants to enrich the data. . . .enable the researcher to keep track of and preserve ideas that may be potentially valuable. . . .and noting important thoughts about similarities of emerging theory to establish theories and concepts” (p. 160). This is a strategy and source of confirming the findings with the data.



In this research memos were written in a separate lined pad. Questions were asked of the data and thoughts and analysis of these were written. For example, early on in initial coding of the data, a descriptive theme which was emerging to explain the phenomenon under study was “we don’t talk about it.” The code for which this was a property was labelled “lack of talk.” It soon became clear from examining the data that there was more than “lack of talk” that represented the phenomenon. The memo written at this point directed the researcher to make theoretical comparisons across all interviews for evidence of other properties besides “lack of talk.” The analysis led to understanding that there was a “lack of discourse” at many levels, extending as far as and including participants’ relationship with the community. It soon became clear that there were also properties of “lack of disclosure” and “lack of naming.” The question then became whether there was an overarching concept that would explain and subsume all of these subcategories. At this point, the word “blocking” was noted throughout an interview with a patient. It was used to describe all of the previously noted subcategories. A memo was written to theoretically compare all interviews for evidence of what was described as blocking. As data was analysed at a higher conceptual level, all subcategories previously identified through constant comparison within and across interviews, fit logically under this major ‘in vivo’ code “blocking.” This then directed the researcher to theoretical sampling for dimensions of blocking. Hence writing memos helped stimulate thinking, facilitated the analysis of data at a higher conceptual level and helped greater emersion into the data, identifying and directing further theoretical comparisons and theoretical sampling.

Axial coding involves “relating categories at the dimensional level” (Strauss & Corbin, 1998, p. 126). It forces the researcher to identify the contexts in which a phenomenon manifests itself and helps to elucidate the complexity of how certain events occur and also why they occur, so that explanations of the phenomenon under study are deemed more plausible and understandable. In the present research, dimensions of blocking were identified through use of a “flip-flop technique” (Strauss & Corbin, 1998, p. 94) on the central concept. These authors suggest turning the concept ‘upside down’ or ‘inside out’ to examine it from a different perspective. The question was then asked about what properties existed and whether there were dimensions of the core concept in this current research. Hence a theoretical note was made of what was thought to represent the opposite of blocking. The data was searched for evidence of Un-blocking and its properties. This directed theoretical comparisons of incidents where any dimensions of an open rather than closed dynamic existed with respect to blocking. The conditions under which Un-blocking occurred was also explored. Answers to these questions directed further theoretical sampling for evidence of properties of this dimension of blocking. Axial coding for major subcategories explaining why blocking was manifested, were found to be based on a need for protection vs. exposure to harm and maintaining connections vs. alienation from cultural and spiritual beliefs.

It was during constant comparison of data for the similarities within categories that what is referred to as “atypical cases” (Morse & Field, 1995, p. 139) or “outlying cases” or “negative cases” (Strauss & Corbin, 1998, p. 159), were revealed. These were cases

that demonstrated the range of behaviours that are represented in a category but also showed properties that were contrary or atypical. In the current study, an atypical case which led to further theoretical comparisons and sampling for variation, was the situation of an extreme form of blocking. Strauss and Corbin (1998) noted that “when an odd event arises in the data, there usually are intervening variables or conditions that explain that variability “ (p. 160).

This was borne out in the outlying cases in this study. It was found that those who attempted to “un-block” and returned to their traditional spiritual rituals in order to ensure the recovery of their relative, lost their faith upon the death of the relative. They then reverted to blocking. However, the form of blocking they reverted to had all the characteristics of blocking noted in the other incidents of blocking, but it now also included the abuse of alcohol and drugs. Hence, discovering these cases in the analysis, and including them as a part of building the theory with explanations of their properties and the conditions under which the variability occurs, increases the “generalizability and explanatory power” of the theory (Strauss & Corbin, 1998, p. 160).

Categories, events and actions that underlie categories were evaluated throughout the process and a matrix was developed in which to present the core category. Strauss and Corbin (1998) stated that the relevance of a matrix is that:

locating a phenomenon in context means more to us than simply depicting a situation descriptively, as would a good journalist or novelist. It means building a systematic, logical, integrated account, which includes specifying the relationship

between significant events and phenomena (p. 182).

Hence, the matrix represents a set of ideas that explain relationships between categories and is related to “action/interaction as it evolves and changes over time” and provides information about “ structure [conditions], properties, dimensions, and consequences” (Strauss & Corbin, 1998, p. 183). The matrix developed in this study was helpful in directing further theoretical sampling and in constructing diagrammatically (as seen in Figure 1, later in the analysis section of this document) the process involved in the overarching conceptual model derived in this research.

Controlling for researcher bias through ‘bracketing’ was an important goal of this research effort. One of the things worth noting was the insights the researcher gained when using an open-ended interview structure for data gathering. There is the illusion that one brings no preconceived ideas to the interview session, and that one attempts to allow the respondent, rather than the investigator, to focus the interview. The actual experience is far more difficult than anticipated, given instructions on this in the literature. Although specific efforts were made to gain insights into one’s own biases, to bracket ideas presented in the literature and to stay neutral in the researcher’s stance, this became a challenge when conducting interviews for this research. Unlike the quantitative interview which is “. . . something to be slavishly followed” ( Hedges, 1985, p. 77), the open-ended conversational interview required enormous effort to permit the conversation from moving away from the point (that is, the researcher’s idea of what the point should be). It is important to caution oneself to remember that is discovery of the respondent’s point of

view that is the goal, not validation of the investigator's viewpoint.

One particular challenging point at the beginning of the initial interviews that was puzzling and frustrating was to find on re-reading the transcripts that respondents were answering the questions on the pain of cancer with horrific stories of painful life experiences. The questions posed for the researcher were: Why were they going there? Were questions not being asked correctly? These questions were a springboard for gaining a valuable insight into truly understanding what 'suspending preconceptions' meant, and recognizing the degree to which one thinks one has suspended those preconceived ideas when in actuality one has not. It was at this juncture that the investigator began to carefully reexamine what these stories had to do with cancer-related pain. The cancer pain the respondents were talking about was more than pain related to tumor growth, it was a pain of life: a pain equated with every horrific experience of that life. There was nothing wrong with the questions posed or the answers given. It was simply the unique perspective from which these respondents saw cancer pain. Theirs was a perspective that was foreign to the investigator in whose mind cancer pain was pain related to cancerous growth not pain that reached all dimensions of what was painful in life.

It was at this point that the investigator could fully appreciate Strauss and Corbin's (1998) advice to use analytic tools such as questioning (and writing an analytic note) in order to enhance one's sensitivity to the data and to recognize personal biases. These authors noted that "questions are especially useful to the analysts when they are blocked in their analyses and cannot seem to see anything but the standard ways of explaining

phenomena” (p. 90). They pointed out that “although some analysts claim to be able to “bracket” their beliefs and perspectives toward data, we have found that doing so is easier said than done. We find it more helpful to acknowledge that these influence our thinking and then look for ways in which to break through or move beyond them” (Strauss & Corbin, 1998, p.99). This strategy of questioning and writing analytic notes enabled a greater in-depth analysis of the dimensions of cancer pain which might have otherwise been dismissed as irrelevant had the researcher not questioned the extent to which she was imposing her biased interpretation of what was meant by ‘cancer pain’. These strategies all contributed in increasing the possibility of trustworthiness of the findings.

### Ethics

Confidentiality was maintained by using a numerical code to label all data. No names or addresses or specific naming of community was mentioned in this report. Informants were informed, on the onset, of the voluntary nature of participating in the study and were again informed that participation in the study was not contingent on any care or other services received at the Health Centre (see Appendix D). All transcripts were tape recorded and transcribed by a typist, following confidentiality rules as outlined on form (See Appendix D). This form was also used for the interpreter. All material is stored in a locked cabinet at the University of Manitoba and will be held for seven to 10 years as required by The Medical Research Council (MRC) regulations.

In addition, all participants in the study were verbally informed of the measures that were taken to ensure confidentiality, at the beginning of the interview and then again

**in a written consent form. They then gave written permission to participate in the study (Appendix D). The proposal for this study was approved by the Ethical Review Committee of the University of Manitoba, Faculty of Nursing (Appendix A).**

**A description of the methodology and efforts used to ensure rigour in the research process has been discussed. The results of this research are outlined in the following chapter. A discussion of the findings, implication of the study and implications for further research follows this.**

## CHAPTER 5

### Analysis of Data

#### Introduction

This study consists of eighteen Ojibway respondents from a reserve in Eastern Manitoba, Canada and thirteen health professionals (nurses and physicians) from a hospital located in close proximity to this reserve and which is accessed by these Ojibway people for health care. The aims of this research were to: 1) describe and explain how cultural beliefs framed how Ojibway people, living on a reserve community, understood the illness experience of cancer and related pain and, 2) to describe differences and/or similarities between Ojibway respondents and health professionals' explanations and perceptions of cancer and related pain. The Ojibway respondents consisted of those people who were considered to hold discrete knowledge on this subject due to the circumstance of either having had cancer and related pain, having lived with a relative with cancer and related pain or having acted in the capacity of "healer" or medicine man to those afflicted with this illness experience.

#### Cancer and The Pain of Cancer: An Ojibway Perspective

#### The Core Concept: Blocking

#### An Overview

"Blocking" emerged as the predominant and central scheme which characterized all actions, reactions and interactions by these Ojibway persons, when confronted with the reality of the disease cancer and related pain. The inherent properties of blocking were

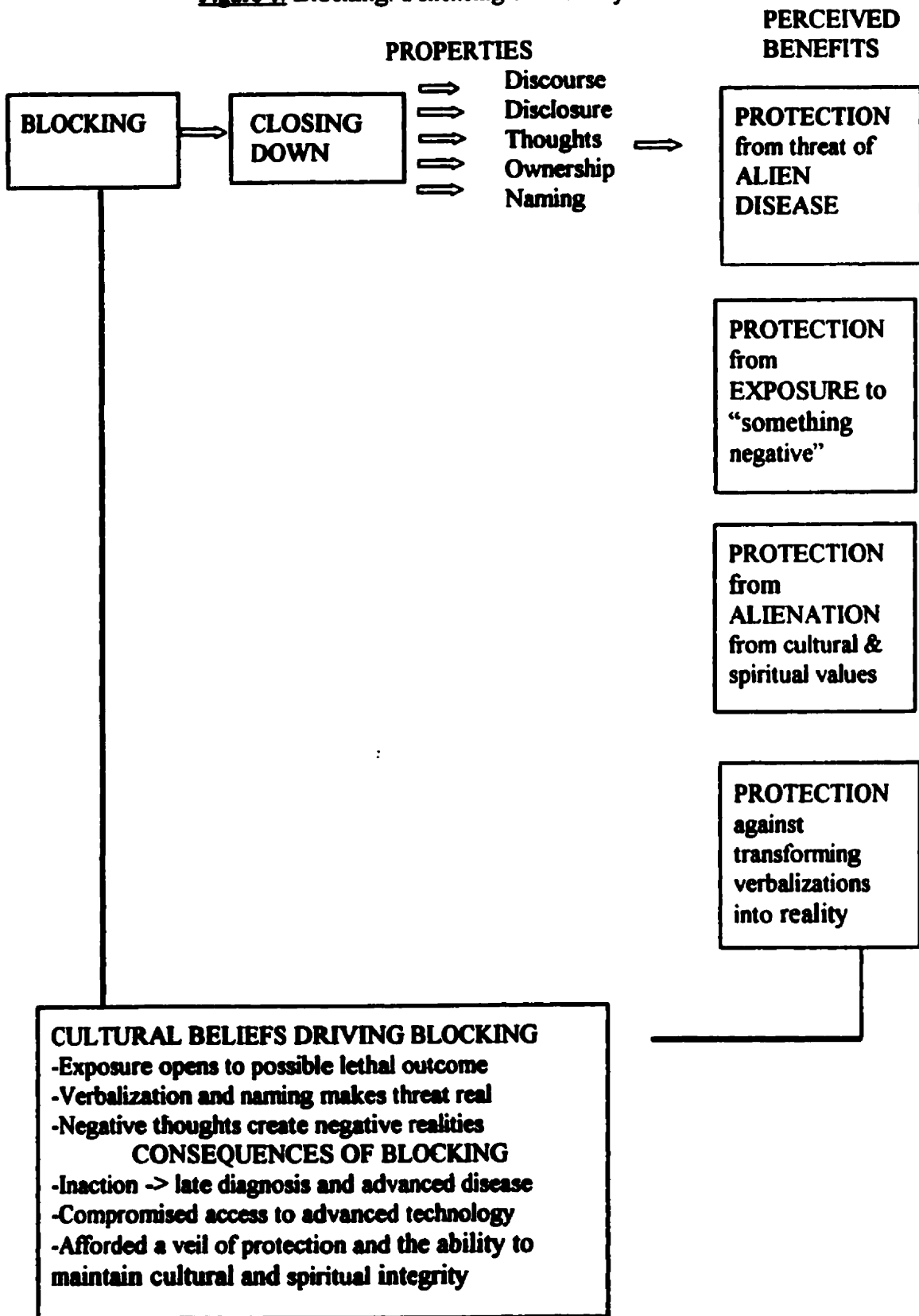


represented as a dynamic tension that swung between becoming “open” or “closed” to the vulnerability presented by a “foreign” and life-threatening illness. This dynamic tension to being “open” or “closed” about cancer is activated by a capacity for an action/inaction response between the disease and a person’s personal perception of vulnerability to it. Hence, conceptualizations about any aspect of this illness experience were couched in the operations of blocking. It was observed by respondents in their descriptions of a) the response of the disease itself b) the response to the disease c) the response of those afflicted with the disease to each other, relatives and community members and d) the response of seeking or not seeking help. Two major categories which were found to have relational properties to blocking were 1) exposure vs. protection and 2) alienation vs. connection to core cultural values. Hence, the inherent properties of blocking, represented in closing down or silencing on the subject of cancer, were directly related to efforts to protect rather than expose to harm and to maintain connections to core cultural values rather than become alienated from them.

Figure 1. Schematically outlines the construction of this explanatory scheme.

Blocking is evident in closing down on all discourse, disclosure, thoughts, ownership or naming of the illness cancer. This was a “respectful retreat into silence” in order to protect against the threat that an alien disease posed and the exposure it brought to a negative force which held potential for alienation from cultural and spiritual values. Clearly articulated cultural beliefs about exposure both physically and metaphorically and, the transformation of negative thoughts into negative realities were identified as the processes

Figure 1. Blocking: a silencing on the subject of cancer



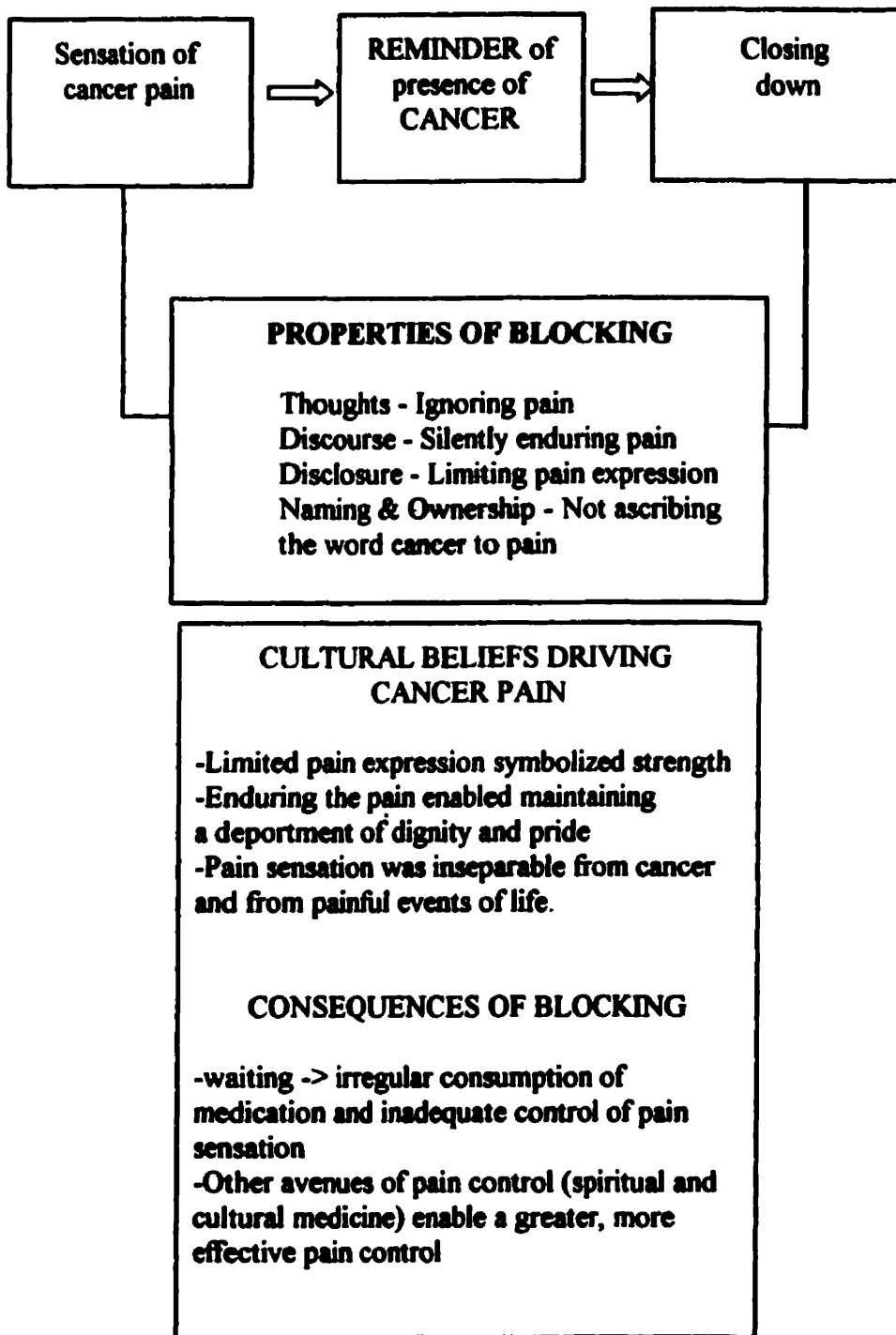
driving blocking. The consequences of blocking in the case of cancer, given the cultural beliefs held, offered protection and the ability to maintain cultural and spiritual integrity. The cost of blocking however, was the progression of the disease to a more advanced stage and denying one's self access to advanced technology at a point when it could have the potential to reverse the progression of the disease.

The same properties of blocking characterize cancer pain as noted in Figure 2. Silencing is characterized by ignoring the pain, enduring the pain silently, limiting pain expression and not ascribing the name cancer to pain. Beliefs about symbolic expression of strength, deportment, dignity and pride were noted to be the inherent characteristics of the cultural beliefs driving blocking in cancer pain. The consequences of blocking in cancer pain was evident in inadequate control of the sensation of pain. However, there was evidence of tremendous fortitude in enduring and controlling pain through spiritual and culturally informed means.

The supportive data for the construction of the concepts which demonstrate the explanatory power of blocking as a theoretical model for how participants in this study conceptualize and understand the illness cancer and related pain will be presented in the following pages. Further, the inherent properties of the central concept 'blocking' are shown to be grounded in the data. The dimensions of blocking, the contexts that trigger blocking and its consequences are also explicated by the data.

### **Blocking**

#### **The Response of The Disease: Action/Inaction Paradox**



The features of blocking, as described above, were evident in the discourse respondents had on the response of the disease cancer itself. The cancer or “manajoosh” in Ojibway, was defined as a “worm eating away at your stomach and insides.” The disease was presented as having an action oriented capacity. Not only did cancer eat away at one’s insides, it had the capacity to move to different parts of the body. When the disease moved from one part of the body to another it was perceived to be the point at which it became “serious.” A care-giver relative’s description of her mother’s illness course supported this assumption: “She had cancer in her lung but at that time it didn’t bother me . . . It wasn’t really like a serious thing . . . she got it in her throat at the beginning this time.” Her lack of perceived seriousness of lung cancer was further explored. She explained that the point at which she perceived the disease to be “serious” was, “not until she [her mother] contacted it again.” The response of action by the disease was obviously related to its enhanced lethality.

Interestingly, responding to the disease initiated a complex posture of blocking which was characterized by inaction on the part of the individual affected and all others threatened by it. This inaction was expressed in elaborate efforts to close down all avenues of a threat. The posture assumed in order to protect oneself at all levels of awareness was captured in the recurring themes of: “We don’t talk about it” . . . “I cut her off right away” . . . and “I blocked it out.” All of these responses seemed to be efforts at closing off any discourse on the subject.

The parameters of blocking extended to include perceptions around the action to

physically “open” or “close” the body by any invasive measures (e.g., surgery). The following responses from the perspective of patient, care-giver relative and healer illustrate this.

Patient: “ I can’t have them open me up ’cause as soon as they do that you’re done.”

Care-giver relative: “If you open it up, it just goes all over”

Care-giver relative: “I don’t know if it’s certain types of cancer, I guess, but it’s almost like it wants to be left alone. You leave it alone because, for some reason, once you open the body they seem to thrive on the air . . . I don’t know. This is just what I think.”

Healer: “Cancer creates an opening for something negative to enter his body.”

Taking action to expose the disease by invasive measures was perceived to have the effect of opening the possibilities of fatal consequences. It also held the potential to stimulate action on the part of the disease: the “spread” of the disease. This in turn exposed the body to “something negative” and activated the disease on its lethal course. Inaction could prevent this: “You leave it alone.” Therefore, blocking involved not only closing all discourse on the subject, as discussed above, but it also involved containing the disease by permitting it to remain closed within the body. The dynamic properties of closing rather than opening and of inaction rather than action were again the properties of blocking which clearly made it operational as a means of assuring protection from harm and exposure to “something negative.”

### The Response to the Disease: No Name, No Claim, No Threat

The response to the disease cancer by these Ojibway participants was again characterized by the dynamic properties inherent in assuming a blocking posture. In the context of discourse or disclosure with respect to cancer, blocking accounted for a closing down rather than an opening up on the subject: an inaction rather than action oriented posture to seeking help. The central property of a blocking posture was an avoidance of “talk” on the subject of cancer. This included any efforts aimed at opening discourse on the disease or exposing the existence of the disease. Statements such as the following excerpt were repeatedly found in the data:

Care-giver relative: I will say that my parents never really discussed it. Mmm . . . that some of the people we knew who developed cancer, ah . . . died of cancer. There weren't too many a long time ago in the community. We've been told recently that, ah, cancer started to be killing our people. So they didn't really talk about it.

