Perceptions of Care

Aboriginal Patients at the Winnipeg Health Sciences Centre

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Thesis
Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements
for the Degree of

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Perceptions of Care
Aboriginal Patients at the Winnipeg Health Sciences Centre

BY

Nichole Margaret Marie Riese

A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University

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ABSTRACT

Aboriginal people comprise a large percentage of admissions to the Health Sciences Centre, an 850-bed tertiary care teaching hospital in Winnipeg. Issues such as the perception of systemic and individual discrimination have come up at the hospital in the past decades. The objective of this study was to develop an in-depth understanding of the current urban hospitalization experience of Aboriginal patients on medical, surgical and rehabilitation wards.

Semi-structured qualitative interviews were done, both in English and in Ojibway with patients who self-identified as Aboriginal. As directed by key informants, the areas explored included communication, family involvement, discharge planning, and racism. Interview data was analyzed, coded and categorized and emerging themes were corroborated with the key informants. A case study of Aboriginal people's involvement at the hospital was done also, in particular looking at the outcome of a 1992 report on Aboriginal services.

Important themes to emerge from the interviews were control, and endurance. Racism, separation from both family and community, and communication problems were frequent concerns. Many patients lacked knowledge about the Aboriginal Services Department, with few interpreter-caseworkers involved with patients.

Increased utilization of the Aboriginal Service Department's interpreter-caseworkers as patient advocates and promotion of the hospital's cultural awareness workshops could contribute to resolving some of the problems described by patients. The partial fulfillment of the 1992 Report of the Aboriginal Services Review Committee recommendations, including increased Aboriginal representation in employment and governance at the hospital may point to inherent difficulties in

resolving such issues or to systemic discrimination towards Aboriginal people. Leadership at the highest corporate levels will be needed to ensure they are implemented so that Aboriginal people can feel well served in the Winnipeg health care system.

ACKNOWLEDGEMENTS

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I am indebted to my five Aboriginal advisers, Gerald Berthelette, Nellie Erickson, Matrine McLellan, Katherine Morriseau-Sinclair and Marilyn Tanner-Spence. Their advice over the past three years made me more confident that what we were doing was important and they ensured that my work would reflect the concerns of Aboriginal people.

Ms. Olga Houle, my research assistant, helped perform all the interviews in English and Ojibway. Dorine Benoit assisted in translations of the Ojibway interviews. Elder Diane Morriseau and Rev. Barb Shumski, and the staff of the Aboriginal Services Department assisted and supported the project. Most important, I want to thank the patients who participated in the interviews, who made this study possible.

This study is part of a larger study at the Health Sciences Centre, titled "Aboriginal Patients at the Winnipeg Health Sciences Centre, Part 1 Utilization of Services & Part 2 Perceptions of Care." The investigators include Dr. Pam Orr, Dr. Lindsay Nicolle, statistician Mary Cheang and this author. I thank Drs. Orr and Nicolle for initiating this project and for their insight and guidance along the way. Part 1 is an analysis of hospital admission data to compare demographics, disease patterns, and utilization of services of Aboriginal and non-Aboriginal inpatients over a two-year period in the Health Sciences Centre. This thesis "Perceptions of Care" is

Part 2, looking at Aboriginal patients' experience in the hospital system. I want to thank the Health Sciences Centre Research Foundation, directed by Dr Luis Oppenheimer, for funding this study.

Lastly I want to thank my family, friends and co-workers for their input and support over the many years I was a student involved in this project.

DEDICATION

This manuscript is dedicated to my friend Wendi Brown Dube, who died in this hospital before I finished this thesis. We shared discussions about the difficulty patients endure as they negotiate the health care system. It is my hope that this thesis will contribute to better health care for patients.

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EXECUTIVE SUMMARY

This study examined Aboriginal patients' perception of care at the Health Sciences Centre.[1] The Health Sciences Centre is an 850-bed teaching hospital serving patients from the city of Winnipeg, the province of Manitoba and parts of northwestern Ontario and Nunavut. In the past, the hospital's Aboriginal Service Review Committee identified issues with the care of Aboriginal patients including "the widespread perception of systemic and individual discrimination (1992:18)." The lack of Aboriginal representation in hospital staffing and board membership and insufficient funding of the Aboriginal Services Department were documented in the 1992 report of the Aboriginal Services Review Committee.

This qualitative study was performed to develop an in-depth understanding of the current hospitalization experience of Aboriginal patients. It involved a case study of the institution and semi-structured interviews of Aboriginal key informants and patients. Hospital documents were reviewed and interpretation of the information was verified with people working in the system. In particular, I focused on exploring the hospital's progress fulfilling recommendations of the 1992 Report of the Aboriginal Services Review Committee.