The disease was perceived to be lethal: it was “killing our people.” As well, it was seen by many as alien to the Ojibway people. The statement: “it's a foreign disease to our people” was presented as a typical response to queries related to knowledge of the disease. Cancer was acknowledged by the majority of respondents to be called “manajoosh” in the Ojibway language. No one could offer a correct spelling for this word as, they explained, it was only ever referred to phonetically, never written. Others, especially the healers, denied knowing an Ojibway word for this disease. However,

**“manajoosh,” as reported by the majority of respondents, carried with it an enduring image of being eaten by a worm or a bug of some sort. One respondent was actually physically repulsed as she graphically explained what “Manajoosh” meant and what it looked like on X-ray of her mother’s breast.**

**“Manajoosh,” which is sort of like a bug . . . like a black locust, some kind of a locust . . . just feasting away into the body . . . icuk! Just horrible [physically shivers].**

**Not only were these repulsive images of cancer in the Ojibway word used to describe cancer, but there were also frightening meanings ascribed to it. For example, one respondent noted, “the first time I heard about it, it was scary.” One simply said, “deadly.” Many associated it with the word “death” and “terminal.” One patient’s description captured the element of life being snatched away from him at the point of learning about having cancer with the prospect of never returning to life as it was before hearing that name. He offered:**

**Cancer means uh, sickness like your life is going to stop. Like uh, it's not going to go on. Like, like with mine, uh, when I heard about me getting cancer, it's like my life was stopped right there. Like my life flashed in front of me . . . . It will never be the same.**

**These descriptions reflected the threat that this disease held for these people. The response to that was a blocking posture which was for the most part characterized by closing all discourse on the subject: “So they didn’t talk about it.” This became a repeated**



theme in the response to the disease cancer. Paradoxically, this inaction represented by 'not talking about it', was designed to protect them from harm. A rapidly progressing disease such as cancer, which holds little promise of retardation of its lethal outcome without early detection and quick action, was approached with retardation of action. Hence, this attempt to close and therefore protect oneself from harm unfortunately had the potential to render one open to the pathogenesis of this biomedical disease called cancer.

Hence the question arose: what was driving this paradoxical course of events? The pieces of the puzzle came together through a series of incidents describing why "they didn't talk about it." In an incident where a daughter-in-law was diagnosed with cancer, her care-giver relative reported "and yet she never ever said the WORD leukemia or cancer, never! It was like a taboo. Like I said it was . . . er . . . you didn't talk about it" The respondent then revealed a story about a visit to a close friend with cancer. They both knew of the diagnosis, but throughout the entire visit, no one mentioned the word cancer. At the end of the visit, there was mention of probably not seeing each other again. However, no other inferences were made to the illness or naming it. The respondent concluded this story by saying, by way of explanation, "That's something cultural, . . . I don't know . . . er . . . but it's not a state of denial. It isn't." This demonstrated the difficulty in unraveling the intricacies surrounding this lack of discourse and disclosure on this topic. However, it provided information about what this particular circumstance of "not taking about it" was and what it was not. It was a taboo subject: it was not denial. The reason it was not denial was because the patient knew about it and so did the friend.

It was simply taboo to talk about it.

A further rationale for not talking about cancer was elaborated upon by this respondent. She noted “. . . it makes it very real! Yes . . . If I don't talk about it, then it's out there, maybe it's not mine, it's not, you know, it isn't.” The idea of it being “out there” is related to the belief among these respondents in this community, that cancer is a disease of the white-man and is seldom found among First Nation people. One respondent explains that she “read a lot about the disease” following her sister's death from it and concluded that:

The likelihood of it (cancer) occurring is not there because it's not something that is prevalent in the Aboriginal community, it's not. It never has been. I don't think. It's just in recent years that it has become more and more prevalent.

Many other respondents concurred with this opinion. Therefore, the implication was that talking about it made it part of the reality of their world. Hence, the less one talked about it, heard anything about it or claimed ownership of it as part of a common life experience, the less potential it had for becoming entrenched in the psyche of the community as a bonafide threat. Closing off discourse on the subject therefore had the potential to minimize the threat of personal vulnerability to it.

Another way of closing off discourse on the subject was not to name it. It was noted that the Ojibway healers, when asked about the disease cancer, denied any knowledge of an Ojibway name for the disease. Some of the respondents in the study also stated that they knew no other name for cancer in Ojibway. Some indication of a deeper

cultural interpretation of the dynamics of blocking can be gleaned from this healer's explanation about naming diseases, especially in the case of cancer:

It's really . . . ah . . . very interesting when you [silence] when the western world has identified the various types of sicknesses. In my language there is no term for, for cancer. Ah . . . in our healing ceremonies we, we treat whatever is affecting the human being, physically or mentally as a sickness, but there is no specific identification of sickness when it comes to our understanding of dealing with a problem that ah . . . a human being may go through.

Clearly, according to this healer, naming of diseases is a preoccupation of the medicine of the "Western world." He (the Ojibway healer) dealt with sicknesses of human beings. This needed no label, no name. Since he treated the human beings he came in contact with "physically and mentally," there was no need for this. Naming, especially in the case of cancer, according to this healer, had the effect of influencing the mind. He offered, "Cancer has been a sickness of which . . . in the human being's mind is fatal." Hence, influencing the mind with a name, especially one that had lethal implications, forced ownership of all that the label connoted. He continued to explain that: " So, once you put something in your mind, your mind usually becomes the fulfiller of that thought . . . becomes self fulfilling in terms of what you think and what you have read." Therefore, he concluded, a name is not required "in order to defeat a sickness such as the one you are talking about."

It was also significant to note that the name "cancer" was not referred to in this

context by the healer. As if to demonstrate his point, he spoke about the disease in a manner consistent with his beliefs about naming sicknesses. That is, he concluded his statement with “a sickness such as the one you are talking about.” He did not name it and neither did he own it. Rather, he implied ownership of the name to be that of the researcher’s. This deflecting of ownership to another source “out there,” as noted earlier, was in keeping with a similar position taken by many other respondents on the subject of cancer: it was “white man’s disease.” Moreover, not accepting personal ownership of this disease was further expanded to actually include the perception of a possible tacit immunity to cancer. This was well illustrated in the following incident:

I recall one elder saying, well . . . er . . . he was smoking and he said, well, Native people don’t get cancer so I’ll smoke all I want because we just don’t get it. It’s not our disease. It’s white man’s disease.

Clearly, these data demonstrate evidence of a well-articulated process in blocking, which explained the response by these respondents to the medical disease referred to as cancer. It was characterized by not naming it, not talking about it and not claiming it as part of their personal world-view as First Nations people. It was well grounded in a discrete set of culturally shared beliefs about the meaning attributed to cancer and the need for protection from a perceived threat to life.

#### The Response of Self to Others and the Community: Retreat Into Silence

In keeping with the beliefs held about the disease and the well-orchestrated efforts to close off any discourse on the subject of cancer, a blocking posture was also evidenced

in the interactions between care-giver relatives, family, and community. This is not to imply in any way that family, close friends and community are not important to Ojibway people at the point of illness. On the contrary, the data revealed that there was a profound need for connections to family and community at the time of illness. All respondents testified to the need for having family within close proximity at this time due to the immense support and connection to cultural and spiritual values that this offered. This was clearly demonstrated by the pejorative nature of the statements used to describe the loss of these connections when hospitalized (which will be discussed later). As well, this need for close family connections were specifically evidenced in the responses given by both care-giver relatives and patients about their interactions with each other. There is a clear distinction noted between the need for these families to maintain closeness while, at the same time, a decided effort to change the nature of the interaction as it pertained to discourse on the disease cancer. These incidents clearly reflect this.

In the situation of a patient at the time of her hospitalization she noted: "I strongly would believe, to each their own but, I think the biggest medicine is my family, my mother and my sisters." This represented a typical response of patients with respect to the importance of family. Further, in the situation of a daughter and care-giver relative, the need for family closeness is expanded upon. She offered: " It is important for our people: for the person that is sick. And, like I said, that they are not, they are not by themselves." Here the importance of togetherness was pointed out and the reason for this given. That is, a sick person should not be alone. Interestingly, this incident portrays an

acknowledgment of the importance of this belief, not only in reference to a specific individual, but to “our people”: the Ojibway people.

However, when the disease cancer becomes the identifiable “sickness” that a family must confront, a blocking posture presented as an integral part of the interactions noted between the patient and loved ones. The nature of the closeness changed when the person had cancer. Therefore, despite a desperate need for closeness when someone was sick, the discourse between families was marked by an absence of “talk” about the illness. This is captured in an incident related by a care-giver relative.

*I couldn't, I couldn't . . . I don't ever remember comforting her . . .*

*At that time I could, because I slept with her and stuff like that . . . to be close . . . to be closer to her. I laid down with her a lot, but I never told her that everything is going to be Okay or anything like that. I'm sorry, I don't know how a person would interpret that culturally.*

There is an obvious absence of comforting “talk” that transpired between these two people in a situation that so desperately demanded it. The respondent declared her need for closeness in the situation and hinted at some regret in her inability to offer some kind of comforting word. She hinted at a cultural interpretation which eluded her at this time. The blocking posture however, did not preclude a need to maintain close family connections or a need to be close. It did however mute the interaction between loved ones. A similar dynamic is characterized in the following incident:

*She spent the weekend at my place and she and I sat up until 6:00 in the morning*

and just you know, not necessarily talking, but just to be with each other . . . and there was not a time where I brought up her illness. We talked about her pregnancy.

Here we are introduced to the expanse of time spent together in a supportive interaction between patient and care-giver relative. Yet, concomitantly this supportive interaction was decidedly devoid of “talk” on the subject of the illness cancer. The respondent reported talking about other things, like her pregnancy, but the interaction was closed on the subject of cancer: an unspoken agreement not to talk about it, driven by the belief that talking about it made it “real.” Blocking afforded a degree of protection from the dreadful situation being encountered.

Repeatedly care-giver relatives admitted to the difficulty in talking about the cancer and of deliberately blocking any discourse on the subject with the patient, as this statement typifies: “When she was going through her illness, the cancer, I had a difficult time of talking about it with her. There was a real blockage there.” Patients as well, engaged in blocking by not disclosing to wives and children that they had the disease.

He just said it was a minor operation and that’s what he told the kids too, he didn’t tell us it was cancer . . . No, he didn’t tell us how serious it was . . . The doctor said they told him . . . but after his operation he never said another word.”

The reaction of the family, as reported by the wife in this incident, was that “we numbed ourselves, we didn’t have to think about what was going to happen, so we could cope.” Numbing oneself being presented here as a property of the blocking posture. In this

situation the patient died a month after surgery. Neither he nor his family had talked about the cancer when it was possible for them to do so. He was silent: they numbed themselves. Interaction on the subject of cancer was closed in this blocking posture.

Again, what is significant to note in this particular incident, is the compelling evidence of the families' need for physical closeness at the point of illness, despite the need to temper that closeness with a blocking posture. The care-giver relative referred to above, shared with the researcher that this patient had been both an abusive husband and father. Yet, at the time of his illness, the family all felt compelled to be by his side. She noted: "We sort of knew we had to be there, but we weren't sure, well by myself anyway. I knew I had to be there, but I wasn't sure if I cared." This offers compelling evidence of the intensity of the need for the family to be physically close to each other and the need to maintain family connections when ill. It would appear to go well beyond a specific family's need to be close to a special loved one. It was expressed as an expectation and a perceived duty of any Ojibway family in the situation of serious illness and hospitalization "to be there," regardless of the relationship one had with that family member. This respondent narrated in graphic detail, the abuse she suffered at the hand of the now seriously ill individual. She had finally had the courage to leave that abusive situation. Yet, at the time of serious illness and hospitalization, she returned to be by this ill person's side despite the fact that he had been her abuser. At the same time, because that serious illness specifically involved cancer, the dynamics of the closeness afforded the ill individual was modified by family members. Therefore, although still compelled to be there physically, they were seen



to close all discourse on the subject of cancer. The interactions were overshadowed by a blocking posture, characterized by not talking about it.

In a similar situation involving a daughter and her mother, the frustration experienced by family members around the issue of “not talking about it” was evident. The respondent reported:

*She knew the symptoms. She worked with a woman, one of her best friends who had died of breast cancer. She knew, but she didn't want to say anything to us because I knew it was her way, she was protecting. . . . She carried a lot of fears but she didn't want to look weak in my eyes or she wanted to be strong all the way and that kind of made me so angry, pissed me off because like. “I DON'T NEED YOU TO BE STRONG. I need you to get well.”*

Here, another revelation of why a blocking posture was assumed by the patient was noted. The lack of disclosure or discourse on the subject was revealed to be an attempt on the part of the patient to “protect” and to “be strong.” In this case, the daughter felt anger in response to this, yet maintained her counter role of silence. This silence on the part of families with respect to disclosure went as far as inhibiting family members from even seeking confirmation of the presence of the disease. As one respondent offered in response to having had a brother with the disease. “He must have had cancer.” He continued to describe his brother’s weakened state as “skin and bones” before his death. However, he noted that “when a doctor told him he couldn’t help him very much, that’s when he went down. So, that must have been cancer, but nobody in the family wanted to find out what’s

wrong with him.” Other respondents reported similar revelations. One care-giver relative offered that the reason for her silence was because “I respected her privacy.” They all expressed feelings of helplessness while silence on the subject prevailed.

Blocking not only applied in interactions between families, it also applied in interactions with the broader community. At the point that it became “known” that the person had cancer, patients were reported to actually break strong previously held connections with their community. There appeared to be a suggestion of embarrassment about having cancer. That somehow having succumbed to this “white man’s disease” had the potential to somehow weaken that person’s stature in the eyes of the community. This was well illustrated in this incident:

I recall this lady who was a prominent lady and a leader in the community. She was struck with breast cancer and at first, you know, not talking about it. Eventually it was well known that she had breast cancer and she went into virtual recluse. She wasn’t seen anymore publically even when she was a leader, and she died that way.

A dynamic tension is seen to exist in the effort on the part of patients and loved ones to close interaction on the subject of cancer as a means of protection and paradoxically, open themselves to the possible loss of valued connections. The stories narrated around this conveyed an almost tragic yearning for closeness and support at a time of profound need on the part of all involved. Yet, what ensued was a carefully negotiated avoidance of “talk” about it, “numbing” and breaking of all ties with the community, on the part of the players. Anger and feelings of helplessness were endured by

loved ones as a measure of respect and the understanding that blocking afforded a silent gesture of protection for all involved. As one respondent offered when re-contacted for confirmation of the researcher's interpretation of the research findings, this property of blocking was a "respectful" retreat into silence.

#### The Response of Seeking or Not Seeking Help: I Wait

This stance of blocking and thereby "not talking about it" greatly influenced the extent to which patients were prepared to seek help before the disease reached an advanced state. Over and over again, care-giver relatives spoke of having to force relatives to see a doctor because of reported complaints of distressing symptoms. All patients reported discovering by accident that they had the illness cancer after visiting the physician for one or more severe, persistent symptoms. The two most frequently identified experiences that prompted a visit to the physician were any signs of blood or pain. Some visited a healer before visiting a physician. Regardless of who was sought out eventually for help, it was usually done too late to effectively retard the progress of the cancer. "They wait too long" said one wife, "probably if he listened to me to go see the doctor, it would have been a lot more hope." The word "wait" was repeatedly used by patients or care-giver relatives to describe the response to seeking help. It was revealed as one of the most unfortunate properties of blocking as it hindered any possibility of early intervention with respect to the cancer or amelioration of pain. It was remarkable to note the number of incidents where a patient responded with two simple words: "I wait," or a care-giver relative remarked "he would wait." Obviously, waiting held the potential to delay the

inevitability of confirmation of the disease.

Patients admitted to having had many symptoms or of having some intuitive knowledge that they had cancer. Yet, they only sought help when symptoms became too severe to ignore. Clear examples of this were revealed in incidents such as when a caregiver relative reported that “It was the bleeding that caused her to go to the doctor and I . . . ah, remember even hearing her say that she was in pain . . .” or another, where the drama of the desperate efforts needed to persuade a patient to seek medical help was captured.

With my mom it really made me angry when she was diagnosed with it because I said to her, let’s go to a doctor mom. She said, no, I don’t want a doctor to touch me. ‘Well he has to look at your breast mom’, I said, ‘in order to see what it is.’ I cried and I cried when she showed me her breast and the way it looked. It was like a . . . her breast was hard like a rock . . . Oh, it was at the end . . . Even at that point she was reluctant to see a doctor . . . ‘It’s okay mom,’ like, when she showed me her breast, I said, ‘why didn’t you say something, why couldn’t you tell us something was wrong?’ I kind of noticed there was something for about six months, she was always complaining of being tired. She couldn’t have enough rest. She was losing weight. Her skin color was getting a different color.

Later in the discussion, this respondent offered an explanation for her mother’s reluctance to see a physician. There was a cultural dictate underpinning this: “We, as a native people, as woman, we were taught to uh, not to flaunt our bodies, not to show our bodies . . .

tradition handed down is not to show yourself, it's a sign of respect." Again, a dynamic tension is created between strongly held cultural beliefs and action necessary to confront this disease and seek the required help.

Cultural dictates prohibited exposure of private parts of the body: breast cancer created a circumstance where private parts of the body are required to be exposed. Furthermore, the very assessment for the presence of cancer involves exposure of private parts of the body to examination. Therefore, to take action to expose the body to the physician in this case, was in direct conflict with the strongly held beliefs of this Ojibway woman about not exposing the body.

The dynamic of properties of blocking characterized by closing rather than opening and assuming inaction rather than action is again evident here. Here, these dynamic properties of blocking are related at the conceptual level to exposure vs. protection at both a concrete and symbolic level. Exposure, created by the act of literally opening up the body to inspection and examination by a doctor, was couched in fears and taboos. Inaction, on the other hand, served as a protection from the vulnerability to harm that exposure brought. This notion appeared to be the recurring theme which underpinned the dynamic tension inherent in the blocking posture. That is, a tug between taking the risk to symbolically expose ("open") oneself to possible harm by not respecting the dictates of culturally held taboos, or remaining "closed" and protected in inaction. Unfortunately, in the case of cancer, this inaction in an effort to keep the body protected from examination and inspection, carried with it the potential to expose it to fatal consequences.

It was acknowledged at this point of analysis that 'blocking' as a concept could easily be mistaken for the defense mechanism 'denial' and dismissed as a theoretical construct already identified in psychoanalytic theory. It was incumbent upon the researcher in analysis of the data, to make theoretical comparisons in order to explicate the differences in concepts. Strauss and Corbin (1998) suggested that:

when we are confused or stuck about the meaning of an incident or event in our data, or when we want to think about an event or object in different ways (range of possible meanings) we turn to theoretical comparisons. . . . Derived from the literature and experience. . . . are tools for looking at something somewhat more objectively rather than naming and classifying without a thorough examination of the object at a property and dimensional levels" (p. 80).

It was necessary therefore to examine and compare the properties of 'blocking' with a similar construct in psychology called 'denial'. In discussion of denial in psychoanalysis theory, the theory of defensive mechanisms is theoretically linked to psychopathology. Denial was regarded as a defense against the external reality which, although not viewed as pathological in childhood, was viewed as such when observed in adulthood (Freud, 1946). Freud's representation of denial, as discussed by Eagle (1984), was as a primitive defensive process which was associated with severe character disorder for which treatment was aimed at correcting unconscious motivations and distorted beliefs. The premise therefore was that by definition, denial, when conceptualized from the traditional psychoanalytic perspective was a "forceful unconscious defensive act in the

perceptual process that leaves the basis of threat outside the patient. It is an 'unconscious selective blindness to unpleasant facts'" (Salander & Windahl, 1999, p. 277).

In contrast to the psychoanalytic theoretically defined concept of denial, the properties explicated in blocking speak to deliberate conscious action ("a respectful silence") on the part of the participants of a cultural group, not to openly talk about, disclose or recognize ownership of cancer as a disease common to the Ojibway. There are clearly articulated cultural beliefs around protection, respect and maintaining of spiritual and cultural integrity which were identified as driving blocking. As well, consciously orchestrated actions described in blocking demonstrated no evidence of unconscious motivation. Salander and Windahl (1999, p.272) explained that, ". . . it is dubious to implicitly define 'denial' as a conscious point of view." Therefore, there is good evidence that 'denial', a psychoanalytic defensive process is conceptually different from and should not be confused with 'blocking', the emerging theoretical model for understanding cancer in this Ojibway community. Further interviews and observations gave rise to the dimensions of blocking and more specific and defining information.

### Partial Blocking

#### Indirect Talk

It was in the context of making a decision to seek help that yet another dimension of blocking was revealed. Although blocking remained the operating modality responsible for delay in seeking help, this did not represent a continual closing off of all discourse on the subject of cancer. There were efforts on the part of some to break the silence and hint

to a close relative that they suspected that they had cancer. Partial blocking was identified as a dimension of blocking that was characterized by “indirect” talk and/or disclosure about possibly having cancer. This care-giver relative’s response aptly described this partial blocking posture expressed by some respondents: “No, we never could really talk about it openly. Uh, it was just almost like when she did talk about it, it was indirectly. I had to pick up the message from what she was saying.” Another type of indirect disclosure was in the form of voicing suspicions of having cancer to a close relative. Many respondents reported in surprise, responses as reflected in this statement: “She knew before the doctor knew, that she had cancer and I didn’t believe her.” Although in this particular case, the daughter had trouble confronting the possibility that her mother had cancer, this intuitive knowing was often respected. The disclosure of the suspicions about the symptoms was often the prompt that forced the behaviour of seeking help.

The data revealed that, other than mis-diagnosis, time lost in not talking about seemingly suspicious symptoms and hiding them from family members could well have contributed to the number of cases discovered in an advanced state. As reported by this respondent, “The interesting thing is that when someone is stricken with cancer in the community, more often than not, they succumb to it, rather than being survivors and that’s because . . . it’s diagnosed later as opposed to early diagnosis.” However, at the point at which there was some talk on the subject, it was often in an oblique or indirect fashion. Although this partial termination of a blocking posture was late and limited only to a close relative, it did serve to initiate the response of seeking consultation from a medical person



or a healer. Unfortunately, once the naming of the disease was pronounced upon the person by way of a diagnosis confirming the presence of cancer, the blocking posture was resumed. As noted in the earlier discussion, disclosure was again blocked. In the following incident, a daughter explained what happened after she was finally able to persuade her mother to visit the doctor. Here are explicated the critical elements of blocking, resumed after diagnosis of cancer:

When she came out of her appointment I said, 'What did the doctor say mom? . . . 'Never mind,' she said 'you don't have to know' . . . Nobody would talk, not even my dad. We couldn't talk about it. You never really knew, it was always guessing from day to day. It was difficult.

The number of incidents demonstrating this identical dynamic attests to the fact that blocking was not a static state. The appearance of severe symptoms or intuitive knowledge of the possibility of cancer, occasioned a posture of partial blocking which was characterized by indirect talk about the subject to a close relative. Family members tried at this point to mobilize action for physician consultation. Although stubbornly adhering to a blocking posture by waiting until symptoms could no longer be denied, there was a critical point at which there was evidence of a desire to break the silence. This prompted only a temporary opening of discourse on the subject, but it presented the potential for a small window of opportunity for possible disclosure, discussion and seeking of help, albeit often late. Unfortunately, a blocking posture was fully resumed by the ill individual upon confirmation of the diagnosis of cancer.