Despite efforts since the 1992 report to increase Aboriginal employment, less than one percent of the hospital's workforce is Aboriginal. The Aboriginal Services Department has expanded now to thirteen staff, including a full-time Elder. This department provides interpretation, liaison, advocacy, support and cultural services for Aboriginal patients. To address cross-cultural concerns cited in the 1992 report, the

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[1] Seventy-five percent of Manitoba's Aboriginal people are Treaty status, referring to persons who are members of a First Nation and/or report being a Treaty Indian or a Registered Indian as defined by the Indian Act of Canada (Statistics Canada, 1996). The remaining 25% are Metis, referring to people of mixed ancestry, Indian and usually French.

hospital's education department has offered two-day cultural awareness workshops to employees since 1996. There is a perception that the workshops are increasing cultural awareness amongst participants (Leskiw & Associates, 1996). Thousands of employees have attended however there have been few physician participants.

In this study, patient interview questions were developed after interviews with five key Aboriginal health care workers familiar with the communities served by the hospital. On the recommendation of these Aboriginal informants, the areas explored with patients were communication, visitor and family involvement in care, discharge planning, respect and racism and involvement of the Aboriginal Services Department. Patients were asked if they perceived any changes in their care since any previous admissions and what would help make their stay better.

Aboriginal patients were recruited on the medical, surgical and rehabilitation teaching wards to participate in interviews. Patients who self-identified as Aboriginal and were able to speak English or Ojibway participated. Ojibway was chosen in order to compare English responses with those of people who spoke their native language. Patients were excluded if they were too ill to participate or admitted for less than 2 days. Participants for interviews in English were recruited in July and August 1998. Interviews in Ojibway were more difficult to obtain so recruitment efforts continued for a longer period. The researcher and assistant did twenty-three interviews in English and five interviews in Ojibway. All interviews were transcribed word for word for analysis. Using modified-grounded theory, themes were generated inductively from the interview data.

The main themes identified from analysis of the interviews were *control and endurance*. Patients described a range of control issues. Some felt events were out of control regarding what was happening to them, others indicated they understood the system and could speak up for their rights. Problems of poor access to information and lack of involvement in planning their care were common concerns related to lack of control. Patients described issues of endurance related to perceived racism, disrespectful communication and waiting. They described their difficulties as inpatients and their ability to cope. Some had endured poor bedside manners from health care workers. Many patients had expressed concern for others who did not speak English well and who would likely have to tolerate uncertainty about their care. Other significant problems endured by patients were the lack of emotional support and separation from family and community. Aboriginal patients with more experience as hospital inpatients and knowledge about their rights reported fewer problems.

Communication problems included insufficient sharing of information with patients and their families about their medical problems, treatment and discharge plans. These are consistent with general patient satisfaction literature and are likely concerns for many patients at the Health Sciences Centre. Concerns for people who do not speak English fluently were brought up repeatedly, as was the lack of Aboriginal employees. Some patients commented that the foreign accents of other minority groups represented in the hospital workforce made it difficult to understand the information being shared.

Family and visitor involvement in patients' care varied. Some patients, especially older people, wanted more involvement to prepare for their up-coming discharge. A number of patients complained of problems with access to information for families. Separation from family more often affected patients from remote communities. Emotional support and family participation in patient's care could improve some patients' satisfaction. Some patients had concerns regarding the unnecessary enforcement of visiting hours.

Patients' lack of knowledge about their planned discharge was a concern. Rehabilitation patients with multiple previous hospitalizations expressed concern for other rehabilitation patients who might be given insufficient or inaccurate information regarding disability services and funding. They hoped patients would be better informed than they had been. Rehabilitation patients were more likely to be involved in their discharge planning.

These findings suggest the need for increased use of the Aboriginal Services Department interpreter-caseworkers to work in the role of advocacy. Advocacy goes beyond interpretation. Patients need to be informed of the available services for Aboriginal people on admission. This will increase demands on the department, but could help prevent the types of problems described by patients. Increased employment of Aboriginal people as ward staff could increase advocacy for Aboriginal patients, if such staff are sympathetic to the patients' concerns. The 'normalization' of Aboriginal culture within the hospital requires increased representation of Aboriginal people in all areas of staffing.

The Health Sciences Centre Board is now part of the new Winnipeg Regional Health Authority. The Health Authority is reviewing the expansion of Aboriginal services to all Winnipeg hospitals with increased staffing at the existing programs, including dedicated social workers. The Health Sciences Centre has a policy of preferential hiring of people with knowledge of Aboriginal language or culture for wards with higher percentages of Aboriginal patients but has had little success in the past of hiring new Aboriginal workers. Retention of Aboriginal staff has been difficult also (Aboriginal Affairs Committee, 2000b). The Winnipeg Regional Health Authority has made a major declaration to increase and improve Aboriginal employment in Winnipeg, by signing partnership agreements with the Manitoba Metis Federation, the Ministry of Aboriginal and Northern Affairs and the Assembly of Manitoba Chiefs.

There are longstanding issues regarding satisfaction with patient care for Aboriginal people at the hospital. Cross-cultural issues of concern included differences in communication styles between cultures, lack of cultural awareness and negative attitudes towards Aboriginal people on the part of health personnel. A feeling of depersonalization is common because of the broad context of lack of control for hospital patients, as cited in the Aboriginal Services Review Committee's report (1992). Patient perceptions of racism may relate to past experiences and the historical context of Aboriginal people's lives in mainstream society.

The results of the patient interviews in this study reinforce the need to continue addressing the recommendations from the 1992 in-house report. Similar recommendations emanate from the Royal Commission on Aboriginal People (1996). The Health Sciences Centre must address these concerns if services to Aboriginal people are to improve. While there has been slow progress in fulfilling the recommendations of the Aboriginal Services Review Committee, the barriers to change may well be related to systemic and individual discrimination. The Winnipeg Regional Health Authority has the opportunity to re-organize the urban hospital system to improve the delivery of patient care to Aboriginal people from Winnipeg and remote communities in Manitoba, northwest Ontario and Nunavut.

All patients want a chance to participate in decision making about their care. Making informed choices would give patients a sense of personal control about health and it improves patient satisfaction. Hospitalization experiences should improve if institutions like the Health Sciences Centre offer patient-centered, culturally appropriate holistic care to all patients. Increasing Aboriginal representation in employment and governance and increasing cultural awareness of non-Aboriginal staff within health institutions are steps towards amelioration of the power imbalance that Aboriginal patients currently face in the health care system. Support of change must come from the governance and corporate leaders. Trust will only be built on action.

RECOMMENDATIONS

Monitoring progress:
1. To ensure the problems identified in this study and previous reviews are addressed: The Winnipeg Regional Health Authority at its highest corporate level must ensure that systemic and individual discrimination is eliminated. It should monitor the progress of the Health Sciences Centre's implementation of the 1992 recommendations of the Aboriginal Services Review Committee and other identified needs to better serve Aboriginal people. This should be built in to the institution's quality improvement program. Other urban institutions should work towards these same goals.

Services at the Health Sciences Centre:
2. To increase Aboriginal patients' sense of control in their care:

a) The Health Sciences Centre should advise nursing and physician staff to consult the Aboriginal Services Department more often. The interpreter-caseworkers can help orient patients to the hospital system, assess potential communication issues, language problems, and assist in discharge planning in their role as advocates and support workers for Aboriginal patients.

b) The Winnipeg Regional Health Authority and Health Sciences Centre should assess the Aboriginal Services Department's funding resources to handle unmet patient needs at the Health Sciences Centre.

c) The Health Sciences Centre needs to support family involvement in the course of patient care.

Cross-cultural training
3. To address cross-cultural issues:

a) Mandatory orientation of new staff and ongoing cultural awareness training sessions for all staff are needed at the Health Sciences Centre. Sessions should include a review of the historical context of Aboriginal people's lives in mainstream society and Aboriginal values of family and community involvement in patient care. Periodic review sessions with more in-depth presentations will possibly increase cultural competency. Case reviews to demonstrate practical application may be beneficial.

b) Governing bodies such as the College of Physicians and Surgeons of Manitoba and the Manitoba Association of Registered Nurses should ensure that professional standards of communication are met by physicians and nursing staff at all health institutions.

c) The Winnipeg Regional Health Authority with Aboriginal organizations, the University of Manitoba Continuing Medical Education Department, the Faculty of Nursing, the J.A. Hildes Northern Medical Unit, and the Aboriginal Health Committee of the Manitoba Medical Association should work together to establish accredited workshops as an incentive for physicians and nurses.

Hospital employment:

4. To help increase patients' sense of control at the hospital:
The Winnipeg Regional Health Authority should continue to implement its Aboriginal Employment Strategy to increase representation of Aboriginal people in the health care workforce at the Health Sciences Centre and elsewhere in Winnipeg. Aboriginal representation on hiring committees and exit interviews for all Aboriginal employees are needed. Greater Aboriginal representation should decrease perceptions of racism and improve communication.

Community Relations:

5. To improve communication at the governance, corporate and administrative level and increase Aboriginal peoples' sense of control:
The Winnipeg Regional Health Authority and urban hospitals need to communicate with Aboriginal organizations. Community site visits by the members of Winnipeg Regional Health Authority Board and hospital boards should be undertaken.

Regional Services:

6. The Winnipeg Regional Health Authority should ensure that Aboriginal services are universally available and appropriate at all Winnipeg hospitals.

CHAPTER 1

INTRODUCTION

1.1 Significance of the Study

Aboriginal people[2] comprise 11.7% of Manitoba's population of 1,113,900 (Statistics Canada, 1996). Almost half of this total provincial population resides in the city of Winnipeg; 6.9% of city residents are Aboriginal. At the Health Sciences Centre in Winnipeg, up to fifty percent of the adult beds are occupied by Aboriginal patients (Aboriginal Service Review Committee, 1992). It is not uncommon to find half the pediatric beds occupied by Aboriginal children (Postl, 1995). Yet, Aboriginal children make up only ten percent of the total provincial child population.

This study explores the in-hospital experience of Aboriginal people at the Health Sciences Centre. The hospital has identified issues regarding the care of Aboriginal patients in the past, including "the widespread perception of systemic and individual discrimination (Aboriginal Service Review Committee, 1992:18)", the lack of Aboriginal representation in hospital staffing and board membership, and insufficient funding of the Aboriginal Services Department. This study describes the outcomes of a 1992 report and relates these issues to the current experience of Aboriginal patients.