### The Response to Cancer vs. Other Diseases

The data revealed that there were clearly articulated cultural beliefs which were the driving force behind the assumption of a blocking posture. Given this, it seemed logical to ascertain whether the blocking posture identified in response to cancer by these Ojibway respondents, was a general response to chronic diseases with no known cure, or whether this was a stance taken with respect to cancer alone. Theoretical sampling for characteristics inherent in blocking as they pertained to other chronic diseases with no known cure was carried out. Two other diseases were identified by care-giver relatives as those with which they had previous experience: Parkinson's disease and diabetes. A care-giver relative's perspective on her and her family's response to her father's diagnosis of Parkinson's disease was instructive:

My father now has Parkinson's and my whole family is more involved with what happens to my dad. There they look at the progression of his Parkinson's and we accompany him to the doctor's office for his appointments whereas with my mother, I was the only one that like, accompanied her to the city. I don't know if the difference is because they knew my mother had cancer and they didn't want to be too closely involved . . . I don't know what it is. I haven't, I haven't figured it out yet.

The most impressive revelation noted here was that the experience was different. Further, the difference was noted in terms of the involvement on the part of family members when dealing with Parkinson's disease as apposed to that of cancer. She voiced a puzzlement at

why there was a difference and could offer no reasons for this although impressed by the change in her family's reaction in the two situations.

Another incident served to further elucidate this difference. A discussion on this topic between the investigator and a respondent, captured the distinctive differences about cancer, which made the response to it different from that of other diseases. In this interaction there was an attempt at providing an explanation for the difference between the response to cancer and that of diabetes.

Care-giver relative: That's because there's just such a taboo against having Manajoosh or something . . . It's easier to start up diabetes support groups, for instance.

Investigator: Because people will talk about diabetes?

Care-giver relative: Yeah, it doesn't . . . yeah . . . I guess um, you equate that [Cancer] with a death sentence. And yet, in the end, diabetes . . . er . . . complications of diabetes, is a death sentence too!

Investigator: But it doesn't have the same "stuff" attached to it as cancer?

Care-giver relative: Yes, yup, . . .

Investigator: Do you know why? . . .

Care-giver relative: That uh, the word itself is so insidious, it's something like an invasion on your body, like this something is eating at you whereas diabetes is not.

Investigator: It's "eating you away," and you can't do anything about it.

Care-giver relative: Yeah, and that doesn't have the same implications as someone

who has diabetes.

In keeping with the fearful images offered earlier with respect to the Ojibway word “Manajoosh,” this explanation lends credence to the reason offered for the difference in conceptualization of cancer. The perceived “invasion” by cancer was such that it rendered the body captive to its fatal onslaught. Clearly, the fear and loss of control that accompanied this was far more overwhelming than in the case of diabetes. Diabetes did not have the same dreaded implications of an automatic death sentence and invasion of the body that cancer promised. Therefore, the idea of not making it “real” through acknowledgment in word and action, served to assuage the overwhelming implications of this particular disease called cancer. Hence, as this respondent continued to explain, it was not difficult to understand how “the secrecy,” a property inherent in blocking, could at least offer some degree of temporary solace.

#### Summary

In summary, a distinctive set of behaviours were demonstrated to represent the blocking posture assumed by Ojibway people in this community, in response to the disease cancer. Blocking was observed by respondents in this study to explain a response specifically related to the disease cancer as opposed to other diseases with no known cure. Blocking encompassed a whole range of behaviours at the core of which was deliberate action to close off all discourse or disclosure on the subject of cancer by “not talking about it.” This extended to involve a well articulated set of behaviours undertaken for the sole purpose of maintaining a silence and secrecy around this disease in an effort to

protect self and family from its deadly course. These behaviours ranged from: not talking about it to self, relatives or community; not naming it, not owning it, not disturbing it by any invasive means; and finally, making a decision to “wait” until appearance of severe symptoms and then only to indirectly talk about it. Partial blocking, characterized by “indirectly” talking about cancer to a close relative and opening up a discussion about seeking help, revealed another dimension of blocking. Unfortunately, in partial blocking, upon confirmation of the disease by a physician or healer, indirect talk and action were again closed and there was a resumption of blocking. This demonstrated the dynamic properties of a blocking posture. It proved not to be a static state.

Interestingly, cultural beliefs surrounding exposure vs. protection, were the driving force behind assuming a blocking and partially blocking posture. Paradoxically, inaction and lack of discourse about cancer (inherent properties of a blocking posture) held the potential to: expose to deadly outcomes, prevent possible chances of arresting the disease before it reached advanced status and modified the quality of both family and community interaction and support. Therefore it could be concluded that from a biomedical perspective, blocking afforded none of the protections it was designed to offer with respect to the lethal course of this disease. However, from a cultural perspective, it did serve as a protective veil against the perceived embodiment of “something negative.”

#### Contexts Which Trigger Blocking

It can therefore be concluded from the previously cited incidents in the data that there were certain contexts in which a blocking posture was triggered. These contexts had

in common two major relational themes: exposure and alienation due to loss of the connectedness with all that was culturally meaningful and supportive. This occurred in 1) the context of affixing the name cancer to the illness state being experienced 2) the context of hospitalization and 3) the context of death from cancer: the final breaking of connections to spiritual integrity.

### Affixing the Name "Cancer" to the Illness State

The disease cancer was itself perceived to be alien to the Ojibway culture as noted in the many accounts describing it as "foreign to our people." Not only was it alien, but it was also alienating. This was noted in the recurring statements used to describe the meaning attributed to cancer such as: "deadly"; "death right away"; "death sentence"; "alone." As noted in the previous discussion, the data was replete with telling incidences of blocking with reference to the possibility of having the disease cancer. Although it is unnecessary to repeat the points made earlier on this topic, it is critical to illustrate the magnitude of the alienation that is experienced when a blocking posture is assumed. From the very point at which the word "cancer" was affixed as a diagnosis to the illness being reported, efforts to avoid "talk" on the subject were mobilized by both patient and relatives close to them. In the following situation a patient explained her reaction to the diagnosis:

Well, to me it's . . . er . . . something devastating to me, my life, my family . . . For me, I try to block, leave a block ever since I've heard I have cancer. I've learned to block it out of my life . . . I haven't been talking to no counsellors or been in

contact with anybody that's had this disease. I haven't been able to talk about it to anybody.

There is an almost tangible sense of alienation and aloneness captured in this respondent's statement. Interestingly, this was a patient who admitted to having received this diagnosis over a year ago and had received a mastectomy and chemotherapy as treatment intervention. From the point of having had the illness diagnosed as cancer, she assumed a blocking posture which created for her, a climate of alienation from possible medical and psychosocial support from health professionals. It was also important to note that it was not only those persons diagnosed with cancer who created this climate of alienation from social interaction in the broader community, but support persons were also noted to behave similarly upon learning of a relative's diagnosis of cancer.

In an incident where the patient took the risk to share the information about her diagnosis with her husband, it was clearly evident that her news was the source of his alienation from her at least at a verbal interactional level. One respondent noted: "I went in my house and my husband was home already. He said 'what's wrong?' So I told him I got cancer. It just came out! 'I got cancer'. Then he got up right away and went outside to walk around." They did not talk about it after that, she explained. Even in this situation where the patient, to her own surprise, had not initially assumed a blocking posture but blurted out her diagnosis to her husband, the response to her was to literally move away. Hence, there seemed to be no escape from the alienating ramifications of having the illness named cancer.

### Alienation and Loss of Connections

The genesis of the alienation that was expressed within the context of being diagnosed with cancer was revealed to have roots in the history of a larger alienating force: that of the coming of the white man. This was seen to represent the beginning of an onslaught of devastating diseases which were imposed upon First Nations people. As one healer lamented “our people are dying of cancer, dying of diabetes and whatever other disease there is, and it is hard to describe the pain we feel as Anishinaabe.” This was a sentiment shared by many respondents on the disease cancer, which they described as one that “they have brought us.” As noted in the following response of another elder in this community, there was a definite connection made between the effects of oppression and the loss of a more healthy indigenous lifestyle, and the susceptibility to cancer.

It could easily bring you back to . . . the history of the first coming of the white-man, and of all the things that ever happened to the Anishinaabe. Gradually, in all these years, it has taken its toll. The rejection, the resentment, etc. etc . . . the lack of respect. *It (sic. cancer) could generate from that.*

There was also a sense that things were better in the past: “Before the European people came here” another respondent explained, “our people lived in peace and harmony. They lived with the land, they lived off the land. They were healthy, you know. They didn’t need a white doctor to tell them how to live.” Hence vital connections with that which was significantly meaningful to them as a people in the past were now lost, rendering them vulnerable to disease.



Furthermore, it was the adoption of the lifestyle of the mainstream society that further rendered them susceptible to health hazards. This was revealed in the statement of an elder, who noted: "Well, times have changed, we have lost our livelihood. We've lost our traditional medicines and we begin to try to live like the rest of the larger society, which is very unhealthy for us." Central to the beliefs expressed here, was a sense of alienation from a way of life that once protected them from becoming vulnerable to disease.

Even more critical was the expressed belief that this alienation from the land created a susceptibility to cancer. This resulted from wide spread contamination of their water and land with chemicals, and pollutants and other measures devised for the sole purpose of controlling the natural events of nature. In a well-articulated statement on this subject, a father whose twenty-one-year-old son was dying from cancer surmised: "You know, we look at things in different ways as Anishinaabe people." He proceeded to provide an explanation of what he meant by this:

Our immune system is not used to the preservatives that are being put out there, and our natural diet is gone. We don't have the luxury of living off the land anymore. You put a net outside here, without a bag, I guarantee you that within a day your net is full of garbage. You can't use your net anymore. You've got to pull it out every day and then, what guarantee do you have that the fish is any good? ...You can't eat the fish. You go into the bush. You try to get wild life. If the law doesn't come by for you for hunting them, if you are lucky enough to bring

one, are you sure it's clean? Because that animal has to eat all the pollution that the mill sends within this area. He is eating off of the land. So, how do we know what that animal ate . . . I suppose our medicine would have been potent but not now, because of the chemicals being sprayed . . . it's all those chemicals that kill the plants . . . You know, the Red River Valley is the most fertile land in all of North America, but at the same time, it's the most abused land because of the chemicals they use . . . About the flood that was done here in the south, it's mother earth that will clean itself, you know. And she did, and now they are trying to turn that around . . . building more dams and everything. Now they are going to cheat her from cleaning herself.

Here the respondent clearly pointed out the domino effect that chemical and technological contaminants have had in causing susceptibility to cancer. The ramifications of contamination broke the cycle of vital connections to sources of food, water and even the healing medicines once enjoyed. The technological structures built to control nature resulted in prohibiting the "cleaning" away of these contaminants through natural processes.

Interestingly, in keeping with this point, there was a repeated refrain of "it's the water" given as the reason for what was thought to cause cancer in this reserve. The nearby "\_\_\_\_\_ mill" on the outskirts of this reserve was thought to be the main contributor to the pollution of the river which runs through the reserve. Many angrily spoke of what they thought to be convincing evidence that their river was contained with

toxins that were predisposing them to cancer. This was noted in a persuasive argument offered by one respondent:

Like, we used to have life in our river, like simple little things like the frogs. There is no more frogs, there is no more muskrats, there is no more beavers in here . . . We've been crying out on this . . . and the people, they come and test our waters, that's their people. Naturally they are going to say the water is good. . . . We have to get our own people from elsewhere to come and sample our water . . . er . . . But I don't think the government will listen, because of the power plant that we have close by . . . and the \_\_\_\_\_ mill ah . . . they're not gonna listen . . . We've been fighting for this for years now. We never had this kind of disease before.

What this account had in common with other accounts on the same topic, was that Ojibway (Anishinaabe) people on this reserve firmly believed that contaminants are being spewed into their river by the powerful paper industry. This is perceived to be supported by the government over the health of the First Nation people living on the reserve downstream from it. As one respondent noted: "Meanwhile, we are dying over here, on the wrong side of the tracks." As well, there was a sense that this was an abuse that was imposed upon them. An abuse of all that was important in maintaining the healthy lifestyle they once knew. An abuse over which they felt a sense of hopelessness and helplessness about the possibility of anyone listening to their plight. Hence cancer, the product of lost connections with nature, stands as a metaphor for a larger cultural alienation and epitomizes the destructive elements of abuse and oppression. Ironically, awareness of a

diagnosis of cancer triggered blocking: having no “talk” about having succumbed to this disease. Unfortunately, this silence in of itself serves only to magnify the existing sense of alienation.

#### Hospitalization: A Source of Alienation and Broken connections

The consequence of having cancer necessitated entry into what was conceptualized as the most alienating environment one could experience as an Ojibway person coming from a reserve setting: it necessitated entry into the medical system and hospitalization. There was a sense that this setting represented a context in which there was loss of connections with family and their spiritual and cultural rituals necessary for healing. “They cut us off from . . .” was the statement repeatedly used to preface a litany of restrictions imposed by the hospital. These restrictions were perceived to break vital connections between families and loved ones at a time when this was most needed, as well as to separate them from all that was culturally meaningful, supportive and spiritually and socially enhancing. There were repeated incidences in the data where this was addressed as an issue which forced patients to leave or families to remove a patient from the hospital at the request of the patient. The following are the perceived circumstances which were imposed by hospitalization and which made people feel “ just so vulnerable in there.” Such that, hospitalization or even the prospect of being hospitalized was enough to trigger the assumption of a blocking posture:

#### Imposition of Rules that Disconnect Rather than Connect Families

When you walk into the hospitals, what do you see? You will see the Anishinaabe

sitting over there, you know, . . . afraid and scared. Who is there to talk to them? . . . Can you go in there any time or point of day to go visit? . . . There is always that restriction. Laws!

This statement illustrates the sense of aloneness experienced by the Ojibway person in a hospital and the alienation the families experience as a result of imposed restrictions (or as another respondent described it, “their rules”). This respondent continued to explain that it was not until “down to the last minute,” that is, the point at which the person was dying and nothing else could be done, that the hospital deemed it “okay” to raise restrictions. He noted: “Now we got the doors open.” He argued that families should be unrestricted in visitations from the onset of hospitalization because “healing begins at the start.” Herein lies the obvious conflict of beliefs between those held by the institution and those held by First Nations people coming from the reserve. What the hospital believed to constitute a healing environment, separated families and restricted time spent together and it created a context in which the ill individual felt vulnerable and alone.

On the other hand, what the First Nations person believed to constitute a healing environment was maintaining close contact with family members: “I want my family around me” said one patient. Another admitted to removing her mother from a hospital because she didn’t want her to be alone, “My mother didn’t stay in the hospital for very long. When she came back (sic. home) she said I am not going back in. She won’t have to be alone.” Rather than a healing environment, the hospital represented for these Ojibway people a lonely, sterile, isolating environment which disengaged people from involvement

with “the living” and those who cared about them. This was well summarized by a relative in the following explanation:

I think when you are sick, slowly deteriorating, you'd rather be in the house than in a formal atmosphere where everything is super clean, where everybody has to keep their distance and you are alone with one or two visitors at a time . . . When you are at home many people come and go as they want. And you feel like you are part of the . . . you are still part of the living instead of being isolated in the hospital where, it almost overpowers the fact that you are going to be, you know, gone.

#### Imposition of Forced Choices in Treatment Decisions by Medicine

Cancer necessitated consultation by the Ojibway people on this reserve with a physician. It also required hospitalization at some point, preferably early in the onset of the disease, when decisions and choices about treatment are made. These decisions were made with a sense of urgency on the part of the medical establishment based on biomedical knowledge about the rapid progression of this disease. Therefore the physician encouraged and expected prompt action for treatment intervention to ensure that his/her perceived healing outcomes could be realized. Again, a time restriction was set even in terms of decision making regarding intervention and it was based on the more powerful and credible biomedical beliefs: those of the physician and the hospital. They were then imposed upon the First Nations patient with no acknowledgment of that person's cultural beliefs regarding treatment decision making. A conflict in belief systems inevitably

developed causing attempts at understanding to be suspended. A father explained this dilemma well in the following incident:

We had some pretty awful experiences with the doctor. His belief was that right away, now, I want to cut you . . . right now. He says, you know, it's the only way. So, I guess it's just the one doctor I talked to who doesn't understand the traditional ways of our people. But . . . er . . . modern society, the white society, believes in the operation right away. They truly don't understand, we as Anishinaabe people sometimes go to ceremonies for guidance, but he thought it was a waste of time.

Surgical intervention was the immediate action required from the perspective of the physician. Seeking "guidance" from sacred ceremonies was the most immediate action required from the father's perspective. What the physician considered "a waste of time," the Ojibway parent considered to be critical decision-making time to ensure the best healing outcome for his son. The lack of understanding from either perspective, of what constituted appropriate use of critical time highlighted the conflicting views of these two cultural orientations. It also reflected the degree of frustrations expressed by many respondents as they spoke of their experience with the medical system. Many of them admitted that they "gave up," "signed myself out" or "wanted to go home" because they felt their beliefs were discounted.

In another incident, a patient presented a similar situation. In this situation however, the patient actually took the time he required to first seek "guidance" and

participate in spiritual cultural rituals before agreeing with the doctor's proposal for immediate surgery. He explained it this way:

Okay, what happened was that they were going to open me up finally. They took this last X-ray and then they found a ball there, they were going to take it out . . . but I went to a medicine man and then he did a ceremony for me. I kept going back to him and he says, 'Don't go to that, cancel the operation, we'll go to this warrior dance to be held next week.' So I cancelled out, you know, cause the beliefs are strong, eh . . . so we came back, and then uh, of course there were messages all over saying that 'You need to call the doctor, it's really urgent.' So I went and they said I didn't have to go for the operation . . . so when I came back I went to the hospital and they hooked me up on chemo. right away. What I was told by the grandfathers and the Great Spirit was, 'We've got to meet them halfway [sic] now. I've got to go to the hospital.'

This incident was particularly explicit in demonstrating what happened when an Ojibway man was allowed the opportunity to consult with his source of strength and seek *guidance through cultural and spiritual ceremonies before making the decision about having surgery.* Interestingly, both the medical doctor and the medicine man came to the same conclusion about the proposed surgery. They reached their conclusions, guided by different sources of knowledge and both proposed independently, that the patient did not require surgery. The end result was a cooperative patient who returned to the hospital for treatment with confidence that he was doing the right thing because the decision was



endorsed by a credible source from his cultural orientation.

### **Imposition of the Omnipotent Beliefs of Medicine**

Besides discounting the value of the time spent in consultation with their own medicine man, the hospital was also seen as the place where physicians “figured their way was the only way . . . because he has a piece of paper that says that he is a doctor, he wants to play God.” The issue of doctors wanting “to play God” was reported to be an inevitable part of the hospitalization experience when diagnosed with cancer. There were repeated incidents where respondents reported that the manner in which the information was given instilled in them a sense of hopelessness. Given the cultural belief, as presented earlier, that “cancer has been a sickness, which in the human being’s mind is fatal” it is thought that “once you put something in your mind, your mind usually becomes the fulfiller of that thought.” Hence, when a physician announces a diagnosis of cancer in the context of an inevitable deadly outcome, he or she is ostensibly pronouncing a death sentence by influencing the person’s mind to think in those terms. This belief was often the root cause for dissatisfaction with the way in which physicians presented information about having this illness. This was explained in the following manner:

Now, how can I give you an example. Many years ago I had a brother, you know, He was given . . . they wrote him off, they said in six months he would be dead. He lived for another ten years! Now what kind of mentality does that person have to tell another person ‘you only have six months’. What is he playing? Is he taking the place of the Creator? He’s the judge, jury and executioner? You should never tell

people like that and be disrespectful . . . that enhances the sickness

Unfortunately, what the medical physician disclosed in an attempt not to withhold information, the First Nation patient interpreted as disrespectful. It was perceived as disrespectful because it demonstrated that the physician did not take into consideration or respect the strongly held cultural beliefs of the patient about “the mind” becoming a “. . . fulfiller of that thought.” Hence, from the First Nation person’s perspective, the prognostic information itself held the potential to enhance the possibility of a fatal outcome for this patient. In offering this predictive information in terms of life and death, the physician was perceived as setting himself above the ordinary human, with the ability to access information not legitimately accessible to any one other than the Creator. As another respondent commented, “Well for us, there is only one healer and that is the Creator.”

This disdain for physicians assuming the role of the omnipotent healer and taking credit for healing outcomes, which these Ojibway people attribute to the Creator, was a repeated theme echoed by patients, relatives and elder/Healers. A most revealing explication of this was reported by a patient who, after a diagnosis of cancer, had been hospitalized. He had been in a coma and near death, when he miraculously regained consciousness and continued to improve, whereupon he immediately “pleaded [sic]with the nurse, you know, I want to go home.” He explained that his doctor visited him when he came out of the coma. The doctor noticed the eagle feather he was grasping in his hand and “like they question the eagle. ‘What’s this? What’s that?’” to which he (the patient)

responded “well, that’s why I’m here. That’s what brought me back.” Whereupon the physician responded “I thought I brought you back.” This patient laughed as he recounted the arrogance of this physician who dared to take credit for what, from his perspective, could only be attributed to a “faith in Spirit.” Again, there was evidence of conflicting beliefs about healing outcomes for which the physician took credit and the First Nation patient’s perspective was discounted.

### Loss of Connectedness to Spiritual and Core Cultural Beliefs

#### There is no Spirit There

A particularly salient feature of the discourse on cancer was the expression of a fierce adherence to spirituality through prayer and/or traditional sacred ceremonies. Connection to a greater power referred to as the “Creator” or God, was the single most consistently named source of healing and/or treatment for cancer by these Ojibway respondents. At the core of this spiritual belief system was a mix of Catholic and cultural traditions. Among the Ojibway people on this reserve, there were those whose spiritual beliefs originated completely from their cultural traditions. The beliefs of a healer in this investigation were typical of those respondents who adhered to the traditional spiritual beliefs, as noted in the following:

So that is why today I take this opportunity to sit with you because I have something I feel is very significant and important to give and what I give are the teachings of my ancestors that have lived for thousands and thousands of years without the sicknesses that we see today . . . They were doing something right . . .

**They were living right and they were tuned into the Spirit. There was an unbelievable belief and connection to the Spirit and this connection to the land . . . Whether they be dealing with this particular sickness or some other that they have in their life, my first advice as a healer is that they must find a passage to the Creator.**

**Those who adhered to this belief system spoke of the importance of using rituals, artifacts, ceremonies in the traditional cultural ways, as well as consultation from a traditional medicine man, to help them through this illness experience of cancer. Interestingly, however, although all of those interviewed had in common a belief in the role of spirituality in helping them through this illness experience (whether cancer patient or relative) many admitted to having as great a connection to mainstream religions as they did to their own traditions. Remarks ranged from having no connection to traditional cultural ways as indicated here: "To tell the truth, I'm lost at my culture. I don't know nothing about my culture . . . I'm a church goer . . . I'm Catholic," to those who acknowledged having lost connection with their traditional cultural beliefs early in life, but who had currently returned to them and integrated the two. An example of this was offered by a relative:**

**My mother never really taught us any traditional culture because of the fact that I was brought up in a boarding school . . . but once I started learning more about my traditional ways of life, being good to your fellow man, you know, and it helped ease the way, the way you feel, but you still pray.**

Some spoke of the comfort derived from “saying the rosary” and “singing hymns” together, yet admitted to the importance of consultation with a medicine man/cultural healer. All respondents believed that for a disease such as cancer, it was necessary to consult both bio-medicine and traditional medicine for healing. This, by a devout catholic, explicates the comfortable blending of both orientations, with the spiritual component, the common thread necessary to both for healing to be complete.