The Health Sciences Centre is a tertiary care teaching hospital with approximately 850 beds serving patients from the city of Winnipeg, the province of Manitoba and parts of northwestern Ontario and Nunavut (the former Northwest

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[2] Statistics Canada's 1996 Census defined Aboriginal persons as people who reported identifying with at least one of: 1) North American Indian 2) Metis (mixed European and Indian ancestry) or 3) Inuit and/or persons defined as Registered or Treaty Indians under the Indian Act, and/or who were members of an Indian Band or First Nation.

Territories). The Health Sciences Centre mission statement describes the hospital's role regarding Aboriginal people:

> To recognize and promote the special role of the centre in developing and providing provincial patient care programs, in providing patient care to the core area of the City of Winnipeg, and providing patient care to the Aboriginal people of Manitoba, Northwestern Ontario and the Keewatin District of the Northwest Territories (Health Sciences Centre, 1998: Appendix 1).

This tertiary care hospital delivers secondary and tertiary level care to the citizens of Manitoba. This includes residents living in proximity to the hospital in the core area of Winnipeg, and residents from remote communities that lack inpatient diagnostic and /or therapeutic services. Most of the remote communities are First Nations with adjoining Metis settlements.

The limitation of health care resources in northern Aboriginal communities is a significant factor in the decision of health care workers to transfer patients for hospitalization in larger communities. People from small rural communities lack alternatives to acute care hospitals. Non-urban health care workers have difficulty referring their patients to alternative care systems in larger centres. This contributes to the increased rate of hospitalization of rural patients (DeCoster, Peterson & Kasian, 1999).

Numerous factors determine referral patterns to specific hospitals. These factors include availability of beds, existing communication and transportation patterns, the expressed wishes of the patient or family and the need for specific resources. The specific resources may include diagnostic or therapeutic resources, such as CT scan or dialysis, but may also include Aboriginal services. At this time, only the two teaching hospitals in Winnipeg have support services for Aboriginal patients so northern health professionals are reluctant to refer some of their patients to the urban community hospitals. The Health Sciences Centre is larger than the St. Boniface General Hospital, the other teaching hospital.

A Manitoba Health document in 1996 stated the Health Sciences Centre would "be further recognized as an Aboriginal health centre (Manitoba Health, 1996:18)." The direction of this provincial government policy suggested the need for further funding to provide culturally appropriate hospital care to Aboriginal people. Documentation of Aboriginal patients' perceptions of the care in this teaching institution is a necessary step in assessing the strengths and weaknesses of the facility's present services and opportunities to improve those services. Dr Pam Orr and Dr Lindsay Nicolle of the Department of Medicine are credited for initiating this study out of concern for Aboriginal patients. They assisted in the planning of this research project.

This qualitative study was undertaken to develop an in-depth understanding of the current hospitalization experience of Aboriginal patients. In semi-structured interviews, we asked Aboriginal patients to speak freely to describe what aspects of care were important to them. The information gathered is reflective of patients' needs and their relationship to the health care system. The results of this patient satisfaction study contribute to our understanding of the needs of this unique and important population, and will facilitate change to better serve those needs.

1.2 Literature Review

1.2.1 Patient Satisfaction:

Patient satisfaction is well documented in the literature as an important outcome measure of health care. Patients' positive perception of care is desired in health care since it is related to improved clinical outcome and the quality of care (Bull, 1994; Donabedian, 1988; Lohr, 1988; Pascoe, 1983). Measurement of patient satisfaction provides an opportunity for assessment of quality of care (Cleary & McNeil, 1988; Cleary, Edgman-Levitan, McMullen, & Delbanco, 1992; Ford, Bach, & Fottler, 1997; Nelson, 1990). The negative outcomes of health care include the five D's: death, disease, disability, discomfort, and dissatisfaction (White, 1967). Physicians trained in the biomedical model have focused on the first three, with relative neglect of patient concems (Hall & Dornan, 1988).

Satisfaction is not always related to the actual process of the care or to the outcome of the care (Avis, Bond & Antony, 1997; Woolley, Kane, Hughes, & Wright, 1978). Pascoe described patient satisfaction in his review of the literature as a cognitive evaluation and an emotional reaction to the structures, process and outcome of services (1983). Nelson reviewed the literature and made similar observations from his own research (1990). He stated that patient satisfaction surveys should look at patients' expectations, continuity of care issues, and patients' assessments of the effect of the medical encounter on their health.

Some researchers suggested patient satisfaction is related to expectations, health status, and experience with health services (Stewart, 1999; Owens & Batchelor, 1996; Clearly et al 1988, Cleary et al, 1992). Others have found negative correlation of satisfaction to discrepancy with patients' expectations (Like & Zyzanski, 1987; Nelson & Larson, 1993; Williams, 1994).

Kravitz's review of the literature specifically looked at patient expectations and satisfaction (1996). Both his review and that of Williams, Weinman, Dale, and Newman (1995) found that few studies defined expectations rigorously, and:

> most used the term *patients' expectations* in one of two ways.... *probability expectations*: patients' judgments about the likelihood that a series of events would occur .... *value expectations*: patients' hopes, wishes or desires concerning clinical events - expressed as wants, perceived needs, importance (either absolute or relative), standards, or entitlements (Kravitz, 1996:12).

Kravitz concluded that expectations are like beliefs or attitudes of patients about interactions with health professionals that they use to evaluate their perceived care. He suggested that the expectations 'in action' (such as being able to ask questions of the physician) can modify care, and care can modify expectations.

Sitzia and Wood (1997) state that expectations would be based on previous experience with hospital services and their beliefs about what the service should provide. Older people express more satisfaction in research and may have modified their expectations to avoid frustrations (Carmel, 1985, Fox & Storm, 1981). Webb, Clifford, and Graham (1999) describe how inexperienced inpatients may lack awareness of their rights. They may have high expectations, while "more seasoned patients, however, are likely to have lower expectations but a greater knowledge of how to exact the most from services (1999: 402)." They suggest that dissatisfaction may be a better predictor, compared to satisfaction, of compliance and cooperation among patients.

Patient satisfaction is alternately known as consumer satisfaction but unlike other consumers, patients generally have less choice in their care and are dependent on the knowledge of others (Avis, 1992). Hospitals in Canada have participated in the trend of allowing more consumer input into the service they receive as health care has become known as a consumer good (Berwick, 1989; Avis, 1995). With the growth of consumerism in public policy and total quality improvement programs, consumer comments are used more often to audit health care quality. High levels of dependency on health care professionals in the past prior to the consumer movement may explain expressions of high satisfaction in many patient satisfaction surveys (Owens & Batchelor, 1996; Nelson, 1990).

Patients' evaluation of care will be influenced by their experience of power, control and autonomy in the professional-patient relationship (Carr-Hill, 1992) and the ease with which they can adopt what they consider to be an appropriate patient role (Avis et al, 1997). Patient satisfaction and compliance are related to patients' perception of maintaining a locus of control (Butler, Rollnick & Stott, 1996).

1.2.2 Communication in Health Care:

Patient satisfaction is related to health professional-patient communication. In a literature review of physician-patient communication research, Stewart (1995) found communication problems are generally related to problems of diagnosis, lack of patient participation in decision-making, or inadequate provision of information to the patient. Good communication was seen to improve patient health outcomes, including symptom resolution, functional and physiologic status and pain control as well as emotional health.

A literature review by Ong, De Haes, Hoos, and Lammes (1995) looked at different aspects of physician-patient communication such as purpose, behaviors, and influence on outcomes. The authors proposed a theoretical framework relating the patient's background, the care process and outcome variables all affecting a patient's satisfaction.

Many studies advocate patient participation to increase personal control and satisfaction (Golin, DiMatteo, & Gelberg, 1996; Speedling & Rose, 1995; DiMatteo, 1994; Brody, 1980; Hayes-Bautista, 1976). DiMatteo states "patients' perceptions of care is an outcome of the physician-patient interaction. It is related to their adherence to recommended treatments, and changes in (perceived) health status (1994:153)."

Empowering patients by sharing information with them makes them more active participants in their care and more responsible to make rational decisions regarding their own health (Laine & Davidoff, 1996). Good communication with thoughtful listening assists providers with determining the patient's diagnosis and an effective treatment (Cleary, Edgman-Letivan, Roberts, Moloney, Thomas, McMullen et al, 1991; Veith, 1972). Sharing information and promoting patient participation was found to be positively related to adherence to the physicians' recommendations. Noncompliance may be a form of gaining control and must always be understood in the socio-political context of the medical encounter (O'Neil, 1989; Anderson, 1986). Bull (1994) found that elderly patients were more often dissatisfied with their hospital care and discharge plan when they did not have adequate opportunity to ask questions. Outcomes of care such as patient satisfaction with discharge planning and preventing re-admissions were improved when sufficient time was allotted for patients and families to ask questions, to receive answers and to question inconsistent information.

Even in countries like Canada and England with equitable access to health care, often people of greatest need are under-served in the sense of quality care (Klein, 1995). Patients with less experience dealing with health care providers may find the hospital system over-whelming. Klein suggested social confidence, ability to articulate, and knowledge as factors in the way health services are used. Adding language differences and/or cultural differences to this also affects how successfully people navigate the system and how they will perceive their care.

In the United Kingdom, a 1994 audit of National Health Services found problems with information sharing and communication for all patients, especially minority groups for whom interpreter services were not always available (MacAlister, 1994). The auditors found patients were ill informed about their medical condition with little access to written information about their condition or possible alternative treatments and when these were available, it was in English. The National Health Service was lacking in an appropriate range of languages for the multi-linguistic society it serves. The National Health Service has subsequently developed "principles for good practice" so patients can compare their own experience against these guidelines (Webb, Clifford & Graham, 1999). This was designed to increase patients' knowledge of their rights and for better measurement of levels of patient satisfaction and dissatisfaction.