Three elements: the medicine man, the doctor, the spiritual leader: the three pulled together, support one another. The healer sees through ceremonies, those things that don't show sometimes, don't show in the X-rays . . . Faith in the Lord . . . talk to the Lord. Talk to him, He's there and he's listening.

Of the reasons offered by the Ojibway people interviewed in this study for their aversion to the hospital, the one most typically observed was captured in a succinct but poignant statement offered by a patient: “There's no spirit in there.” For these people, the hospital experience presented a context in which there was a systematic erosion of all that was sacred and culturally meaningful in the context of healing and comfort. The hospital experience for patients, families and healers/medicine men represented an environment where restrictions were made. “Doing our rituals. We can't do that. They cut us off from smudging, they cut us off from our sacred tobacco . . . from our beliefs, the way we believe that we can help this person heal.”

Incidences were recounted that described how the actions taken by the hospital's medical professionals in response to artifacts of cultural medicines. One patient stated:

“They weren’t respecting what I have there, like my beliefs and that, you know.” In the situation where patients while in hospital chose to take their medicines given to them by their medicine man, they reported being confronted by the hospital’s medical professionals who “wanted to patent it and all that” or “they wanted to send it to the lab and see what was in it.” For whatever reason these actions were taken in the hospital, it was clear that the Ojibway people to whom they were directed, interpreted them as acts of suspicion and unnecessary scrutiny of their medicines. A relative warned the nurse in reference to cultural medicines: “You can’t touch it” and a healer explained, “The elders are very, very careful not to expose medicine to anyone.” Yet, patients claimed the health professionals were insistent in demanding they “expose” their medicine. One relative noted: “She (the nurse) came back with ‘no, the doctor wants to know what’s in it.’ I told her, ‘well no’ . . . but no, we have to! And I know we don’t have to.” It was clear that these medicines were perceived by them to be sacred and requiring protection from exposure. Given this cultural belief, it is not difficult to understand why patients’ and families’ described these incidences as “really disrespectful.”

As well, in the situation where Ojibway relatives wanted to perform a ritual to “Smudge the person” or “smoke the pipe,” they reported, “We hear this, you are killing the patient by giving him smoke.” It was concluded from these reactions of the medical professional that “they don’t understand the meaning of these rituals.” In an attempt to help the investigator understand the importance of these rituals to the hospitalized person, one patient reflected what others reiterated:

They should be allowed . . . to take their stuff and their medicine men to come into the room and do the prayers. Because, it helps when they come and smoke their pipe and do their rattles and their prayers in there. They lift you up. They cure the sickness, you know.

Again, the Ojibway cultural beliefs about healing and approaches to “cure the sickness” appear to be in conflict with that of medical beliefs in this regard. Particularly striking in contrast to the views of the medical professionals were the views held on “smoking” by these First Nations people. One respondent was particularly informative in his explanation of this: “You know, to us the Anishinaabe people, tobacco is very sacred. I choose to abuse the cigarette . . . the tobacco. If I use it in the ceremony, it becomes sacred.” In other words, cigarette smoking of tobacco was not perceived to be a healthy behaviour. Tobacco used in cigarette smoking was understood to be an “abuse” of its sacred potential. The small amount of smoke used in what are believed to be “sacred rituals” was not intended to be equated in any way with cigarette smoking. Hence to equate the “smudging” ceremony with “killing the patient by giving him smoke” was another example of what these Ojibway people offered as a misunderstanding and discounting of their cultural beliefs in hospitals.

Some respondents revealed that a smoking room had been provided at a large teaching hospital in Winnipeg, where a relative was hospitalized for cancer. This was seen as a positive gesture to those who admitted to knowing about it. As one relative remarked in reference to this “I think they are trying.” However, one respondent who had actually

taken the opportunity to use this resource when his son was hospitalized for cancer, pointed out the extent to which this resource was designed without an understanding of the cultural needs of those who would be using it. The following incident demonstrates this respondent's attempt at carrying out a "pipe-ceremony":

Like M. was in Winnipeg. Now for me to smoke my pipe I got to go . . . er . . . to the traditional woman that's working there, she had to take us all the way around . . . you know, walk for I don't know, 10 to 15 or 10 minutes or whatever, to walk to this special room that they have. You are away from him, you are smoking your pipe and you know, you would like to have him there and you can't.

No one could deny that the hospital had provided a space, but ironically rather than this space creating a forum for bringing families together in participation of their cultural and spiritual ceremony, its geographically distant location, actually served to isolate the hospitalized family member from participation in the healing ritual. Unfortunately, it also created a situation where the family members were forced to make a difficult choice between two equally important needs: the need to be in close proximity to the hospitalized family member in order to offer support, and the need to connect with "the Creator" to gain spiritual strength and healing through cultural rituals.

#### Imposition of an Unaccommodating Climate

The culmination of all the above impositions rendered the hospital setting a less than favourable place to be, especially when one was sick and feeling vulnerable. As one respondent remarked: "She used to hate going to the hospital . . . I don't know how many



times she signed herself out of hospital!" In response to what she thought was the reason for this she stated: "the fact that she was just so vulnerable in there and that she had no control or power in her own life, in her own decisions when she was in hospital. Whereas, she could make certain decisions when she was at home." Further, respondents repeatedly spoke of incidences where they experienced insensitivity to their distress and a palpable sense of disregard when in the hospital setting.

When encouraged to describe what was meant by this, one respondent noted "Yeah, and you feel it! . . . That's something you can't hide. It's there. There is no room you can hide something like that in." This denoted what at a feeling level was a vividly impressive experience, but a difficult one to verbally explain. Respondents reported guardedly on this and often prefaced their responses with, "I don't know how to describe it . . ." or "It's something that you can't put your finger on . . ." or "It's not something that I can articulate . . ." There were problems in articulating what "it" was but it was very much a part of what defined the aversive climate felt in the hospital. They, however, described incidences where they felt "it." Explanations such as this one offered by a daughter, described her visits to the hospital with her mother for chemotherapy:

When I started taking her to chemotherapy . . . I was given one pamphlet . . . and when I took her there and I waited with her, nobody talked to me to see like 'It's your mother, how are you feeling. I would wait and nobody would, you know. You would think that because they are in a unit getting chemotherapy, the person that brings them there should be asked, you know "Do you know enough of

what's happening?" and stuff like that.

Another spoke of the times he had to take his wife in for relief of cancer-related pain and the reception he got:

Sometimes we had to go there at night, and especially in the town here. . . . A lot of the times, it's written now when you go to emergency there's 1, 2, 3, and four, categories they follow. I guess, when they call in a doctor. I think if you go there often enough I think they go, 'Oh, it's him again,' you know . . . I don't know, just a lot of times . . . from my own personal feelings I would say, like I was a nuisance to them. And er . . . what can I do, eh?

Here we begin to discover the unspoken but powerful cues which created a cold and insensitive atmosphere for the First Nation person. The numbered categories used for defining emergencies by the hospital were dehumanizing and singled out whose distress was the most legitimate to call the doctor about. No one actually told him he was a nuisance but he sensed it from the way people reacted to him.

A healer also passionately offered what from his perspective created this lack of accommodation that was felt by Ojibway people in the hospital setting. He explained that there were lack of considerations:

What I mean by considerations is showing kindness, showing love, showing respect, you know. When you look at the English language, it has many definitions. You can play with it any way you want within this word 'consideration.' People say "What are you talking about? What are you saying?"

In simple language, I am saying kindness, love, respect, understanding, being able to listen the person in pain. Do we take the time? Do professional people take that time to show that kind of consideration? We have our people laying in the hospitals, where people walking around in pain . . . do we take that time and that's how we look . . . we as Indian people are looking at this way very strongly.

He went on to explain that he felt, as a healer, that there was no respect for him or his medicine. He spoke of "the negative views" of the so-called professional people to his style of healing. "Some of the medicines that we bring to use are forever being questioned. Is that fair?" There was again a sensing, an inference, a feeling of disregard that was as vivid as if it were directly given by the spoken word.

A patient offered that, at her request, a nurse referred her to "one of the cancer victims." She explained that, "she came to see me, gave me a bunch of pamphlets and then she walked out and I never saw her again . . . I found that part so cold. I think people should be more caring." Here we see reflected the same type of insensitivity recounted above being perceived by a patient who described it as "cold." Others spoke of similar incidences such as: "The doctor I had wasn't communicating with me . . . All he did was come in and check my breast, look at it and leave." These approaches were obviously impersonal and devoid of human warmth.

Other attempts at describing the climate of the hospital were: "it might be a tone of voice . . . compared to that person that has that compassion." Another stated, "Um, it was the . . . I guess the approach to her, I don't know . . . it's just the subtle . . . I don't

know.” Others spoke to insincerity in the approach of health professionals: “I just hate when white people say ‘Oh, I understand what you are going through.’ No, they don’t!” They also spoke of the lack understanding health professionals had of the human distress that accompanied having the disease cancer. One patient noted that health professionals needed “more understanding, they have all the medical terminology but they don’t know what the person’s going through. They just assume. See, they know everything but they only know it from the book.”

So that, the palpable, yet unspoken sense of disregard felt by these respondents was created through the effects of cold; impersonal and insincere approaches; and a lack of consideration and understanding of human distress. It was real and it was a powerful presence. Consequently, those who had cancer and were inevitably hospitalized due to the necessary biomedical regimen implemented for control of the disease, dreaded the degree of alienation they experienced there. Those who had observed the experience of close relatives in hospital, spoke of the inevitable outcome of broken connections from all that was culturally, socially and spiritually meaningful. Traditional healers felt that their medicines and their perspectives on healing were not respected. In general, the hospital was an unaccommodating experience that was not desirable. Blocking with respect to disclosure about the disease cancer was triggered in this context as an attempt to enable protection against having to endure the alienation anticipated by hospitalization.

#### Death: The Final Breaking of Vital Connections to Spiritual Integrity

The particular circumstances of having cancer or having a close relative with

cancer, prompted an intense search for spiritual guidance and spiritual intervention in an attempt to prevent certain death. Although it was believed by many of the respondents that “the gift that the white people have is the operation . . . and the technology and the knowledge to do that,” the ordinary Ojibway person believed that bio-medicine’s power alone was inefficient in averting the lethal course of this disease. Throughout the data, patients, relatives and healers alike admitted to requiring the need to “use the two, the white side as the way for medicine and the traditional way,” rather than one of either orientations to healing. This intense need for spiritual intervention was not merely sought through culturally sacred ceremonies and rituals but was also sought by those who were not currently practising these traditional ways. That is, spirituality was also sought after by those who referred to themselves as a “church goer” and those who “read a lot of, the Bible, and had my rosaries.” It was remarkable to note the repeated evidence of a fervent need for a spiritual connection by those living with cancer or those having a close relative who had this illness experience.

However, the context in which blocking was triggered was where family members, who had abandoned their “traditional way,” had returned to it in earnest in an attempt to save the patient from death. In the event that the patient did die, despite elaborate efforts to change the course of events through prayer and faith in divine intervention by God or the Creator, it was revealed in the data that this death created for these individuals a loss of faith. It created a context in which the individual felt alienation from the loved one through death. This alienation was further compounded by the loss of connection with the

beliefs in the power of sacred ceremonies and spiritual beliefs to afford an outcome other than death. In one incident a mother explained the tragic effect of this on the surviving family members and how it triggered blocking through the closing off of all discourse about the deceased:

I figured that he would get well. I figured that the sweat lodges and all the praying and the pipe ceremonies and all the ceremonies we were doing was going to pull him through . . . One of my sons, the youngest son, he went to a medicine man and he was told to Sundance for his dad. And uh, he sun-danced that summer for four days and then when his dad died, he turned away from the traditional ways because he figured that didn't do any good anyway . . . Yeah, he was really angry. He was really angry about that. I still have a younger daughter who, she's still in that stage where she's, all she says is he shouldn't have died mom. He shouldn't have died. And when he died, well she was already drinking, but then she went, it got really bad, I had to look after her daughter for her. So my granddaughter lived with me for a couple of years till she quit drinking and quit using pills. And uh, she doesn't want to talk about her dad. She won't talk about her dad at all.

This broken connection with the source of spiritual integrity seemed to be the stimulus for the shattering of entire lives through a more extreme form of blocking characterized by self-destructive behaviours such as alcohol and drug abuse. Entire families were observed to be affected by this. Another respondent noted:

One of my brothers, all he did was drink. Another one, all he did was stay away. .

.. My sister kept it all inside you know, and she would show this brave front. I was with my mother when she passed away . . . we said the 23<sup>rd</sup> Psalm, we sang, eh? We said the Lord's prayer and by the time we sang Amazing Grace, we didn't finish Amazing Grace and she passed away. And my sister cried for about a second! She said, you know, the whole family, Mom left them all alone. Mom left them alone. She never cried again!

An elder attributed this spiritual anguish to the fact that "our people are guilty today of leaving, you know, the ancient teachings." It would appear that cancer forced confrontation with the ultimate threat: the threat to life and spiritual integrity. When core cultural values were not strong enough to sustain the challenges presented by these threats, there was a retreat to anything that further blocked exposure to the pain.

#### Summary

There were three salient contexts in which a blocking posture was triggered. This occurred at the point at which either a patient or a family member received confirmation that the illness they were experiencing was actually cancer. The label itself was infused with deadly connotations and people retreated from talking about it to family and the community. Having cancer necessitated hospitalization. It became another trigger for a blocking posture due to the alienation anticipated when one once entered the hospital setting. The sources of alienation in hospital arose from the institutional structures that imposed its dictates upon those who entered it, without consideration of those things which were spiritually and culturally meaningful. When a patient died of cancer this

represented the final alienation from family, friends and community. Blocking was triggered in this context when efforts to summoned spiritual intervention from the Creator failed to result in a curative outcome for the patient. This was revealed to lead to a loss in faith and resulted in a more pathological form of blocking characterized by dysfunctional behaviours such as abuse of alcohol and drugs.

### **Un-blocking**

Blocking, although predominantly the posture adopted when dealing with cancer among these Ojibway people, did not account for the responses of all patients and care-giver relatives. Conditions which evidenced a change in blocking to one of “Un-blocking” was demonstrated in those patients who had experienced the detrimental effects of “blocking.” That is, those who had seen themselves as having survived the cancer and those care-giver relatives who had witnessed the impact of blocking on themselves and family. The inherent characteristic of Un-blocking was that it involved confronting the reality of cancer and opening discourse on the subject of cancer. Those who engaged in Un-blocking demonstrated 1) insight and spoke of actions they were currently taking to prevent the devastating consequences of blocking and they 2) spoke of what they had learned from having experienced the consequences of blocking.

#### **1) Insight**

The inherent characteristics of Un-blocking were revealed by those respondents who voiced insight into the cost to their lives that blocking had wrought. This was based on two premises:



a) Loss of time. In this case, blocking was seen as responsible for the loss of valuable time necessary for early intervention and possible prevention of the fatal outcome witnessed in the relative's case. Statements of regret that "they wait too long," "people go for help too late" were repeatedly made by these relatives.

b) Loss of support. In this case, blocking was responsible for prohibiting many patients from gaining the necessary support they needed to cope with this disease. This was demonstrated in the responses given to the suggestion that there was a need for some forum in which Ojibway people could feel comfortable enough to talk about their cancer experience and gain access to support. The idea of support groups was mentioned as a possible resource. An example of a response to this was: "I really don't know how that would work. That someone on the reserve is diagnosed with cancer, would start in a support group with other people who've had it. I cannot see that happening at the moment." The explanation for this was conclusive: "That's because of the strong, that strong taboo," "It is to be kept a secret."

Clearly, in this example there was evidence that the respondent recognized the role that blocking would play in disallowing participation in any context that would require them to "talk about it." The idea of gaining the benefits afforded by a support group were lost through blocking because it required the very antithesis of what blocking afforded. Therefore in so doing, First Nations people could not take advantage of the expanded support that a resource such as support groups could offer.

## 2) Learning from Experience

Witnessing the suffering of a loved one who succumbed to the ravages of this illness instilled in these care-giver relatives a determination to prevent the same thing from happening to themselves or their children. They could articulate strategies for ensuring early detection of this disease. They spoke of having “learned” from the experience as noted in the following response:

I've learned from that, because . . . from when this happened to my mom, I go to the doctor every year and I get myself checked out and that. I have a mammogram and you know, it's taught me . . . ”

They also spoke of the importance of talking about it: “You know, . . . they have to talk about it and they have to start opening up, seeing, this is a reality today, you know.”

Further, they articulated strategies that they were currently employing and teaching to their children: “ I talk about it openly with them. That's one of the things I've learned through my mom too is, I want to share with my daughter, with my kids, my older son.”

Other comments included how a mother taught her sons after their father's death from prostate cancer. She described: “explaining to them that if they feel pain in their groin, other than from exercise . . . or if they've checked themselves for lumps and . . . go see a doctor right away. That's what I urge them.”

These statements were all clear evidence of lessons learned and efforts being made to institute preventive measures. They suggest avenues for addressing this very difficult barrier to early detection of cancer imposed by the “blocking.” This also suggests the possible source of credible harbingers of a message to unblock. This should necessarily be

someone from this cultural community who has acquired that wisdom which could only be gained through having experienced the devastating experience of blocking.

Un-blocking however, was not a static state. There were incidences where patients articulated at a cognitive level an intention to unblock but reverted to a blocking posture when faced with actually taking action to un-block. So that, taking any action that involved actually talking about the subject of cancer could again trigger blocking. The following incident clearly demonstrates this. This patient explained:

It would be interesting for me if I could talk to people with this sickness if I could get myself to join these groups . . . I already have a group I'm thinking of joining, they're at the YWCA. They have a group there on Tuesdays. Like I'm not working now on account of the cancer, so right now I have lots of time to join these groups.

It would appear from the above quotation that this patient had full intentions of joining a support group and that it was not her lack of time that prevented her from taking this action. However, when the investigator queried whether it was "time" that prevented her from previously joining a support group to talk to others and gain support, she noted "No, no, no. It wasn't time." She explained that it was "the blocking, yeah. Because I've tried a lot of ways to keep myself busy during the day, keep myself occupied or something, without me attending these groups to remind me I have this disease."

Clearly attempts were being made by this patient to try to open discourse on the subject. She even had a plan, but never followed through to the point of actually joining a

support group. Where the patient began at a cognitive level to perceive the need to break the silence and stop the blocking, this was only a temporary posture. She deliberately reverted to blocking in an effort to protect herself from focussing on the reality of having cancer. The attempt to seek out and participate in a support group was to her a cogent reminder of the threat that having cancer posed.

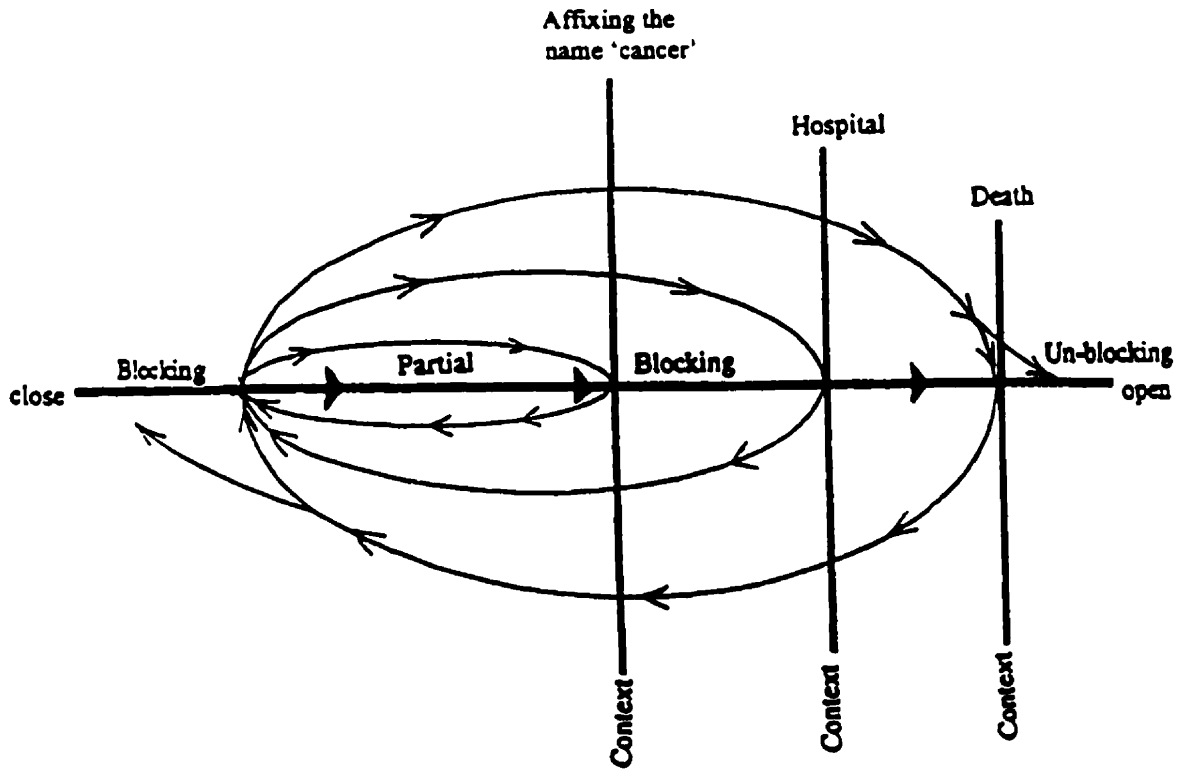
Hence Un-blocking was revealed as another dimension of blocking. This dimension of blocking was shown to have properties that represented an “open” rather than a “closed” dynamic when operational. Un-blocking was characterized by opening discourse on the subject of cancer. It was evident in care-giver relatives and in those patients who had experienced remission of symptoms. The trigger for Un-blocking was revealed to have been based on 1) insight gained from having witnessed the devastating consequences of blocking and 2) learning from experience. The consequences of blocking which had the impact of causing a change to Un-blocking were a) loss of time and b) loss of support. Un-blocking however, was not a static state and patients could revert to blocking when faced with actually having to assume actions which forced them to have to open discourse and confront the reality of having cancer. Un-blocking, however, represents a possible window of opportunity for affording a change in blocking.