1.2.3 Cross-Cultural Care:

Cultural influences on patient satisfaction have not been well studied. Some studies have looked at cultural differences in illness perception relating to dissatisfaction and utilization of health care (Katon & Kleinman, 1984; Kleinman, Eisenberg & Good, 1978). These authors found that illness and patterns of use of health care providers are shaped by cultural perceptions, labeling, and explanation. Discussing the use of health care services, Kleinman et al state:

> How we communicate about our health problems, the manner in which we represent our symptoms, when and to whom we go for care, how long we remain in care, and how we evaluate that care are all affected by cultural beliefs (1978: 252).

The researchers felt that inattention of healers to a patient's illness experience contributes to issues of dissatisfaction and noncompliance and results in inadequate care in North American populations. Medical language and explanations can be very different from lay explanatory models even within the same culture and social class. Kleinman (1980) suggested that patients have cultural expectations of their healers (indigenous or modern) and that the patient's:

> illness is treated by taking into account the cultural explanatory models for the illness experience and the clinical resolution of personal and social problems constituting illness as a human experience (1980: 360).

The patient's cultural explanatory model is their understanding of their illness in the context of their social and cultural values. Failure to consider the patient's explanatory model may delay the patient's healing. Westermeyer (1987) felt understanding the patients' socio-cultural milieu was especially important in cross-cultural medical relationships. This was necessary for diagnosis, and assessing coping skills and resources. Anderson (1986) also did much research on cross-cultural care. She too observed that physicians often provide information to patients according to the physician's ideology. This leaves little room to negotiate with the patient, especially one outside the system of thought of Western health practices.

Ong et al (1995) found that cultural differences were thought to influence outcomes of patient satisfaction. These outcomes were listed as compliance, information understanding and recall, and long-term health status. They called for further investigation of the impact of culture on these outcomes of satisfaction.

Sitzia and Wood (1997) did research on patient satisfaction and considered various patient characteristics. They found patient expectations were the most important determinants of satisfaction, followed by demographic characteristics including ethnicity. They describe the influence of ethnicity as one of the most complex patient determinants to compare, especially with its interaction with socioeconomic status. They found gender and ethnicity played a less important part than age and educational attainment in determining patients' satisfaction.

Kaufert and O'Neil (1989), working with interpreters have studied communication with Aboriginal patients in urban hospitals. Cross-cultural and socio-political factors were seen as important in the information sharing processes. They also explored communication with dying Aboriginal patients and their families (Kaufert & O'Neil, 1995; Kaufert, 1999). Differences in beliefs and appropriate behaviors around death led to misunderstandings between institutional caregivers and their patients (see also Carrese and Rhodes, 1995).

Studies have been done on the role of interpreter-advocates and patient satisfaction (Kaufert & Putsch, 1997; Kaufert & Koolage, 1984; Kaufert, 1990). Kaufert (1990), as did O'Neil (1989), found that health professionals communicating with Aboriginal patients need to be aware of cross-cultural differences, including perception of time and explanatory models of illness. O'Neil (1989) studied Inuit patients' clinical encounters with southern caregivers in northern Canada. He found the southerners' mis-interpretations of Inuit social experiences had a negative influence on the patients' satisfaction. Physicians applied their own explanatory model to the patient's story, and could distort the meaning that the patient had intended.

Elsass, Christensen, Falhof, & Hvolby (1994) studied patient satisfaction in indigenous Greenlanders served by Danish health care workers. Patient dissatisfaction was highest when interpreter services were not available for the Danish staff to explain the medical diagnoses and treatment plans. There are few other published patient satisfaction studies related specifically to minority groups (Hulka, Zyzanski, Cassel & Thompson, 1971; Ahmadi, 1985; Hennessy & Friesen, 1994). Several used survey methods and found no significant differences in patient satisfaction between the minority patient group and white patient group. However some of the authors suggest that minority patients may have greater difficulty criticizing the service.

1.2.4 Hospitals, Power and Aboriginal History:

All individuals are situated within a network of power relations, especially those who are sick (Foucault 1994). Being hospitalized is a disempowering experience for most patients. Goffman (1961) noted that loss of control by patients was due to "encompassing tendencies (1961: 4)" of institutions such as hospitals and prisons. "Patients are often subject to loss of control over bodies, personal space, privacy, diet, use of time, and full knowledge of their condition (De La Cancela, Jenkins, & Chin, 1998: 63)." Goffman found that hospitals and other "total institutions" have an internal culture of their own, with daily routines. He noted some patients develop an informal culture that serves as a strategy to endure an environment that is foreign and alienating.

Kleinman (1980) felt that cultural healing that takes into account the explanatory models of the patients is:

> *least likely* to occur in the health care institutions of modern professional medicine, whose clinical reality is so constructed as to discourage this most traditional type of healing of illness from happening, at the same time that it strives to maximize effective treatment of disease (1980: 361).

French philosopher Michel Foucault (1994) describes hospitals as places where society observes abnormal (diseased) people while examining and questioning them carefully. Patients often feel powerless. Foucault wrote extensively on the medical profession's use of patients to gather information through observations to gain clinical knowledge. Patients are often made submissive and dependent on others for their needs, with room for few independent decisions. Moreover, patients who try to maintain a sense of control and respect may risk being considered noncompliant when not conforming to the institutional 'rules' (Edelman, 1974). Marginalized individuals can be disempowered in institutions often and they are more likely to have any resistant behavior on their part labeled as pathological.