### Summary

Happenings and events as they are located in context show the conceptualization of process in blocking. Figure 3. diagrammatically shows the closed/open dynamic of evolving dimensions of blocking, partial blocking and Un-blocking. This is depicted by the solid horizontal line showing movement from a closed to an open posture on discourse and disclosure about the illness cancer. The vertical lines which cross the horizontal line depict contexts which trigger blocking and thwart attempts at becoming open on the subject. They are contexts in which a) the name cancer is affixed to the illness being experienced, usually following a visit to a physician and receiving the diagnosis b) the person is hospitalized or hospitalization is suggested in order to carry out specialized tests and treatments and c) there is death of a relative as a result of cancer despite great efforts on the part of a family member to use traditional cultural medicine and rituals in effort to prevent the death. Arrows on the ellipses depict the dynamics of movement through the dimensions of blocking and the consequences of the impact of specified contexts in changing the direction of action.

The diagram shows that at each point following entry into any of the contexts, blocking is triggered and resumed. Partial blocking can occur for patients at points after treatment and remission of symptoms. However, this is not lasting and they revert to blocking when faced with taking action to unblock. Upon the death of the patient, the final context in which blocking can be triggered, some people unblock and remain open. Some, after starting to unblock, turned fervently to traditional spiritual beliefs and rituals to effect

**Figure 3.** Dimensions of blocking and contexts that trigger blocking.



**Note:** The horizontal line with solid shaded arrows extending from left to right, shows the closed/open dynamic of evolving dimensions of blocking, partial blocking and unblocking. Vertical lines represent contexts that trigger dimensions of blocking. Arrows on the ellipses show direction and change in action following impact of context.

healing in the patient. Upon the death of the loved one there is a loss in faith and traditional rituals as they failed to protect their loved one from death. These persons revert further into blocking than initially. Here properties of blocking are observed but they now include dysfunctional actions such as alcohol and drug abuse.

### The Pain of Cancer

#### Introduction

The pain of cancer was invariably presented by these Ojibway respondents within the framework of the beliefs that structured their understanding of the disease itself. Interestingly, respondents would present their perceptions and understanding of the illness cancer as inseparable from the pain of cancer and in turn, the pain of cancer as inseparable from the pain of life. In short, pain meant the cancer experience and the cancer experience epitomized that which was most painful in life. Throughout the interviews, when respondents were asked about the pain of cancer they would invariably embark on horrific stories of the pain endured in the context of physical, sexual and social abuse as a people. These stories were infused with themes of helplessness, hopelessness and loss; of having to endure; and of having to make cruel choices. This puzzling interweaving of cancer and related pain with the pain of life was finally elucidated in this statement offered by one of the respondents, a healer. "If you are going to understand this sickness then we have to understand life." It was from this vantage point that it became possible for the investigator to fully appreciate the full breadth of the dimensionality of what was perceived as the pain of cancer.

The pain of cancer was not only conceptualized as a hurt, at the level of a sensation, but reached into the recesses of deep psychological, social and spiritual anguish. For according to one healer, the pain of cancer manifested itself through “various kinds of pain.” This was demonstrated in the descriptions of pain offered by those who suffered with it and those who stood helplessly by in fervent attempts to help relieve it.

**Properties of Pain: Seamless Intertwining of Dimensions**

Cancer pain was described by patients in this investigation as having the physical properties of a sensation such as: “burning” pain, “sore,” “aching,” “heavy and sometimes dull,” “sharp” pain, “it hurts . . . I went to the ceiling!” The word “sore” was the term that recurred most frequently as the initial response to the sensation they were experiencing. Further probing usually stimulated a more descriptive response. Pain had dimensions of intensity ranging from “not too bad,” “bad” pain, “a lot of pain” to “severe” pain. It had the capacity to move, as one patient with leukemia vividly explained what he described as “severe pain”: “like it’s a little ball and it burns and then it moves, it moves fast. Like it travels. That’s why they can’t get rid of it.” In the case of a patient with cervical cancer the pain “went through to my back.” Pain could be “constant” as a patient with stomach cancer described it, or it could be intermittent as a patient with breast cancer (complicated with elephantiasis) whose pain was “not too bad” described it: “It’s not there all the time, eh.” Clear and precise descriptions of the properties of the pain experienced with cancer were easily reported by respondents.

However, what was most impressive about these descriptions of cancer pain, was

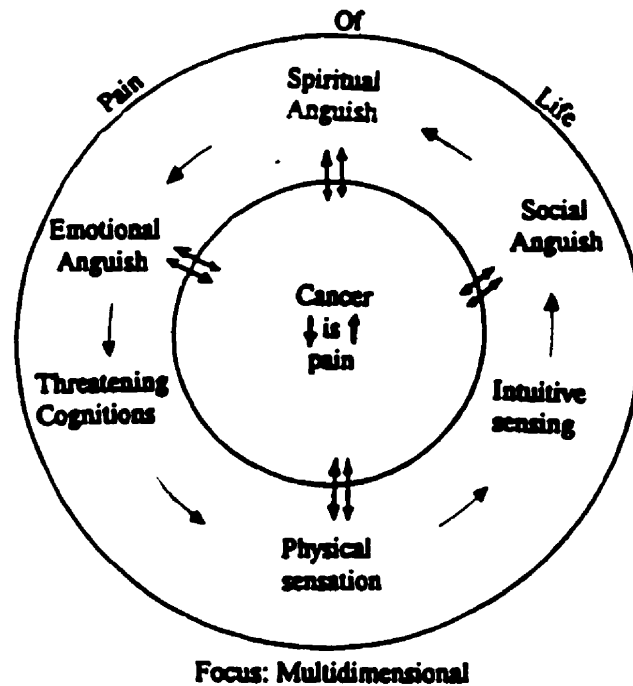


the additional dimensions of pain that were simultaneously elicited in relation to experiencing the physical sensation of pain. It was revealed that patients reacted at an emotional level to the pain of cancer. That spiritual anguish reflected the pain of cancer as well as the threatening cognitions about cancer. They perceived at a cognitive level what the pain indicated and they reacted at a behavioural level with a range of actions that helped them to manage the pain. This did not necessarily mean actions that, from a biomedical perspective, removed the sensation of pain. It did however always mean actions that ameliorated the pain. These actions were often directed toward maintaining spiritual integrity and core cultural values and protecting against being disconnected from these. The response to cancer pain was therefore complex. The dimensions of cancer pain were described as though seamlessly intertwined. This pain was multidimensional and integrated, not compartmentalized (see figure 4).

#### Pain is Cancer and Cancer is Pain

Patients who had cancer associated the experience of a painful sensation with the confirmation of the reality that they had cancer. As one patient noted when she started to get pain “That thought occurred right away: It’s probably the cancer.” There were repeated incidences where feelings such as “scared” and “helpless” were used to describe patients’ response to the experience of cancer pain. It was what they thought the presence of pain indicated that was often cited as the stimulus for this response. The most frequently used reason for these feelings was typically that it indicated the severity of the illness as noted in the following: “Like, I was really sick” or that this it was evidence of

**Figure 4** The multidimensionality of pain: An Ojibway perspective



**Note.** The arrows indicate the fluidity and integration of the dimensions of cancer pain. The middle circle indicates that cancer pain is inseparable from the illness cancer. The outer circle indicates the dimensions of pain. The arrows pointing inwards and outwards, indicate the connections of cancer to the dimensions of cancer pain. The space on the outer aspect of the circles indicate the integral connection between the pain of cancer and the pain of life in the broader context.

exacerbation or spread of the cancer: “ Its coming back.” It also indicated the possibility of “having more surgeries,” and that hospitalization was required: “When the pains come I know I’ve got to go back to the hospital” and that to many, was a most dreaded anticipation of separation from cultural supports and a stark reminder of the reality of the presence of cancer. As noted by one patient, “Yeah, like when I have the pain, I think ‘oh, I’ve got cancer . . . .’” Hence, threatening cognitions were intertwined with sensation of pain.

### Blocking in Cancer Pain

It is at the point of acknowledgment of having cancer, signalled by their experience of the sensation of pain, that patients explained the actions that they took when confronted with this reality. In the last person quoted, this patient finished her sentence as many others did “ . . . then, like I said, I’ll try to ignore it [the pain].” In other incidences, the statement “I wait” was the most strikingly remarkable response of patients in taking action to alleviate cancer pain. Features of blocking therefore emerged as one of the possible strategies taken to deal with cancer pain just as it was used for dealing with having the disease. Cancer pain was obviously an embodiment of the cancer experience. All of the adverse conceptualizations of the disease (noted in the earlier discussion) were signalled by the presence of pain. The dreaded hospitalization experience was also perceived as the inevitable consequence of experiencing pain when diagnosed with cancer. Again, this created a context in which “blocking” seemed to inevitably manifest itself. As in conceptualizations of the disease cancer, it also presented as a way of dealing with the

pain of the disease cancer. "I keep myself busy. I never, like when I was in pain, I never lay down on my bed . . ." said one respondent.

### Maintaining Spiritual Integrity

Besides admitting to "taking pain killers," there were many incidences where patients' strategy for pain relief was to reach out to their spiritual source. This respondent pointed to the heavens while stating, "I used to think somebody is there for me, like . . . up there . . . Somebody is looking after the pain . . . I went to church." The remarkable aspect about this is the number of incidences where other respondents admitted to similar beliefs about what pain indicated and resorted to the same actions. As this patient stated, "When I was in a lot of pain, if I said my prayers, I wouldn't experience the pain as much . . . My prayers were stronger than the pain so I knew He was there beside me and He would help!" Spiritual connection was a constant yearning and a source of strength for these respondents in dealing with the pain of cancer.

Although blocking, and thereby ignoring the pain, was a strategy used when experiencing pain, all respondents spoke of taking some form of analgesic to help relieve the pain. For example, one patient, who like others who stated they had severe pain, offered "Like [when] I can't stand it, I've got to have pain-killers right away . . . simply to be comfortable." However, there doesn't seem to be a regularity to this taking of medications. There was the suggestion by this, and other incidences that even in severe pain, patients only sought medication when the pain was out of control, and even then, they would "wait." However, whether they took their medications regularly or not, they

all spoke of gaining strength through spiritual powers “The main thing. Like you’ve got to leave everything to the Creator. Yeah, the spirit has to be strong.” Spirituality, whether achieved through conventional or traditional practices, was at the core of every action taken to relieve the pain.

These responses by patients to cancer pain was shown to be multidimensional. Behaviours which were aimed at ameliorating the pain were noted to be similar to those used in dealing with the disease itself. That is, characteristics of blocking were noted in the response to cancer pain. However, faith and maintaining spiritual integrity was the driving force behind the behaviours used for the most part, in the amelioration of cancer pain.

#### Maintaining Core Cultural Values: Enduring the Pain With a “Style”

What was indeed interesting to note was that the care-giver relatives also expressed feelings of “helplessness” when observing their loved ones in pain. Their helplessness stemmed mainly from the reluctance of many patients to take their medication for pain relief. One care-giver relative tearfully recounted the difficulty she had getting her mother to take her prescribed analgesic:

I felt helpless . . . it was really hard . . . I asked her once, she was sitting on the bed and she was squeezing my hand, and I said, “Mom, take your pills, it’s almost time, the four hours is almost up.” “No, I’ll wait,” she said. “I’ll just wait till four hours.” I said, “There’s no point in you suffering,” I said, like that. “Just take the pills now.” And she just squeezed my hand, but she would never cry out.

This stoic posture of a patient waiting, who “would never cry out” in pain, was recounted

too many times by care-giver relatives to be an individual idiosyncrasy. On further examination, it was noted that whenever a care-giver spoke of this behaviour in a patient, they described that person as “strong” and they did so with great pride and admiration, as noted in the following response:

She had so much inner strength. Still, she was a fighter, she was a very strong woman, she was a fighter inside and she said, “I can't [take the pill]. I'll be okay,” she said and she just squeezed my hand. You know.

In another incident, a daughter proudly recounted how her mother only “moaned” in her last stages of life: “But she wouldn't dwell on the pain. She never did that. She would never do that.” She said this with obvious sense of pride in her mother's strength and her stoicism. This was puzzling because at the same time that this sense of admiration was expressed, there was genuine pain and tears shown by these care-giver relatives who explained that seeing their loved one in pain represented the worse part of this illness experience for them. “The day-to-day thing . . . it was stressful, but I was able to handle it. But it was the pain! Watching her in pain and that was the most awful thing I've ever had to experience.” She proudly concluded that her relative had a “style.” The reason for this seemingly incongruous response on the part of the care-givers relatives to their loved one's insistence on enduring the pain was because they understood the reason for this behaviour. This became clear when a care-giver relative reported how her mother explained this to her:

I want you to see the strength in me. . . . I go to the hospital she says, I see

patients starting to, she said suffering, at the G-- Hospital there, she says, you know, you wouldn't believe the people that are crying out loud in pain, just yelling for their next medication she says, I don't want to be like that she said.

The respondent concluded from this that, "It was almost as if this was a dignity thing to her."

This was a powerful example of how cultural dictates mandated what was most important in maintaining personal integrity in the face of enormous challenge. This disease cancer had invaded these people's bodies. They had somehow become weakened physically and in social stature as a result of having succumbed to the disease. It was as if they were determined to maintain a sense of integrity by enduring the pain with a steadfastness that bespoke their inner strength. There was no place for vulgar "crying out." There was a certain deportment that was obviously derived from core cultural values. These patients may have been weakened by having the disease but they would show their strength in the dignified way that they bore the pain of the disease.

#### Cancer Pain Equated With the Pain of Life

In the process of exploring perceptions of cancer pain among these Ojibway people, it was revealed that their understanding of cancer pain was much broader than the illness itself. In explaining their experience and understanding of this pain, they spoke of horrendously difficult life experiences which had to be confronted when faced with a disease, which in all intents and purposes meant "a death sentence." These stories were about the tremendous courage and integrity of people faced with making painful choices

which resulted after a diagnosis of cancer.

A care-giver relative recounted the story of her twenty-one-year-old sister-in-law who was diagnosed with leukemia, days after she was advised that she was pregnant. The physician encouraged her to abort the fetus because she needed early treatment intervention to arrest the progress of the leukemia. She adamantly refused an abortion and planned to have treatments after the birth of the child. As the pregnancy progressed, so did the disease. With it, was what was described as “extreme, extreme pain.” Tearfully this respondent spoke of the patient “not taking any pain-pills . . . She just suffered.” She had decided to endure the pain rather than hurt the growing fetus. She signed herself out of hospital and would not return because of the alienation she felt there. “She bore the pain.” The respondent recalled, “She would always say, ‘oh, the Manajoosh [sic] . . . it’s eating me here today.’” She recalled also how painful that was for her, as a care-giver relative to watch. She spoke of her feelings of “helplessness.” Both the patient and her husband dealt with this by not talking about it: They assumed a blocking posture. “She would never say the word cancer . . . my brother did the exact same thing, but he turned to alcohol because he could not cope.” The patient did make it to term, giving birth to a healthy baby girl. She died the next day never having seen the baby.

Cancer and its related pain had reached into lives. Its impact had rendered an entire family dysfunctional, fatally claiming one of its members. Blocking unfortunately played a big part in enhancing this already difficult situation because it blocked communication at a time it was most needed. Blocking was a way of baring the pain of cancer and the pain of



this difficult life experience. The pain of cancer produced enormous physical pain and it was also an experience of deep emotional anguish. The response to it was one of enormous fortitude by the patient in her resolve to endure the physical sensation of pain in order to maintain her connections with her family in the cultural context of her own community. This she preferred rather than succumbing to the impositions and lack of accommodation that was hospitalization. So, “she bore the pain,” and her care-giver relative remarked proudly that “This was an exceptional woman.”

The pain of cancer was also a source of enormous spiritual anguish. A male respondent spoke of how cancer had created a lasting pain in both his life and the life of his common-law wife who had been diagnosed with it. He spoke of her being in “a lot of discomfort,” about the fact that they felt “helpless.” “We couldn’t do nothing but go through the pain.” Remarkably, his conversation about cancer pain moved immediately from the patient’s sensation of “discomfort” to the pain “we” were going through. The dimension of pain he then described was that of the intense spiritual anguish which his common law-wife was going through as a result of the common-law status of their relationship. This couple had lived together for thirty-one years. However, having cancer had created for her a need to reexamine her lifestyle. He explained that she informed him, “I’ve been thinking about this and it’s been hard on me . . . I don’t want to shack up anymore, we call it shack-up, eh? Living together . . . She said ‘I want to prepare my life for the Lord. . . .’” Hence, the pain of cancer was bad, but the pain of the possible loss of connection with her spiritual source through a perceived sinful liaison, was the greater

pain.

This respondent spoke of the anguish they both felt about separating. After consulting with a spiritual leader he was advised to grant her the wish that they separate.

His voice broke as he tearfully recounted:

It's hard for me to tell you what happened . . . the family . . . thought I was running away from her because she was sick . . . they took it the wrong way! That made me feel worse . . . The last couple of weeks . . . she wanted me, she told the priest that she wanted me, but they wouldn't tell me . . . So I went there and they told me to leave the yard, so I had to go."

Again, the pain of cancer was conceptualized in the context of a painful life event.

Dealing with the disease cancer had created a situation which led to the painful separation from a long-term relationship. It had resulted in alienating the patient from her loved one: the person who represented her partnership in a sinful relationship. However, she believed it would bring her closer to her God and so she made her "hard" decision and chose to leave that relationship. He believed that "Towards the end, I think that's what helped her not to suffer too much, eh." The strength of the belief in the importance of a spiritual connectedness at the time of illness far outweighed the need for the personal connection that could possibly break that connection. Deep spiritual anguish was the impetus for this painful decision. It was embedded in the cancer pain experience.

These incidents as noted thematically throughout the data, defined the expanded parameters of cancer pain to include spiritual dimensions. Interestingly, as noted in these

data, the strategy for pain relief was aimed at removing the source of the spiritual pain. Its amelioration was demonstrated in desperate efforts aimed at maintaining spiritual integrity.

#### Cancer Pain: Intuitively Sensed and Contagious

There were several incidents noted in the data where it became evident that these Ojibway people had a way of knowing that was not within the realm of the concrete or the written word. There was the suggestion that each of the four “races” of the earth had gifts. The ability to experience “visions” was reported to be the gift of the First Nations people. It was however not fully recognized for its great potential by the main stream society. A higher form of knowledge was accessed through this ability to be open to the knowledge presented by “vision.” An elder/healer began the explanation of this when he spoke of the need for “vision to be brought into the world that encloses all of us as human beings.” Therefore, having vision held the capacity to bring us all together through its potential for allowing us to be completely sensitive to the other’s pain. How this pertained to the pain of cancer was explained by another elder/healer who suggested that in healing, the patient needed the “caring and understanding of the pain he is going through.” He explained how this was attained: “We have to visualize the pain that he is going through in order for us to feel that.” They spoke of cultural rituals which facilitated the sharpening of the senses to the pain and distress of others and of the powerful counsel administered through visions. True and genuine support for the patient and a sense of hope was then possible after making this connection with the other’s pain.

Equally as important were the elder/healers who spoke of “the emotional pain that

we carry” in reference to disdain they as healers felt when the legitimacy of the power of these beliefs and their medicines were questioned and not respected. “We carry that emotional pain and it hurts.” He lamented. “We need to be respected for who we are and what we have.” The intensity with which he spoke these words left no doubt that this hurt was very real. This too was cancer pain and in this context elder/healers felt its hurt intensely.

This ability to sense the pain of the other was also reported by care-giver relatives. It was revealed in the response of an abused woman who with her adult children returned to the bedside of her abusive husband. She explained, “As far as we were concerned, he wasn’t the man who beat us up and terrified us for thirty-two years. He was just a man in pain and we were feeling that pain too.” When a similar remark was made by another respondent, the idea of “feeling the pain” was further expanded to reveal actually feeling the sensation of pain of another. Rather than just a sensing of pain, this respondent pointed out. “I knew he was in pain because I felt it and I told him.” She explained that he was taking Morphine for the pain and that “he tried to keep it quiet.” On exploring what she meant by this, she revealed that she had literally experienced his pain. There appeared to be also a contagious element to the pain of cancer.

The dimensions of cancer pain were shown to extend beyond the boundaries of self. It was the kind of pain that could be intuitively felt and literally experienced by others only when they were open enough to reach a certain level of empathy and understanding of its intensity. Cancer pain in this context had a profoundly distressing effect on everyone

who came in contact with it.

### Summary

The pain of cancer has been shown, through the experience of those who had the disease, as well as care-giver relatives, and traditional healers, to be an all-encompassing experience of discomfort at every level of human experience. The pain was cancer and the cancer was pain. It was a pain that reached across the boundaries of self to all that came in contact with it. Some were broken emotionally by the experience and others endeavored to withstand its challenge. Its dimensions extended to disrupt physical, psychological, social and spiritual integrity.

Response to the pain of cancer was also at the physical, emotional and cognitive/behavioural level. The driving forces behind these responses were a fierce need to maintain spiritual integrity, core cultural values and a social posture of strength and dignity. Therefore, responses to the pain and behaviours to ameliorate the pain were intricately related to cognitive beliefs and understanding about the disease cancer itself. Since the meaning of the pain forced confrontation with the reality of having cancer, blocking was therefore a feature of the cognitive-behavioural strategies used to ameliorate the pain.

There were also behavioural responses to cancer pain that involved elaborate efforts at enduring the pain. This was demonstrated in an interesting contradiction in patient behaviour relative to the intensity of the pain sensation reported. Patients actually endured what was reported in intensity to be "severe, severe pain," with little if any pain

medication, in order that they achieved what was perceived to be a far greater relief than merely the relief of the sensation of pain. They endured the pain with “a style”: a deportment that portrayed the ultimate in strength and dignity in the face of enormous challenge. They overcame pain through prayer and ritual connections to their God and Creator: a means of maintaining spiritual integrity and connections with core cultural and personal values. Ojibway people on this reserve endured this pain as they did the difficult and painful challenges of life. Their efforts to ameliorate the pain of cancer were as multidimensional as their conceptualization of what the pain of cancer meant.

### The Biomedical Perspective on Cancer Pain: A Contrast

#### Meaning of the Word Cancer

The discourse on cancer pain by the Ojibway respondents was filled with paradoxes and contradictions which, when analysed from their perspective, revealed a cultural framework with a certain logic. That of the health professionals’ was framed within a strictly biomedical framework. Nurses and physicians, when asked questions with respect to the naming of the illness and meaning and nature of cancer pain, kept narrowly to the medical script they had acquired through their respective educational backgrounds. As a result, their responses were, for the most part, based on a well-articulated conceptualization of the medical model and the pathophysiology of disease. However, there were some similarities identified between the beliefs of these health professionals and those of the Ojibway participants from the reserve community adjacent to this health institution. While health professionals spoke of the other medical names used

to describe cancer with words such as: “Carcinoma,” “malignancy” and explanations of the various types of cancer as related to site of origin, the Ojibway respondents spoke of “Manajoosh,” an Ojibway word imbued with an onerous connotation. Interestingly, it was on the implications of the word “cancer” that both groups of respondents shared a common conceptualization. As in the Ojibway population, the term repeatedly used to describe cancer was “terminal,” and “scary.” Other similar texts were “basically it’s a scary disease” and, “A lot of people are afraid of the word.” The health professionals, never actually mentioned the word “death” but it was obvious that they were talking about death. “Terminal” was as close as they would get to removing themselves from the security of their medically oriented jargon when presenting their ideas. This word “terminal” was used by almost every nurse in the health professional group.