Perceived paternalism in hospitals and institutions may be seen by Aboriginal people to be representative of the history of domination of Aboriginal people by Euro-Canadian society. "Medical institutions are powerful symbols of a recent colonial past (O'Neil, 1989: 341)." Canitz (1988) describes how nurses in northern nursing stations are perceived as powerful and controlling in northern communities. The outsider nurse replaced the traditional Inuit healer. Traditional healers were well integrated in the community, unlike many nurses.

In Discipline and Punish, Michel Foucault speaks of how early French hospitals helped control society through "segmentation, surveillance, and observation (1995:198)." The Hôpital General took in unemployed people, confining them instead of excluding them from the towns as had happened previously in France. With confinement came the right to be fed and housed, at the cost of loss of liberties. The historical segregation of Aboriginal people onto reserves can be loosely compared to the role of the Hôpital General in the seventeenth century in France (Foucault, 1994). The Canadian reserve system brought similar physical and moral restraints for Aboriginal people.

Segregating Aboriginal people onto reserves prevented their traditional nomadic ways. "The transition to life on the reserve was traumatic and dislocating for most bands. They were effectively stripped of the power to control their own lives (York, 1990: 5)." These communities lost their subsistence livelihood and much of their culture, and have been observed and controlled by mainstream society for decades.

The reserve system symbolizes Foucault's concept of "differential distribution" by its defining of Aboriginal populations geographically (1995). The exclusionary mechanisms in place with the reserve system give disciplinary power to those controlling society, with divisions between normal and abnormal. Aboriginal people exemplify Foucault's description of abnormal or 'otherness'. Aboriginal people living on reserves have been the subject of much study in North America because they are viewed as different from Euro-Canadian society. The repeated documentation of the problems of Aboriginal people reinforces their differences to other people, normalizing Aboriginal people as the 'other'. In a critique of epidemiological research, O'Neil, Reading, and Leader state:

> Epidemiological knowledge constructs an understanding of Aboriginal society that reinforces unequal power relationships; in other words, an image of sick, disorganized communities can be used to justify paternalism and dependency (1998: 230).

The increased burden of disease is well documented by researchers. It is described by Aboriginal people as a "symptom" of their history of colonization (G. Courchene, personal communication, April 2000). Many diseases amongst Aboriginal people today are perceived to relate not to cultural or biological problems but to the uniform negative effects of poverty, racism, and marginalization (Waldram, Herring & Young,

1995) or colonization. Haida people living with diabetes were interviewed for their perspectives on diabetes. They regard the disease to be a result of political change imposed on them. "Management of the illness required political action to return control of health and social services to the community (Grams, Herbert, Heffernan, Calam, Wilson, Gzybowski et al, 1996: 1566)." Bruyere and Garro (2000) found similar descriptions in interviews of Cree diabetics i.e. that diabetes was a result of colonialization.

Aboriginal people have had little control over their lives since their ancestors fell into the cycle of dependency fostered by the Indian Act and perpetuated by the welfare system. Their capacity for self-care has been systematically undermined by the colonial system and the resultant disempowerment causes negative feelings to be turned inward (Brant, 1990). According to Singer, alcohol has been used in colonization as a "lubricant of political-economic domination (1986:124)." The medicalization of alcoholism and blaming of victims for moral weakness has normalized the socio-economic conditions causing the overuse. Focusing on the disease of alcoholism and its treatment fails to acknowledge the social class determinants of illness and instead may discriminate against Aboriginal people.

1.2.5 Aboriginal Cultural and Ethics:

The nuances of different Aboriginal cultures and languages need to be considered in a study of Aboriginal patients' patient perceptions of care. In this section, I will describe aspects of Aboriginal culture as it pertains to communication, etiquette, ethics and cultural practice. One must understand the social and cultural meanings in which the hospital and illness experience is grounded (Anderson, 1986; Westermeyer, 1987). "Lack of cultural fit occurs when.... health cultures are dissimilar in crucial ways that make it impossible for a member of one tradition to accept certain beliefs and behavior of another (Henderson & Primeaux, 1981: 245)." Looking at factors in patient satisfaction, Delbanco (1992) described seven dimensions of health care:

> 1) Respect for patient's values, preferences, and expressed needs: 2) communication and education; 3) coordination and integration of care; 4) physical comfort; 5) emotional support and alleviation of fears and anxieties; 6) involvement of family and friends; 7) continuity and transition (p. 414).

These dimensions overlap with many values of Aboriginal culture, including those of respect, caring, and family involvement.

Clare Brant, the first Aboriginal psychiatrist in Canada did much work investigating and collating information on Aboriginal ethics and rules of behavior. He found that:

> All of the tribes seem to have had a holistic view of health, including mental health, and saw mental health (sic) as an imbalance among mind (cognitive functioning), body (somatic functioning), feeling (affective functioning) and spirit (religious belief)(1994: 135).

This suggests a spiritual understanding of health, balancing all domains of life versus a scientific view of health. Canitz worked as a northern nurse with the Inuit and observed "traditional beliefs (amongst the Inuit) that illness developed from societal factors (1988: 177)."