The slightly different twist on this acknowledgment of cancer as “terminal,” by the health professionals was their qualification that this status was dependent on the identified site and stage of the disease. All cancers were therefore not seen to be “terminal.” There was however, connotations of fear and anticipation of fatal outcomes connected with the word. Therefore, regardless of cultural orientation, it would appear that this conceptualization of the disease was a shared one by both health professionals and the Ojibway respondents.

#### Cancer Pain and Pain Control: Differences in Aims and Focus

There were no other similarities in terms of the basic conceptualization of this illness by medical health professionals and Ojibway respondents. Pain was seen from the

Ojibway person's perspective as an embodiment of cancer and vice versa. It was inseparable from the disease. On the other hand, health professionals saw the pain of cancer as specific to certain cancers and as related to the site and the advanced stage of the disease "ultimately end-stage cancer," with "metastasis." Hence, both physicians and nurses shared the sentiment that "some have no pain and some suffer terrible pain."

Adequate pain control medication was the aim of physicians. "To be, um, to give them 100% pain-free." The problem with attaining this goal of "100% pain-free" was that it seemed completely dependent on adequate medication and dosage protocols. This became a problem because there was often a disagreement between nurses and physicians as to what constituted adequate medication and dosage requirements. It was in this context that the discourse on cancer pain was presented by physicians and nurses. Nurses spoke of feeling "helpless," of feeling "hopeless" and of feeling "frustrated." These feelings by nurses were an expression of not having the power to access what they thought was appropriate medication and dosage protocols for their patients.

Physicians alone held the power to prescribe medication, the amount and regularity of a dosage. The subordinate position nurses held in relation to physicians in the realm of prescribing of medications created a power struggle and led to feelings of helplessness on the part of the nurses. In this hospital setting, nurses offered that "We have doctors that tend to seem to want to withhold medications." Others made statements such as "I feel we have to beg for these patients to get medication. It's frustrating." This incident explained the dynamics which hindered their ability to feel confident in adequately



controlling the patient's pain.

Uh, I find my greatest problem I have is with some of the doctors not understanding the pain, not understanding, especially in end-stage. This person's dying, like you can't save them, therefore our best thing is palliative care. We have to keep them comfortable, and for me that's a very strong point. I want to keep them comfortable. I've had arguments with doctors for morphine to titrate to pain, to get that order, where I haven't been able to get it and I've finally approached the family and said if you ask for it, you're more likely to get it because for two days now I've wanted, you know, to just basically to start on a low dose to find that level where they're comfortable, you know, not wanting to sedate them or whatever but just keep them comfortable and I've had to fight with - I don't know whether they, I don't think they have much palliative education, it's a big point.

Nurses had a genuine need to help their patients to be comfortable. They however, had no control over the access to what they perceived as adequate medication to do this.

Interestingly, when talking to the physicians, although the majority of them said their goal with cancer pain was "to get a patient pain-free no matter what it takes," one did actually admit to feeling "scared" about aspects of pain management related to the administering of large dosages of analgesics. This may explain their reason for hesitancy with respect to prescription as noted in the following:

I think uh, I take myself and general physicians, that we are sometimes scared to um, to use certain drugs that um - you don't want to overdose a patient but you

feel more comfortable to know that patient is pain-free and comfortable and is released from this horrible experience.....Yes, I mean, I think we are well aware of side effects of these drugs we use to relieve the pain and it sometimes, that stands in the way of giving them full or total relief but I think that comes with experience, that you know, the more you work with these patients the more comfortable you are with relieving their pain.

There were different perceptions on the part of the physician and the nurse with respect to pain control. However, they both reported having the same goal and focus: the relief of the physical sensation of pain. The nurses however, felt frustrated and helpless to provide adequate control because they had no access to the power to prescription medication (i.e., to independently prescribe ) and, the physicians on the other hand, felt scared and hesitant because they were left with the ultimate power to make that decision. This resulted in pain control outcomes that were reported by nurses to be inadequate. It was on this divide, that the dimensions of pain expressed by the professionals took on a conceptualization skewed in proportionality towards the physical sensation of pain. These nurses were obviously concerned with and acknowledged a degree of dimensionality to the pain of cancer, as noted in this response, "Ya, but there's also . . . a mental pain that they have." However, they seemed to have to focus all of their efforts in a power struggle with physicians and were barely able to provide adequate amounts of medication for relief of the physical sensation of pain. As a result the discourse on pain for these nurses reflected a preoccupation with the physical dimension of pain and a focus on medication

intake for relief of cancer pain.

Interestingly, the feeling words of nurses echoed the sentiments expressed by those First Nations care-giver relatives who watched their loved ones in pain and felt “helpless” as well, to do anything to help them. However, as discussed earlier, the circumstance driving these responses for the First Nations care-giver relatives was the patient’s refusal to take an adequate amount of the medications prescribed for pain control. In the case of the health professionals, their helplessness was driven by being powerless to prescribe the medication they believed would address the level of cancer pain a patient was experiencing. Recall that the First Nations patients admitted to using a number of cognitive behavioural strategies to ameliorate the pain and that many chose to endure the pain. The reason given for this was that their priority for pain relief was the ability to maintain a “style” or posture of strength and dignity and to pull on spiritual sources of strength and core cultural values to help them do this. Medication intake was only but one small piece of the total pain control strategies used by them. Their focus was on the multi-dimensionality of pain.

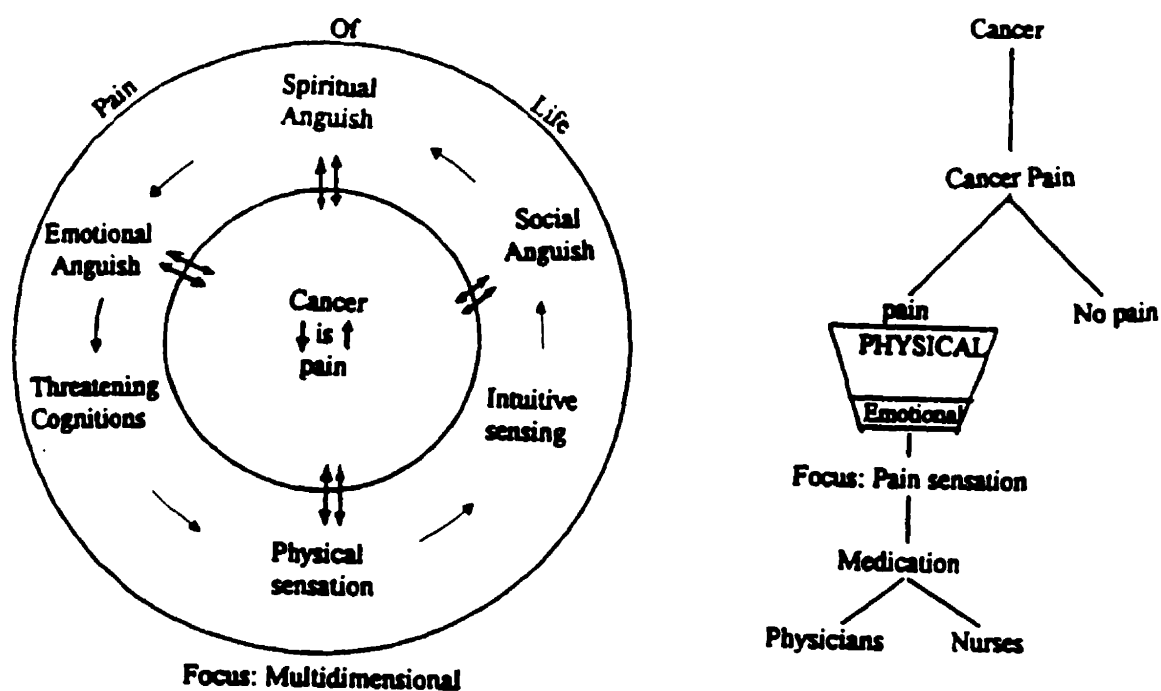
In contrast to the health professionals’ focus on medication for pain control, it was the focus on other dimensions of pain that held potential for the relief of the pain of cancer for First Nations respondents. Their conceptualization of pain melded physical, emotional, social, cognitive and spiritual realms as one comprehensive pain experience requiring an equally multi-dimensional and comprehensive approach for its relief. This was noted in the incidences earlier discussed as well as in the following attempt at explanation by this

healer:

This is something very, very difficult to try to . . . to try to give an explanation because what we are dealing with here is something spiritual. . . . They gave him whatever drug is being prescribed for the pain . . . you know, the drugs are not helping, and they are still are feeling the pain . . . You have the physical pain, you know, but probably the worst pain you can ever feel is the emotional pain and you cannot physically describe it with, you know, using any physical terminology . . . and whatever has caused that, you know that emotional pain . . . if it is not dealt with, it will manifest physically.

Therefore, although both First Nations respondents and the respondents who were health professionals saw a degree of multidimensionality to the pain of cancer, these two perspectives were different. Figure 5 diagrammatically shows the differences between the two conceptualizations of cancer pain. The multidimensionality described by the Ojibway participants was more comprehensive and more complex than that of the health professionals. It was characterized by a fluidity and merging of dimensions. This was not observed in the descriptions of pain given by the health professionals. The health professionals described with detail the physical dimension of the sensation of pain at one level and included the emotional dimension of pain as something that should also be considered. There was the suggestion of levels of pain by the health professionals as opposed to a fluid integration of the dimensions of pain. Pain in cancer was acknowledged by the professionals to be present only in some cancers and this depended on the site and

**Figure 5** Conceptual frameworks of cancer pain. A comparison of Ojibway and health professional



Note. The figure on the left represents the conceptual framework of the Ojibway, depicting the fluid integration of dimensions of cancer pain. The figure on the right represents the conceptual framework of health professionals. In comparison to the Ojibway, health professionals' conceptualization of cancer pain is more linear and pain is separable from the cancer experience. Its dimensions are more layered with the physical dimension representing the largest layer. Pain sensation is the focus of pain assessment and medications are the focus of pain management. Nurses and physicians divide on approaches to medication management.

stage of the cancer. However, for the Ojibway respondents, cancer was pain and pain was cancer and, in the broader context became equated with the pain of life. The point of focus for amelioration of this pain was also different. The First Nations persons' actions focussed less on taking of medications for pain relief and more on taking actions that enabled maintaining spiritual connections, emotional and personal integrity and a posture of dignity.

### Summary

Cancer pain was a challenge for all those who confronted it regardless of the conceptual orientation they brought to the challenge. However, it was the entrenched beliefs acquired either through education or core cultural values that structured the understanding of the illness cancer and drove the actions taken to deal with the challenges of the disease and its related pain. The First Nations population in this investigation held similar aversive beliefs about the word cancer as did the health professionals. However, unlike the health professionals, their conceptualization of the pain of cancer included multiple dimensions that were fluid and integrated. These dimensions merged to become a much broader pain than the sensation of "hurt," which could be endured as long as spiritual integrity and dignity were maintained.

## CHAPTER 6

### Discussion

#### Introduction

In this chapter, the beginning theoretical model which emerged from the data will be discussed in light of the research questions proposed and the contribution of the study to existing theory and to culturally sensitive care. Implications of the study will be discussed as it pertains to the cultural perspectives of Ojibway persons on cancer and the pain of cancer. The implications that this has for health professionals in general and nursing practice in particular, will be discussed. Recommendations for further study will be presented.

The aims of this research were to: 1) describe and explain how cultural beliefs framed how Ojibway people, living on a reserve community, understood the illness experience of cancer and related pain and, 2) to describe differences and/or similarities between Ojibway respondents and health professionals' explanations and perceptions of cancer and related pain. Although there is ample literature available on the measurement of cancer-related pain and the theoretical construct of pain, there was no literature which dealt directly with the Canadian Ojibway's cultural perspective on cancer pain. One study, which will be discussed later, was a Masters thesis by Hart-Waserkeesikaw's (1996) which examined Ojibway people's perspective on cancer.

Given that health professionals are expected to provide care for the growing number of First Nations people who are being hospitalized for cancer and other chronic

diseases (Young, 1989; 1994b), it becomes critical that health providers understand that cultural perspectives can play a critical role in how people understand and experience illness. It is also important for health professionals to recognize that they too have knowledge and beliefs which are equally entrenched in culture: a culture of bio-medicine (Kleinman, 1978). This influences their perspective on illness and in turn, their actions. Misinterpretations and misunderstandings are the unfortunate consequences of failing to recognize the differences in perspectives that are brought to bear on patient/care-giver interactions in the bio-medical context. This serves only to detract from the quality of the care that can be provided. The results of this study revealed the intricacies of the dynamics that create this potential.

#### Derivation of a Cultural Model

The beginning theory which emerged from this investigation delineated at a conceptual level the central unifying concept referred to as blocking. Blocking is an explanatory model which explains the dynamic of the interplay between culture and a dreaded disease cancer, enacted through the people who live them. Conceptual models of the pain of cancer held by both Ojibway and health professionals evolved from the data and they demonstrated marked differences. Qualitative differences of these two world-views in terms of meaning and culturally sanctioned actions related to this illness, revealed contexts in which there was potential for a clash of belief systems. However, it was within these same qualitatively defined contexts that a window of opportunity was revealed for the possible accommodation of both these belief systems, in the pursuit of culturally safe



care for First Nations people.

The findings revealed that people can cognitively understand and process knowledge about illness, drawing from cultural sources. It was revealed that the Ojibway respondents in the current study had a well-articulated cultural model of cancer, which was developed from culturally shared knowledge about a feared sickness referred to as “Manajooosh.” The culturally acquired knowledge about this disease was gained from a number of sources in a particular cultural context.

These results lend support the theoretical postulations of Keinman’s (1978) on the concept of explanatory models. The conceptualization of cancer and the pain of cancer by the Ojibway persons in this study was a well articulated model of a dreaded “sickness.” Kleinman (1978), in his examination of the explanations people gave about illnesses, asserted that lay people have “explanatory models” (EM) which are “culturally constructed” (Kleinman, 1978, p. 254) and which enable them to generate statements about illness based on a specific system of knowledge and values. Further he purported that:

Illness is shaped by cultural factors governing perception, labelling, explanation, and valuation of the discomfoting experience. . . . Because illness experience is an intimate part of social systems of meaning and rules for behaviour, it is strongly influenced by culture: it is . . . culturally constructed (Kleinman, 1978, p. 252).

The theoretical construct of “explanatory models” (Kleinman, 1978) originating from the epistemological orientation of medical anthropology, was found to have a parallel

representation in cognitive psychology. Illness “schemata” (Bishop, Briede, Cavaszos, Grotzinger & McMahon, 1987, p. 21), “the schema concept” (Fiske & Linville, 1980, p. 543), “lay models of illness” (Robbins & Kirmayer, 1991, p. 1029) and “common sense models of illness” (Meyer, Leventhal & Gutman, 1985, p. 115) are all terms in the psychological literature which according to Lau, Bernard, and Hartman (1989), are used to refer to the way in which “people think about or cognitively represent a disease” (p.195). They are the “cognitive structures” (p. 197) people have for illness.

In the aforementioned studies it was shown that people possessed lay understandings of the labels attached to disease, the course of a given illness, the consequences and effects of the illness, the cause of the illness and the treatment or actions deemed necessary for treatment or recovery from illness. These quantitative studies focussed on proving the existence of these cognitive illness structures. Others argued as to the plausibility of a concept such as schema having legitimacy in psychology, given the pejorative statements made about it such as: “the schema concept has been called mush, alien to social psychology and old wine” (Fiske & Linville, 1980, p. 553 ). In defence of the schema notion, these authors suggested that:

*Compared to the cognitive traditions whence it sprung, schematic research uses far more interesting and realistic stimuli. Compared to social psychology, schema research posits more specific and plausible cognitive processes. Thus, the experimental stimuli are being drawn increasingly from realistic social domains, although the methods and questions are heavily cognitive” (p. 553).*

There is therefore a grudging acceptance of the legitimacy of the schema concept in the annals of psychology. However, the two disciplines, psychology and anthropology, share a common definition of the concept despite epistemological differences in orientation. Its application in anthropology as “explanatory models” as defined by Kleinman (1978), offers a useful framework for addressing problems that are confronted in the real world of the health-recipient/ health-provider encounter. Within the health care setting, doctors and nurses adhere to rigidly defined explanations about disease and pathology to the end that “disease, not illness, is the chief concern” (Kleinman, 1978, p. 255). Since disease places humans in circumstances which present problematic issues that are not only physical but psychological, social and cultural, it is necessary to examine issues in health, drawing on theory evolving from these various disciplinary perspectives. Further, it is in the clinical arena that the most impressive argument for the utility of such constructs as explanatory models and illness schemas can be made.

Hence, this current investigation contributes to the knowledge base of both the discipline of cognitive psychology and medical anthropology as it supports the assertion that people have “lay cognitive models” of disease (Meyer, Leventhal, & Gutmann, 1985, p.116) and, that these cognitive representations of illness are culturally constructed (Kleinman, 1978). The explanatory models or schematic representations of illness emerging from the theoretical model in the current investigation were culturally constructed by both Ojibway and health professionals. These models provided a specific way of conceptualizing, interpreting and attributing meaning to the experience of cancer

and related pain.

However, it is imperative that the information garnered by biomedically oriented healthcare professionals on the culturally constructed explanatory models of patients, be used to construct culturally sensitive contexts that permit accommodation and respect for culturally diverse groups. If as Katon and Kleinman (1981) suggested, patients' explanatory models are elicited to provide the medical health professional an opportunity for "negotiation" of a "therapeutic" encounter as defined by these authors, then this becomes problematic. One of the stages of this process requires that "the patient will respond to the doctor's explanations by shifting his or her explanatory model of illness towards the physician's model, and thus making a working alliance possible" (Katon & Kleinman, 1981, p. 103). This form of negotiation is aptly suggested by Scheper-Hughes (1990) to represent a form of manipulation and serves no useful purpose but to perpetuate paternalist medico-centric views.

What this current research points out emphatically is that the culturally constructed models of illness held by patients are real and powerful. They are tenaciously adhered to, even in the face of what would appear to be glaring contradictions if evaluated from a biomedical perspective. It is highly unlikely that trying to change deeply ingrained cultural beliefs such as those which constitute blocking is a possible or even useful enterprise. Using the methodology of ethnohistory, Villarruel and Ortiz de Montellano (1992) traced the historical entrenchment of cultural meanings and expressions of pain by Mesoamericans from ancient times to the present. Interestingly, the researchers were able

to trace vestiges of ancient Mesoamerican beliefs associated with pain in contemporary Mesoamerican cultures. There is good evidence that these beliefs are enduring and serve a special function in specific cultures.

It would seem logical to infer that understanding and more importantly, recognizing the value of these cultural models which drive seemingly paradoxical actions, is critical to affecting any kind of viable and credible avenues for positive influences in prevention, promotion or management of this disease by bio-medicine. Rather than attempting to change them, more constructive efforts are possible. Bottorff, Bhagat, Grewal, Balneaves and Clarke (1999) in a study of South Asian women's beliefs around breast cancer suggested that many of these beliefs held influenced these women's orientation to and participation in breast health practices. A more useful instruction to health professionals offered by these authors was that "while it is important to provide women with accurate information, it is also important not to undermine personally coherent explanations of disease that provide a foundation for coping and self-care" (p. 26). Hence useful strategies such as building on cultural beliefs rather than negating them or attempting to change them to a biomedical cultural belief systems, as suggested in Katon and Kleinman's (1981) approach, would seem to be a more constructive approach.

#### **Pain: A Multidimensional Construct**

The research findings in this study support the postulations espoused by Melzack and Wall's (1965) seminal work on the Gate Control theory of pain. In this theory he concluded that pain was not a unidimensional construct but that it was multidimensional.

From this basis a comprehensive measurement tool, consisting of several word descriptors, was designed to tap the sensory-discriminative, affective-motivational and cognitive-evaluative dimensions of pain (Melzack & Torgerson, 1971). The study reported here demonstrated a qualitative explanation of the dimensionality of pain, substantiating support for those dimensions outlined in Melzack and Torgerson's (1971) theory.

The results of the current study underscore the major tenets of the Gate Control Theory (Melzack & Wall, 1965) in pointing out how lack of attention to all dimensions of pain has the potential to result in ineffective pain control. The clinical relevance of these theoretical underpinnings were demonstrated in this current study and has implications for how health care professionals approach the critical assessment that is necessary before approaching treatment for cancer pain. Bruera and Lawlor (1997), in a paper on cancer pain management asserted that there is need for "Disciplined assessment of patients before proceeding to treatment" (p. 146). Further, these authors offered that:

the approach of [sic] the pain complaint as a unidimensional construct frequently results in opioid dose escalation with increased toxicity and poor response. After a multidimensional assessment, it can become apparent that several other measures are necessary for adequate analgesia (Bruera & Lawlor, 1997, p. 147).

Despite the major advances in pain control treatments currently available for cancer pain, pain continues to be a major problem in cancer (Vainio et al., 1996). The reason seems to lie in the unidimensional focus on the physical sensation of pain in both assessment and treatment of cancer pain. The results of the study reported herein lend support to the need

for attention to the multidimensionality of cancer pain in approaches to pain management.

### **Blocking: Parallels in Emerging Theories on Disclosure**

The core concept which integrated all of the themes and subcategories emerging from the data in this investigation was “blocking.” It explained and described how silence around the topic of cancer and related pain functioned to protect from the exposure to the harm of a life-threatening disease and in maintaining an important connectedness to family and core cultural and spiritual values. In this study the experiences of cancer and related pain were interwoven with painful life events revealing important ways in which these life experiences influenced Ojibway people. Blocking explained how culturally constructed realities can ameliorate the effects of perceived harm; that these realities are very powerful and account for seemingly paradoxical behaviour from the viewpoint of the outsider.

The results of this study on cancer and cancer pain in an Ojibway community is supported by the themes addressing the silence surrounding the patient with cancer which was revealed in a Master’s thesis on cancer in several First Nations communities (Hart-Waserkeesikaw, 1996). Although focused more on the healing practices and the relevance of the Medicine Wheel in guidance and healing journeys, both of these studies independently identified First Nations peoples’ perspective on cancer as a foreign disease. In the current study the data was interpreted to reveal the disease as “an alien disease” which was “alienating” and caused “alienation from family, community and core cultural and spiritual values” as it necessitated people leaving their communities to access health institutions. Hart-Waserkeesikaw (1996) referred to this thematically as “. . . The stranger

in the body,” “becoming a stranger: Leaving the community.” Further, there is evidence of confirmability and truth value surrounding the thematic findings in both studies that with respect to the disease cancer “we don’t talk about it.” The present study however, delved more deeply into the properties and dimensions of the core construct “blocking” which accounted for more than a lack of discourse on the subject of cancer, but encompassed a range of actions, reactions and interactions which created a silence about cancer and cancer pain in an Ojibway community.

The present study differed from Hart-Waserkeesikaw’s (1996) in approach to the extent that her ethnographic data allowed for thematic development to the level of conceptual ordering. At this level the themes found in this research parallel those of Hart-Waserkeesikaw’s findings. Theorizing at the conceptual level allowed for the construction of an overarching explanatory scheme ‘blocking’ (an in vivo code). Constant comparative analysis permitted description of properties and dimensions of this concept and explained how categories were interrelated into a larger theoretical scheme.

The inherent property of blocking characterized by a lack of discourse (“not talking about it”), a lack of disclosure, naming and ownership of the disease cancer was found to be driven by strongly held cultural beliefs, one of which was the transformation of negative thoughts into negative realities. Interestingly, in a study by Carrese and Rhodes (1995) on the Navajo Indians, similar cultural beliefs surrounding the disclosure of bad news was noted. These authors explained that “in traditional Navajo culture, it is held that thought and language have the power to shape reality and to control events.” They



further explained that “language does not merely describe reality, language shapes reality” (Carrese & Rhodes, 1995, p. 826). The similar findings noted in their study underscore the importance of acknowledging that we live in a pluralistic society and that there is good evidence that communities of people bring to the healthcare encounter a belief system that is distinctly different from that held by biomedicine. To discount this or to stereotype all indigenous people as adhering to the same beliefs system is to perpetuate the unaccommodating climate that, according to participants in the current study, is typical of health institutions today.

The results of the current study extends the recently emerging theories on disclosure and concealment practices around the disease cancer which are reported in other parts of the world and with various cultures (Good, Munakata, Kobayshi, Mattingly & Good, 1994; Gordon, 1994; Gordon & Paci, 1997; Mitchell, 1998; Muller & Desmond, 1992). These emerging theories show remarkable parallels to the theoretical model of blocking in the current research. The feature that these research enterprises have in common with the present study is that they all describe non-disclosure practices around cancer. This Gordon and Paci (1997) aptly describe as “a world of secrets and silences; of cultivated vagueness.” (p. 1433). These non-disclosure practices all arise out of the need to “protect” from the reality of the dreaded disease cancer and to construct a less threatening reality by closing off communication. As well, all of these studies of non-disclosure around cancer point out that this is a shared silent agreement among the participants which is embedded in cultural dictates. Finally, the studies all have in common

the fact that non-disclosure practices are tenaciously adhered to.

Gordon and Paci's (1997) description of concealment in non-disclosure practices of people in Tuscany, Italy almost directly parallel those of the Ojibway people in this Canadian study. The following statement by the authors demonstrates this:

Everybody knows the other knows, but nobody says anything. In this context, non-disclosure is not experienced by the patient as a 'lie' or a 'conspiracy of silence.' On the contrary, the family and the patient enact it as a moral duty, a very engaged way to help each other, to support someone they love through this threatening story. The responsibility of the burden is shared. The players continuously reassure themselves that the main actor is playing her/his role, unaware of her/his destiny (p. 1444).

These parallels with the theoretical model blocking, offers some degree of confirmation of the explanatory power of the concept. That is, according to Strauss and Corbin (1998, p. 267), "the ability to explain what might happen in given situations such as and stigma, chronic illness, or closed awareness." These findings also extend our understanding of the issues that present for people confronting the illness cancer.

In Tuscany, non-disclosure practices were carried out not only by patients and their family members, but also by biomedical health professionals (physicians and nurses) and their patients (Gordon & Paci, 1997). What was particularly interesting about this study was that it examined the narratives of health professionals and patients concerning provision of information about a diagnosis of cancer, at a time in history when doctrines

from the United States (such as patients' rights to information, changing medical ethic codes and better communication practices between patient and physician) were noted to be causing signs of change. It was noted that despite a number of younger people arguing for their right to be told of their diagnosis of cancer, when a family member or they were actually diagnosed, the silencing and concealment of this information was enacted.

Since many older physicians believed in not disclosing terminal diagnosis and some patients felt that their rights were being violated by not having access to this information, conflicts and tensions inevitably arose. The clinical arena became the setting where conflict and tensions were played out by people with varying disclosure practices. Interestingly, people continued to tenaciously adhere to the non-disclosure practices of the past despite the larger social changes encouraging them not to do so.

Similarly, in a case study analysis by Muller and Desmond (1992), we are introduced to the situation where issues of non-disclosure further complicate a situation where culture and language difference already presented tensions and strains in the clinical encounter. In this study, ethical dilemmas emerged in a cultural context when American physicians attempted to provide care for a Chinese patient who was in the terminal stage of cancer. Given her poor prognosis, issues of continuing active treatment, of foregoing emergency rescue approaches, and of even informing the patient of the seriousness of the condition became very complicated. The American physician's actions to inform about these issues were driven by his belief that ethically, patients were to be provided information about their diagnosis and treatment course and that active treatment was not

recommended at an advance stage of cancer with a poor prognosis. These beliefs clashed with the Chinese patient's and family's cultural beliefs that disclosure on such matters, and discussion on plans to discontinue active treatment would be tantamount to a death sentence. This conflict escalated to the point of accusations on the part of the Chinese patient's family of inadequate care of their relative, racism and threats of litigation against the physicians.

Herein lies the dynamics that constitute conflict and discontent with care in the clinical arena: the reality that the dominant biomedical model of what is correct, ethical and important in health care is the only legitimate viewpoint from which to evaluate clinical problems. In a culturally diverse society health care professionals must not ignore the fact that people hold alternate models for explaining what is ethical and important and, that these are grounded in cultural dictates. These alternate models should be recognized to be of equal value in defining what is ethical and important in health care. Otherwise, the very tenets upon which the medical standards of ethical care were based is put in peril. More important, the failure to recognize alternate cultural models has the potential to create health care contexts that are filled with conflict and a sense of dis-ease.

Situations such as this demand a completely different perspective from which to consider the importance of cultural orientation in the clinical encounter. It is not merely that health professionals should recognize cultural differences in patients, but that they should be aware of the critical issues which might be of cultural significance to patients and families who are dealing with a life threatening illness such as cancer. Emerging

theories on non-disclosure observed all over the world attest to its relevance as a critical issue to be considered in cancer care, especially when dealing with patients of different cultural orientations. Moreover, the discovery of blocking, an extension of these emerging disclosure theories demonstrated in an Ojibway community, has critical implications for how health care professionals in the Canadian context address the issue of culturally safe care for First Nations patients with cancer.

The issue for health care providers then becomes one of ensuring that they secure knowledge about issues of disclosure in culturally varied societies and that they recognize that cultural perspectives held by patients need to be evaluated with equal legitimacy as is afforded the biomedical perspective. This should not however be interpreted as a qualification to expect that all persons of a specific cultural orientation will have disclosure problems with respect to cancer. However, using the information gathered on disclosure in this and other studies earlier discussed, in an effective way, will demand that the health care provider refocus his/her approach from one of anticipating stereotypical behaviours of members of a particular cultural group, to one of discovering pertinent cultural information which will enable them to help patients feel safe and well cared for.

#### Implications of the Study

Unfortunately, according to Mulholland (1995), the nursing profession prefers to ignore the fact that the clinical arena is fraught with situations which create conflict and discontentment. This author suggests that nursing clings tenaciously to the humanist orientation and brackets out the reality of the clinical setting as this “avoids having to get

one's hands dirty with the social realities of conflict. . . .Humanism appeals to nursing because of its idealism, because of its 'sugar coating of ambiguity'" (p. 443). Hence, she argues that nursing will have difficulty in refocusing its position on cultural care from the one it is presently grounded in: one with profound limitations such as that purported by transcultural nursing models. These transcultural models suggest that cultural sensitivity to differences in cultural orientation is the way of improving care for culturally diverse populations. However, Mulholland (1995) argued that these models fail to recognize the realities of racism, conflict and tension in the clinical arena and power imbalances that create them.

What is now being called "Cultural safety: a new concept in nursing people of different ethnicities." (Polaschek, 1998, p. 452), grew out of an endeavor on the part of Maori nurses in New Zealand to analyse nursing practice from the perspective of the indigenous minority people in that country. They emphatically denounced 'cultural sensitivity' as having anything to do with cultural safety as it is thought to be:

a social construction of the dominant white group. . . .Although the transcultural view approaches other cultures with respect, it does not recognize that no health care interaction is ever simply objective. Rather, the nurse always operates from her/his own cultural mind set which influences how she/he relates to those she/he cares for. . . .It ignores differences in power among various ethnic groups which affect their lives in a society, manifested ultimately in racism (p. 453).

The concept of cultural safety has particular relevance to the current research findings in an Ojibway community. In Ramsden's (1990) report on cultural safety, she noted that "Maori people perceived the health care service alien and not meeting our needs in service, treatment, or attitude. It is culturally unsafe. A dangerous place to be" (p. 18). A remarkable parallel is seen between the statements made by the Maori and the descriptions given about the hospital in the current study of Ojibway people. As noted in the theoretical model of blocking, certain contexts were described in which blocking was triggered. One of those contexts was the hospital setting. It was seen by the Ojibway participants be a source of alienation from that which was culturally and spiritually meaningful and it imposed an unaccommodating climate. It is not difficult to conclude from the descriptions offered by the Ojibway people who took part in this study, that the hospital setting for them was a dangerous place to be.

The courageous stance taken by the Maori of New Zealand in changing the orientation on transcultural care to one of cultural safety is a challenge that has profound possibilities for improving the approach to health care for people of minority cultures. The following definition of cultural safety could offer a useful framework within which Ojibway people could feel safe in biomedical hospital settings.

Cultural safety is about power relationships in nursing service delivery. It is about setting up systems which enable the less powerful to genuinely monitor the attitudes and service of the powerful, to comment with safety and ultimately to create useful and positive change which can be of benefit to nursing and the people

we serve (Polaschek, 1998, p. 453-454).

From the perspective of cultural safety as defined by the Maori, cultural safety addresses the power relationships between the health care provider who provides a service and the recipient of that service. It empowers the users of that service to express their feelings of being at risk or their feelings of safety. According to Papps and Ramsden (1996), "someone who feels unsafe will not be able to take full advantage of the primary health care offered and may therefore, avoid the service until dramatic and expensive secondary or tertiary intervention is required" (p. 494). There is a direct parallel between what was demonstrated as the consequences of blocking in the current study on Ojibway people and what is suggested in Papps and Ramsden's (1996) statement about the consequences of not providing cultural safety for culturally diverse populations.

The findings in the current study therefore extend our knowledge about what creates a context of felt risk to cultural safety as noted in the Ojibway people's response to their experiences in health care institutions. They also have implications, from the perspective of cultural safety, for a more relevant perspective from which to approach the care of minority cultural groups in hospitals. A more relevant perspective would necessarily involve using the information gathered around the contexts that trigger blocking identified in this study, and construct contexts that accommodate and build on the cultural beliefs held rather than trying to negate or change them.

#### Limitations and Recommendations For Further Research

This qualitative study of pain in the context of the disease cancer, as experienced



by Ojibway people in a reserve setting, revealed the existence of a beginning theoretical model which explained how these people understood and experienced this illness. There was descriptive data which demonstrated that people in this community used culturally patterned knowledge to construct an explanatory model or illness schema of the pain of cancer and that this was qualitatively different from the model used by health professionals. There is no doubt that the findings show that cultural knowledge framed these Ojibway respondents' conceptualization of cancer and its pain and that there is rich description of the intricacies of the cultural construction of these conceptualizations.

Coup (1996), Polaschek (1998) and Ramsden (1990) in their discussions about the great need for a new approach to nursing care of persons of different cultural orientation, introduced the notion of power imbalances between dominant and minority groups. They questioned whether it could be possible for adequate and safe health care to be administered to minority groups without examination of the broader social context in which much of the power imbalances arose. Ramsden (1990) argued that the individuals seen in a health care context ultimately belong to a social group. If that social group happens to be one which is disadvantaged socially, racially discriminated against and have little social power in the larger society, then it is inevitable that the care these people receive in the health care system will reflect the position they hold in the larger society. Hence, to fully understand the realities of minority cultures and have any impact on creating culturally safe places in health care settings, the researcher needs to examine the power imbalances and the cultural biases that exist in the larger society.

A limitation of the current study is that the impact of power imbalances and description of the broader social context was not examined in this research effort. Strauss and Corbin (1998) in their explanation of developing grounded theory suggested that “micro conditions often have their origins in macro conditions and when appropriate, the analysis should trace the relationship between these” (p. 185). They continued to explain, using an example of their research, that if the notion of larger global context comes up during the interview, then further questioning in that direction should be pursued. It should, however not “take the researcher off course and change the focus of the study from a micro to a macro one” (Strauss & Corbin, 1998, p. 185).

Explaining the social or macro conditions under which a minority culture is viewed and the power imbalances that impact them and their care providers in the hospital setting could be a possible further research project. It was beyond the scope of the current research project. Explanations of what cultural safety means to Ojibway persons could be examined at the macro level and could be compared with health care professionals explanations on the subject. A more feasible approach would be to use an approach such as that used by Gordon and Paci (1997, p. 1433) where they used a survey questionnaire constructed from the ethnographic studies conducted in earlier research. Using case studies from the previous ethnographic studies, they examined the cultural narrative “to capture the types of stories people live in or are trying to construct . . . the ‘cultural’ refers to societal, meta-narratives of broad and deep cultural influence.” The qualitative findings of the current research could be used to construct the survey so that the questions are

grounded in research findings rather than on a priori assumptions.

Further research of this type is important because, as Kirmayer, Young and Robbins (1994) advised :

Every diagnosis or explanation has sociomoral implications that are often more significant than its scientific accuracy in determining clinical outcome. This points to the need to examine practitioners' attributions as well as those of patients since both are products of particular cultural beliefs and practices in specific social contexts (p. 592).

#### Conclusion

In conclusion, it should be noted that a higher value should be placed on the legitimacy of the rich source of knowledge that can be garnered from the cultural models patients hold. To continue to use the biomedical paradigm as the only legitimate source of instruction for those actions deemed appropriate and relevant to the care of the sick, and to ignore the conflict that results from the imbalances in power that exists in the clinical setting, is to seriously limit the capacity to improve the care health professionals provide to culturally diverse groups. For, as Kirmayer, Young and Robbins (1994) so aptly pointed out:

the tremendous ethnic diversity of Canadian society today makes the study of cultural differences a matter of urgent practical importance. Patients have a wide range of explanations available to them that guide their pattern of resort to health care and their response to specific clinical interventions. . . . Therefore, culturally

**sensitive interventions must not simply respect local modes of explanation but appreciate their social implications. (p. 592).**

### Summary of Findings

There was evidence of “blocking,” an ‘in vivo’ code, represented at some point in the interviews carried out on the subject of cancer and related pain. The inherent properties of blocking were characterized as a dynamic tension that swung between becoming “open” or “closed” to the vulnerability brought about by the “foreign” intrusion of this “white man’s disease.” Hence, blocking was driven by strongly held beliefs about the consequences of taking action to “open” or “close” awareness or acknowledgment of the reality of the disease cancer. Embedded in the beliefs that drove those actions to open or close discourse on this subject were the themes of fear of exposure vs. protection; and alienation vs. connection to core cultural values. Blocking was the operating modality used by respondents to explain a) the response of the disease itself b) the response to the disease c) the response of those afflicted with the disease to each other, relatives and community members and d) the response of seeking or not seeking help.

The extent to which a patient or care-giver relative chose to adopt the “open” dimension of blocking was associated with the degree to which that person felt personally vulnerable to exposure to harm and alienation from core cultural values. Conversely, adoption of the “closed” dimension of blocking was associated with the degree to which that person felt less personally vulnerable and protected from harm and maintained connection to core cultural values. Therefore, the properties of blocking ranged from the extreme of not disclosing the suspicions that one had the disease to anyone (i.e., close relatives, community members, cultural healers or physicians); to partial blocking

characterized by speaking indirectly about it to a close relative who would have to “pick up on the message, disclosing only to a close relative (but to no one else), disclosing only to a close relative, physician and/or healer (often after the disease was too far advanced) and withholding disclosure from community members. Un-blocking was characterized by opening discussion on the subject of cancer by care-giver relatives after having experienced the devastating effects of blocking.

Engaging in blocking has the potential for dire consequences when dealing with an illness such as cancer and related pain. Given the rapid and insidious progression of the disease cancer, and the inevitable escalation of cancer-related pain to severe levels if not controlled, early detection and treatment are the recommended course of action extolled by the biomedical establishment. However, it was clear from the data that what was perceived by these Ojibway patients and care-giver relatives as a way of protecting themselves from harm (i.e., “blocking”) was completely antithetical to the perceptions of ‘protection from harm’ held by the biomedical establishment. The reason for this contrast in perspectives became clear on examination of the culturally held beliefs of these Ojibway respondents on the meaning attributed to the word “cancer” and “the pain of cancer.”

There were three salient contexts in which this blocking posture was triggered. It could be triggered by 1) the situation of affixing the name cancer to the illness state of a person or relative 2) the situation of being hospitalized and 3) the situation of death of a relative and the impact of that on spiritual integrity.

The meaning of the word cancer in the Ojibway language conjured up

images of being eaten alive (Manajoosh - "a worm eating away at your insides"). An "invasion" was the term used by a respondent to describe cancer when attempting to compare it to other diseases. Many respondents admitted to the actual naming of this disease in the Ojibway language. However, others said, as did this healer/elder: "in my language there is no term for cancer." All respondents perceived it as having been imposed upon them: as "white man's disease." They couched their rationale for this belief in the many abuses they had observed by way of pollution of their land, their water and their medicines. All respondents perceived it as "'foreign' to our people," and "killing" our people. Hence, the disease itself was perceived as alien to them and as having been imposed upon them by the contaminating effects of the larger mainstream society. Therefore, assuming a posture of blocking served as a type of protection against exposure to an invasion by this disease.

Not only was the disease alien, but its effects necessitated further alienation as one entered the medical system. Both patients and care-giver relatives embarked on a litany of *physical, social, cultural and spiritual necessities* from which they felt "cut off" when entering the hospitalization period. The hospital, as opposed to home, was a major source of alienation from both their source of strength and all that was meaningful to them culturally, so that those who had actually been hospitalized dreaded having to be there. Those who had observed a close relative in the hospital situation spoke of anticipating this alienation. Hence, patients often requested to leave the hospital before it was appropriate to do so, signing themselves out of hospital before completing the required time as

dictated by the doctor and often failing to keep appointments.

Another context at which blocking facilitated the 'closing' off from others (i.e., everyone: relatives, friends and community) was the point of death of the patient. The specific elements triggering blocking at this time were described as a feeling of alienation both from the deceased and most important, from the connection with one's source of strength: the Creator. In the situation where a family member returned to their cultural rituals, ceremonies and beliefs in the power of the Creator in an effort to prevent the death of a family member, a severe sense of loss of faith was reported to ensue upon the death of the patient. Mothers reported that ever since the death, they observed their adult children "turning away" from the traditional ways, and becoming involved in the abuse of alcohol and drugs. Siblings reported similar situations with young adults in the family, and elders lamented the plight of "our young people." Hence, alienation from the deceased through death led to a feeling of alienation from core cultural values and triggered a most extreme form of blocking.

Blocking, although predominantly the posture adopted when dealing with cancer and related pain among these Ojibway people, did not account for the responses of all patients and care-giver relatives. Conditions which triggered a change in blocking to one of "Un-blocking" were evident in those patients who had survived the cancer experience and those care-giver relatives who had experienced the detrimental effects of "blocking." The trigger for Un-blocking was revealed to have been based on 1) insight gained from having witnessed the devastating consequences of blocking and 2) learning from



experience. The consequences of blocking which had the impact of causing a change to Un-blocking was a) loss of time and b) loss of support. Witnessing the suffering of a loved one, who succumbed to the ravages of this illness instilled in these care-giver relatives a determination to prevent the same thing from happening to themselves or their children. Un-blocking, however, was not a static state. It was articulated at a cognitive level by both some survivors of cancer and care-giver relatives. However, there was evidence of reverting to a blocking posture by patients, unlike care-givers, when faced with actually taking action to un-block.

The pain of cancer was conceptualized as embedded in the cancer illness experience. Respondents would invariably present their perceptions and understanding of the illness cancer as inseparable from the pain of cancer and in turn, the pain of cancer as inseparable from the pain of life. In short, pain meant the cancer experience and the cancer experience epitomized that which was most painful in life. This puzzling interweaving of cancer and related pain with the pain of life was elucidated in this statement by one of the respondents, a healer. "If you are going to understand this sickness then we have to understand life." The pain of cancer for the cancer patient was not only conceptualized as a hurt, at the level of a sensation, but reached into the recesses of deep psychological, social and spiritual anguish. Horrific stories of the pain endured in the context of physical, sexual and social abuse as a people, was the discourse embarked upon when care-giver relatives were asked to describe their observations of a close relative with cancer related pain. These stories were infused with themes of helplessness,

hopelessness and loss; of having to endure; and of having to make cruel choices. These respondents also acknowledged an element of contagion (sympathy pain) and intuition as representing a feature encountered in the pain of cancer. Both patients and care-giver relatives attributed meaning to the pain of cancer.

A blocking posture again was also evident in responses to pain. Again, blocking presented as a way of managing the pain of cancer, and an attempt to protect rather than expose one's vulnerability; and to maintain connections rather than alienate them. Worst of all, they endured the pain until it was so severe that the only option left to them was re-entry to hospital. Blocking bought them some time. The predominant statements used by patients to describe how they managed pain was "I wait," "I try to ignore it" and "I block it out" until unable to maintain this. Again, the dynamic of remaining 'closed' rather than 'open' about one's condition was used as a protection against having to endure the anticipated alienation of hospitalization. Pain could be endured: alienation could not be.

Interestingly, it was also revealed that health professionals had conceptualizations and approaches to pain relief which differed from that of the Ojibway respondents. Health professionals' view of cancer related pain was directly related to the site, type and stage of the disease. Although, similar to the Ojibway perspective, the word "terminal" was used to describe what the word cancer as a diagnosis meant, the pain of cancer was conceptualized differently, and the focus of approach to control of cancer related pain was different. Health professionals reported that pain was not evident in all cancers, unlike the Ojibway, who saw cancer as pain and pain as cancer and, in turn, the

pain of life embodying the pain of cancer. The health professionals identified a dimensionality to pain. However, due to access to medication and technology that could take the pain away, their focus was on the physical dimension of the sensation of pain. However, a power struggle resulting from physicians having independent control over type, dosage and frequency of medications, divided nurses and doctors on what constituted adequate pain control. Their conceptualization of pain was therefore somewhat skewed toward the physical dimension of pain, resulting in a dimensionality more resembling stratified layers than an integrated, fluid, dimensionality noted on Ojibway conceptualization of pain.

In conclusion, the data revealed a beginning theoretical model of how Ojibway people understand and respond to cancer and related pain. It revealed that cultural frames structured this conceptualization of an illness experience. The explanatory models of Ojibway and health professionals were revealed to be different on several levels, with respect to meaning of cancer and conceptualization of cancer related pain.

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**Appendix A**

**ETHICAL REVIEW COMMITTEE APPROVAL FORM**

The University of Manitoba  
FACULTY OF NURSING  
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number N#97/14

Proposal Title: "AN OJIBWAY CULTURAL PERSPECTIVE ON THE ILLNESS CANCER AND  
RELATED PAIN."

Name and Title of  
Researcher(s):

DIANA BARKWELL, PHD CANDIDATE  
GRADUATE STUDENT, INTERDISCIPLINARY PhD PROGRAM  
UNIVERSITY OF MANITOBA

Date of Review: APRIL 07, 1997.

APPROVED BY THE COMMITTEE: MAY 21, 1997.

Comments: APPROVED with submitted changes and clarifications dated  
May 14, 1997.

Date: MAY 21, 1997.

Karen Chalmers  
Karen I. Chalmers, PhD, RN                      Chairperson  
Associate Professor  
University of Manitoba Faculty of Nursing

Position

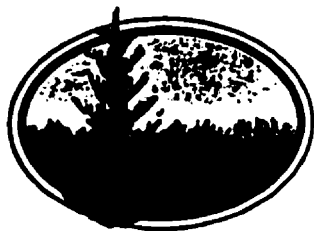
NOTE:

Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

Revised: 92/05/08/se

**Appendix B**

**APPROVAL FORM: HEALTH COMPLEX  
LETTER OF APPROVAL: COMMUNITY**



# PINE FALLS HEALTH COMPLEX

P.O. Box 2000  
Pine Falls, Manitoba R0E 1M0  
Phone (204) 367-4441  
Fax (204) 367-8981

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A NORTH EASTMAN HEALTH ASSOCIATION PARTNER

August 25, 1997

Ms Diana Barkwell  
University of Manitoba  
Faculty of Nursing  
Room 246 Bison Building  
Winnipeg, Manitoba  
R3T 2N2

Dear Ms Barkwell:

This letter is to confirm our telephone conversation granting you permission to proceed with your research entitled "An Ojibway cultural perspective on the illness cancer and related pain." The North Eastman Health Association is pleased to participate in this project.

Yours truly,

Susan M. Derk, R.N., B.N.  
Community Health Manager

SMD/ep

**LETTER OF AUTHORIZATION FOR APPROVAL OF RESEARCH PROJECT**  
**"An Ojibway Cultural Perspective on the Illness Cancer and Related Pain"**

**By Diana Barkwell, R.N., M.N., Ph.D. (cand.)**


**January 14, 1997**

Pursuant to the meeting with the Administrator Fort Alexander Health Centre October 25, 1996, and subsequent meetings and discussions regarding the implementation of the research project entitled "*An Ojibway Cultural Perspective on the Illness Cancer and Related Pain*", we the undersigned, agree to grant Diana Barkwell permission to access this Ojibway community and to invite members of the community who are interested, to volunteer to participate in the study. Persons who may be potential participants in the study will be able to receive information about this study through posted written information exhibited at the Health Unit or from the professionals or the interpreter at the Health Unit making them aware of the research project.

We understand that Diana Barkwell is interested in interviewing persons who have had cancer, those who live with (*or have lived with*) a relative or loved one who has cancer, those who have knowledge of illnesses such as elders/healers in the community and health professionals at the Health Unit. We have read the consent forms and other documents pertaining to the study and understand the Diana Barkwell, the researcher in the project, has made it clear that participation in the project will be strictly voluntary with the option to withdraw at any point of the investigation, and that information accrued from those participating in the study will be kept in strict confidence.

We understand that this research project must and will have ethical approval from the Ethics Committee, University of Manitoba, faculty of Nursing, before Diana Barkwell can proceed with the implementation of the study. Upon receipt of ethical approval, we the undersigned give our approval to proceed with this research project in this community.

On behalf of the Fort Alexander Health Centre  
Board of Directors:  
Chairman, Board of Directors  
Fort Alexander Health Centre

  
\_\_\_\_\_

Date: 25/03/97

*(Diana Barkwell is a nurse and Ph.D. candidate in the Interdisciplinary doctorate program, University of Manitoba. The Ph.D. Committee members are: Dr. Lesley Deegan (Chair), Dr. William (John) Kurland and Dr. Michael Thomas)*



**Appendix C**

**INCLUSION CRITERIA  
INFORMATION FORM (NURSES)**

## **INCLUSION CRITERIA**

- 1. Adults (18 yrs. & over)**
- 2. Aboriginal persons with knowledge of having the illness cancer and related pain**
- 3. Aboriginal Persons who live with (or have lived with) a relative who has cancer**
- 4. Aboriginal Persons who are Healers/Elders in the community**
- 5. Persons who are health professionals at Health Centres (on Reserve/adjoining community)**

**\* SAMPLE INFORMATION FORM (NURSES)**

**My name is Diana Barkwell and I am a nurse who teaches nursing on the Faculty of Nursing, University of Manitoba, and am completing PhD. studies in the Interdisciplinary PhD. Program, University of Manitoba. I will be conducting a study entitled "An Ojibway cultural perspective on cancer and related pain" with the purpose of exploring the cultural understandings that Ojibway people on this reserve have about the illness cancer and related pain. I am interested in having people who have cancer and related pain participate in the study. I would greatly appreciate your help in accessing these people. If you are aware of any patients who might fit the study criteria posted in your front waiting room, could you please draw the notice to their attention, and ask them to contact the interpreter (name) if they are at all interested in participating in the study. Should you have any questions, I can be contacted at (204) 474-7452. Be aware that you have no obligation to do this. Refusal to inform patients of this study will not in any way affect your job or any aspect of your life. Thank you so very much for your time and help in this project. This research project has been approved by the Ethical Review Committee, Faculty of Nursing University of Manitoba.**

**Appendix D**

**SAMPLE CONSENT FORM (PATIENT)  
SAMPLE CONSENT FORM (COMMUNITY MEMBER)  
SAMPLE CONSENT FORM (HEALTH PROFESSIONAL)**

## **\*SAMPLE WRITTEN CONSENT FORM (Patient)**

You are invited to participate in a face-to-face interview for the research study entitled "An Ojibway cultural perspective on cancer and related pain". This study is conducted by Diana Barkwell R.N., M.N., a PhD candidate, Interdisciplinary Program, and lecturer, Faculty of Nursing, University of Manitoba. The purpose of this research project is to explore whether culture plays a part in how Ojibway people experience, understand and seek healing/treatment when dealing with cancer and related pain, and how this compares with health professionals' views. Information about the study will be on display at the Health Unit and to the health professionals working there, who may draw your attention to the study. The investigator will not at any time personally access or see your medical records. Answering the interview questions means that you have agreed to take part in the study. You do not have to take part in this study. Refusal to do so will have no effect on any aspect of your life or health care. Included in this research project will be persons like yourself, who have the illness cancer, persons who are a family member or significant other living with (or has lived with) someone who has cancer, persons who are Elders/Healers in the community and medical health care professionals. The Ethical Review Committee of the Faculty of Nursing has approved this research project.

The interview will be carried out by Diana Barkwell and by an Ojibway speaking interpreter. This will allow you the choice to answer questions in either the Ojibway or English language. The questions asked will involve sharing what this illness experience has been like for you, your beliefs about what cancer and related pain means to you, what you know about this illness and the healing/treatment approaches required to help people deal with it. The interview should last no longer than one hour. It will be tape recorded and all tapes will be typed. You may be contacted a second time only if clarification of your answers is required. Those tapes done in the Ojibway language will be translated to English by an Ojibway speaking interpreter who has consented to the requirements for confidentiality. All of the information given will be treated confidentially and transcribed data only accessed by researcher and her PhD. Committee members. Your name or the name of any one participating in the study, will not be used on any documents, transcripts, reports or future publications. No specific details will be released that could in any way identify you. All tapes and transcripts will be securely locked during and after completion of the study and kept for seven to ten years before being destroyed.

You have had a chance to have all of your questions answered. Should you have any further questions at any time please feel free to ask them. There are no benefits to you personally for being part of this study, but the findings may help health care professionals to better understand the cultural ways of understanding and dealing with the illness experience of cancer and related pain which could lead to more culturally sensitive health care. By taking part in this study you may experience some emotional feelings due to the sensitive nature of the topic. You can refuse to answer any question at any point during the interview, or ask that the tape recorder be turned off, or withdraw from the study. If you so choose, a copy of the findings will be sent to you when the study is completed. Members of the PhD. Committee are listed below for your information. Contact Diana Barkwell at 474-9162, Faculty of Nursing, University of Manitoba. Your signature on the attached page indicates only that you will take part in the study.

Your participation in this study would be greatly appreciated. Thank you.

---

I agree to take part in this study.

Your signature \_\_\_\_\_ Date \_\_\_\_\_

Interviewer signature \_\_\_\_\_ Date \_\_\_\_\_

PhD. Thesis Committee: Dr. Lesley Degner (Chair), Dr. William Koolage and Dr. Michael Thomas. Department of Graduate Studies, Interdisciplinary PhD. Program, University of Manitoba.

**\*SAMPLE WRITTEN CONSENT FORM (COMMUNITY MEMBER)**

You are invited to participate in a face-to-face interview for the research study entitled "An Ojibway cultural perspective on cancer and related pain". This study is conducted by Diana Barkwell R.N., M.N., a PhD candidate, Interdisciplinary Program, and lecturer, Faculty of Nursing, University of Manitoba. The purpose of this research project is to explore whether culture plays a part in how Ojibway people experience, understand and seek healing/treatment when dealing with cancer and related pain, and how this compares with health professionals' views. Answering the interview questions means that you have agreed to take part in the study. You do not have to take part in this study. Refusal to do so will have no effect on any aspect of your life or health care. Included in this research project will be persons who have the illness cancer, persons who are a family member or significant other living with (or has lived with) someone who has cancer, persons who are Elders/Healers in the community and medical health care professionals. The Ethical Review Committee of the Faculty of Nursing, University of Manitoba, has approved this research project.

The interview will be carried out by Diana Barkwell and by an Ojibway speaking interpreter. This will allow you the choice to answer questions in either the Ojibway or English language. The questions asked will involve sharing beliefs about what cancer and related pain means to you, what you know about this illness and the treatment/healing approaches required to help people deal with it. The interview should last no longer than one hour. It will be tape recorded and all tapes will be typed. You may be contacted a second time only if clarification of your answers is required. Those tapes done in the Ojibway language will be translated to English by an Ojibway speaking interpreter who has consented to the requirements for confidentiality. All of the information given will be treated confidentially and transcribed data only accessed by researcher and her PhD. Committee members. Your name or the name of any participant in the study, will not be used on any documents, transcripts, reports or future publications. No specific details will be released that could in any way identify you. All tapes and transcripts will be securely locked during and after completion of the study and kept for seven to ten years before being destroyed.

You have had a chance to have all of your questions answered. Should you have any further questions at any time please feel free to ask them. There are no benefits to you personally for being part of this study, but the findings may help health care professionals to better understand the cultural ways of understanding and dealing with the illness experience of cancer and related pain which could lead to more culturally sensitive health care. You can refuse to answer any question at any point during the interview, or ask that the tape recorder be turned off, or withdraw from the study. If you so choose, a copy of the findings will be sent to you when the study is completed. Members of the PhD. Committee are listed below for your information. Contact Diana Barkwell at 474-9162, Faculty of Nursing, University of Manitoba. Your signature below indicates only that you will take part in the study.

Your participation in this study would be greatly appreciated. Thank you.

---

I agree to take part in this study.

Your signature \_\_\_\_\_ Date \_\_\_\_\_

Interviewer signature \_\_\_\_\_ Date \_\_\_\_\_

PhD. Thesis Committee: Dr. Lesley Degner (Chair), Dr. William Koolage and Dr. Michael Thomas. Department of Graduate Studies, Interdisciplinary PhD. Program, University of Manitoba.

## **\*SAMPLE WRITTEN CONSENT FORM (HEALTH PROFESSIONAL)**

You are invited to participate in a face-to-face interview for the research study entitled "An Ojibway cultural perspective on cancer and related pain". This study is conducted by Diana Barkwell R.N., M.N., a PhD candidate, Interdisciplinary Program, and lecturer, Faculty of Nursing, University of Manitoba. The purpose of this research project is to explore whether culture plays a part in how Ojibway people experience, understand and seek healing/treatment when dealing with cancer and related pain, and how this compares with health professionals' views. Answering the interview questions means that you have agreed to take part in the study. You do not have to take part in this study. Refusal to do so will have no effect on any aspect of your life. Included in this research project will be persons who have the illness cancer, persons who are a family member or significant other living with (or has lived with) someone who has cancer, persons who are Elders/Healers in the community and medical health care professionals. The Ethical Review Committee of the Faculty of Nursing, University of Manitoba, has approved this research project.

The interview will be carried out by Diana Barkwell. The questions asked will involve sharing your knowledge about cancer, what causes it, what characterizes it with respect to symptoms, pathophysiology, course of disease, treatment/healing approaches necessary to effectively deal with this illness experience.

The interview should last no longer than three quarters of an hour. It will be tape recorded and all tapes will be typed. All of the information given will be treated confidentially and transcribed data only accessed by researcher and her PhD. Committee members. Your name or the name of any one participating in the study, will not be used on any documents, transcripts, reports or future publications. No specific details will be released that could in any way identify you. All tapes and transcripts will be securely locked during and after completion of the study and kept for seven to ten years before being destroyed.

You have had a chance to have all of your questions answered. Should you have any further questions at any time please feel free to ask them. There are no benefits to you personally for being part of this study, but the findings may help health care professionals to better understand the cultural ways of understanding and dealing with the illness experience of cancer and related pain which could lead to more culturally sensitive health care. You can refuse to answer any question at any point during the interview, or ask that the tape recorder be turned off, or withdraw from the study. If you so choose, a copy of the findings will be sent to you when the study is completed. Members of the PhD. Committee are listed below for you information. Contact Diana Barkwell at 474-9162, Faculty of Nursing, University of Manitoba. Your signature below indicates only that you will take part in the study.

Your participation in this study would be greatly appreciated. Thank you.

---

I agree to take part in this study.

Your signature \_\_\_\_\_ Date \_\_\_\_\_

Interviewer signature \_\_\_\_\_ Date \_\_\_\_\_

PhD. Thesis Committee: Dr. Lesley Degner (Chair), Dr. William Koolage and Dr. Michael Thomas. Department of Graduate Studies, Interdisciplinary PhD. Program, University of Manitoba.



**Appendix E**

**LETTER OF AGREEMENT  
(INTERPRETER/TRANSCRIBER)**

**LETTER OF AGREEMENT**

**RESEARCH PROJECT: "An Ojibway Cultural Perspective on Cancer and Related Pain"**

**PRINCIPAL INVESTIGATOR: Diana Barkwell, R.N., M.N., PhD. Candidate,  
University of Manitoba,**

-----is hired as an interpreter for the above project from (Date....) for a maximum of eight hours per week at an hourly rate of \_\_\_ per hour. Subject to agreement by both parties, the hours per week and/or number of weeks may be altered.

Duties are:      1) Conduct interviews in the Ojibway language for those participants who would prefer to speak in their first language.  
                    2) Interpret the Consent forms and other information in the Ojibway language where required.

All data are to be kept confidential as required of all research data.

This project is based at the University of Manitoba, Faculty of Nursing

Signature of Interpreter/Transcriber \_\_\_\_\_ Date \_\_\_\_\_

Signature of Researcher \_\_\_\_\_ Date \_\_\_\_\_

**Appendix F**

**QUESTIONNAIRE (DEMOGRAPHICS)  
PATIENT INTERVIEW GUIDE  
COMMUNITY MEMBER INTERVIEW GUIDE  
HEALER/ELDER INTERVIEW GUIDE  
HEALTH PROFESSIONAL INTERVIEW GUIDE**

**GENERAL INFORMATION FORM**

Participant number\_\_\_\_\_

1. Age\_\_\_\_\_Gender (M/F)\_\_\_\_\_

2. Education: Grade completed (kindergarten to high school)\_\_\_\_\_

After high school\_\_\_\_\_

3. Occupation/Title\_\_\_\_\_

4. First language\_\_\_\_\_

## PATIENT INTERVIEW GUIDE

### Preamble

As we discussed earlier, I am interested in understanding what you know about the illness referred to as cancer and what it means to you when you get pain with this illness. I also want to know what having this illness has been like for you and what you have done to help in the healing and treatment of this illness.

1. Could you begin by telling me what you know about the illness cancer?

(probe)

Based on what has been passed down through the teachings of the elders, do you know the illness cancer by any other name? What does that name mean to you?

2. What do you think causes cancer?

(probe)

Can you tell me what You personally believe caused you to get this illness?

Are there any other beliefs you hold about what causes cancer based on what has been passed down by the teachings of the elders?

3. Was there any point at which you had pain?

(probe)

Describe to me what the pain was like and when it started

Where did you get the pain? How long did it last?

Is the pain you have been experiencing with cancer different than any other type of pain you have had before? In what way?

Tell me what you believe it means when you get pain with cancer

What have you done to relieve the pain? Did this help?

What has it been like living with the pain of cancer?

4. Can you explain to me how you came to know that you had this illness?

(probe)

What kinds of things were happening to you to make you think you were ill?

How did you know it was cancer?

How soon after these things happened did you see someone for help?

Share with me how you felt when you suspected or learned you had this illness cancer.

5. What did you do to help in the treatment and/or healing of this illness?

(probe)

-Did you seek help from a doctor in the hospital/clinic, or from an elder/healer or from both?

- What was your experience like when you went to seek help from the doctor in the hospital/clinic? From the Healer? From both?
- What was helpful in treatment and/or healing throughout this illness experience
- What information about treatments might have been of benefit to you in your struggle with this illness.
- Did you find that the beliefs you hold about this illness and its treatment (cancer and related pain), were understood and respected by the person to whom you went to seek help?

## COMMUNITY MEMBER INTERVIEW GUIDE

### Preamble

As we discussed earlier, I am interested in understanding what you, as someone who has lived (or is living) with a relative with cancer, know about the illness referred to as cancer and what it means to you when a person gets pain with this illness. I also want to know what things you believe would be helpful in the healing and treatment of this illness.

1. Could you begin by telling me what you know about the illness cancer?

(probe)

Based on what has been passed down through the teachings of the elders, do you know the illness cancer by any other name? What does that name mean to you?

2. What do you think causes cancer?

(probe)

Can you tell me what You personally believe to be the cause of this illness?

Are there any other beliefs you hold about what causes cancer based on what has been passed down by the teachings of the elders?

3. Is there any point at which you think people experience pain with the illness cancer?

(probe)

Share with me what you believe it means when pain is felt with the illness called cancer

What do you think the pain of cancer is like compared to other illnesses?

Share with me any beliefs you have about what would help relieve the pain of cancer?

What has living with someone with cancer and related pain been like for you?

4. Can you explain to me how you would know that you had cancer?

(probe)

What kinds of things would you notice that would make you think you were ill?

How would you know that it was cancer?

How soon after you noticed these changes do you think you would see someone for help?

5. What do you believe should be done for the treatment and/or healing of this illness cancer?

(probe)

-Would you seek help (or advise any one with cancer to seek help) from a doctor in the hospital/clinic, or from an Elder/Healer or from both?

-What are your reasons for this?

-What do you believe to be helpful things in the treatment

and/or healing of this illness

-What information about treatments do you think was or would be of benefit to you as a family member

-Do you believe that the beliefs you hold about cancer, its related pain and treatment would be understood and respected by the person/s you or your relative went to for help? Why?



## HEALER/ELDER INTERVIEW GUIDE

### Preamble

As we discussed earlier, I am interested in understanding what you know about the illness referred to as cancer and what it means to you when a person gets pain with this illness. I also want to know what things you believe would be helpful in the healing and treatment of this illness.

1. Could you begin by telling me what you know about the illness cancer?

(probe)

Based on what has been passed down through your cultural teachings, do you know the illness cancer by any other name?

What does that name mean to you?

2. What do you think causes cancer?

(probe)

Can you tell me what You personally believe to be the cause of this illness?

Are there any other beliefs you hold about what causes cancer based on what has been passed down through teachings of the elders before you?

3. Is there any point at which you think people experience pain with the illness cancer?

(probe)

Share with me what you believe it means when pain is felt with the illness called cancer

What do you think the pain of cancer is like compared to other illnesses?

Share with me any beliefs you have about what would help relieve the pain of cancer?

4. Can you explain to me how you would know that someone had cancer?

(probe)

What kinds of things would persons with cancer notice that would make them think they were ill?

How would you know that it was cancer?

How soon after anyone noticed these changes do you think they should seek help?

5. What do you believe should be done for the treatment and/or healing of this illness cancer?

(probe)

-Would you advise any one with cancer to seek help from a doctor in the hospital/clinic, or from an Elder/Healer or from both?

- What are your reasons for this?
- What do you believe to be helpful things in the treatment and/or healing of this illness
- What information about treatments/healing do you think would be of benefit to the person with cancer?
- Do you believe that the beliefs you hold about cancer and related pain, and its treatment would be understood and respected by the person/s to whom people on this reserve go for help? Why?

## HEALTH PROFESSIONAL INTERVIEW GUIDE

### Preamble

As we discussed earlier, I am interested in understanding the knowledge base that guides you as a health professional in understanding and caring for patients with the illness cancer and related pain. I want to know what things you believe causes this illness, the symptoms that may present, the course of the disease and what would be helpful in the healing and treatment of this illness.

1. Could you begin by telling me what you know about the illness cancer?

(probe)

Based on your medical/nursing background, do you know the illness cancer by any other name?

What does that name mean to you?

2. What do you think causes cancer?

(probe)

What source of knowledge do you draw on to inform you of this? (i.e. Your medical/nursing education, experience with caring for cancer patients, or any other)

3. Is there any point at which you think people experience pain with the illness cancer?

(probe)

When patients start to experience pain with cancer what is this indicative of?

How would you explain the pain of cancer compared to other illnesses?

What would you suggest for relief of cancer-related pain?

4. Can you explain to me how you would know that someone had cancer?

(probe)

What are the indicators that would suggest to you that someone had cancer?

What processes would have to be implemented in order to confirm that someone had cancer?

How soon after someone noticed changes that could be indicative of cancer, should they seek help?

5. What do you believe should be done for the treatment and/or healing of this illness cancer?

(probe)

-From whom should anyone seek help who suspects that they have cancer or know that they have cancer: A physician in the hospital/clinic, an Elder/Healer or from both?

-What are your reasons for this?

-What do you believe to be helpful approaches in the treatment and/or healing of this illness

-What information about treatments/healing do you think would be of benefit to the person with cancer?

-Do you believe that beliefs which may be held by culturally different patients/families which are dissimilar to your medical/nursing ones about cancer and related pain and its treatment, are as legitimate? Explain.

-Would you say that you (or any of your colleagues) have knowledge of, understand and respect Aboriginal cultural ideas and beliefs about cancer and related pain to the extent that they are incorporated into your interaction and treatment plans? Explain.