Aboriginal cultures have many customs (particularly regarding communication, competitiveness, and the showing of appreciation, generosity, and respect), which are different from Euro-Canadians (Brant, 1990). Aboriginal people practice emotional restraint in their language, communicating with concise speech, intonation, and body language. Emotions may be expressed in non-verbal ways, making interpretation challenging for non-Aboriginal people who may rely more on verbal than non-verbal communication (Ellerby, McKenzie, McKay, Gariepy, & Kaufert, 2000). These differences can lead to frustrations and resistance on both parts. Ellerby suggests that Western health care practitioners may misinterpret the quietness and reserved speech of some Aboriginal people as "an indication of ... a lack of capacity to contribute (1999:19)."

Black-Rogers (1973, 1982) studied interactions and language patterns in Ojibway. She proposed etiquette rules to describe the use of ambiguity and avoidance of directness in questioning. Answering questions also used ambiguity extensively, as well as deflection or silence. Power structures in interactions were respected by the use of these techniques communicating in Ojibway. Preston (1975) did ethnographic work with the James Bay Cree and suffered many "I don't know" answers to his questions, even when working with translators. He realized this might have meant:

> "I don't know how to reply to your question in a way which will be satisfactory to both of us." If (the) question is phrased in a way that is appropriate, especially if the phrasing shows some grasp of the general topic in the appropriate, culturally defined terms, then an answer may usually be obtained (1975: 12).

Ideally, the communication styles of Aboriginal cultures would be considered in both planning and interpreting qualitative research. This study was limited to analysis of content and is not a study of linguistics in English or Ojibway.

In Aboriginal cultures, the ethic of 'non-interference' allows individuals freedom to make decisions based on their own knowledge, and learn from their experience. Giving unsolicited advice may be considered impolite, and when advice is requested, it may only be given indirectly (Black, 1973; Brant, 1990). The individual may be presented with information in a non-threatening form such as a story, from which they could choose to heed the message.

This suggests that many interactions between Western-trained health care workers and Aboriginal people brought up in traditional cultures involve values that clash. People who maintain traditional Aboriginal rules of behavior must deal with the forthright behavior of Westerners when using the health care system. Aboriginal people might not question medical advice as a sign of trust and respect for the healer (Brant, 1990). However, excessive prescriptive statements and lack of opportunity for patient participation in the clinical plan might be taken as physician interference (Kaufert, Koolage, Kaufert & O'Neil, 1984; Kleinman, 1978; Morse, Young & Swartz, 1991). This might affect patient compliance.

Western society acknowledges the importance of individualism and the nuclear family. Aboriginal culture in contrast gives importance to extended family and community. Their values are based on "holism, pluralism, autonomy, community- or family-based decision-making, and the maintenance of quality of life rather than the exclusive pursuit of a cure (Ellerby et al 2000: 845)." Numerous Aboriginal family and community members will often come to visit a patient and support the immediate family. As mentioned previously, some Aboriginal people have a different concept of the use of time. Instead of being limited by set hours things are done when the 'time is right'. Conflict can occur when hospital staff tries to enforce arbitrary visiting hours or numbers of visitors when the family feels their presence is needed.

Each Aboriginal culture has unique ethical systems and ceremonies. Within any one culture, there is individual variation in practice. It is inappropriate to assume that a particular Aboriginal person has either 'traditional' values or Western values (Aboriginal Services Review Committee, 1992). The province of Manitoba has distinct Aboriginal cultures: Cree, Dene, Ojibway, Oji-Cree, Metis and Dakota (Figure 1). The Health Sciences Centre also provides health care to Ojibway and Oji-Cree people from northwestern Ontario and to many Inuit from the neighboring district of Kiviliq, part of the Nunavut Territory.

Longclaws (1996) describes five different groupings of individuals within Aboriginal cultures. This categorization when paired with a meaningful understanding of cultural traditions in Manitoba is a powerful tool. (1) Traditionalist refers to people who have retained their links to the pre-invasion culture. They often socialize within their own groups. (2) New traditionalists have experienced re-birth in their identity as Aboriginal people, and may be racist in their outlook towards non-Aboriginal people. (3) Other people are assimilated and have no ties with their people. They tend to blend into the larger society. (4) The universalist group is described as people who are integrated into mainstream society but also continue to embrace Aboriginal culture. They actively strive to reach harmony in this blend. (5) The last group is anomic individuals. Longclaws describes this group as the largest, most unfortunate and unhealthy: they are economically, socially and spiritually 'bankrupt'.

In a paper on suicide, Brant (1993) describes anomie for Aboriginal people as resulting from the loss of normative rules of Aboriginal society. He describes this as the "loss of the old philosophies and religions which taught resilience, survival and a sense of being one with nature (Brant, 1993:52)." Anomic individuals tend to live in poverty, with addictions, abuses, and a feeling of hopelessness. Members of the anomic group and the other groups described above may have responded differently to our invitation to participate in this study, and in their responses to questions. These possible effects will be explored in Chapter 2, under Data Trustworthiness.

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Aboriginal Cultural Groups of Manitoba

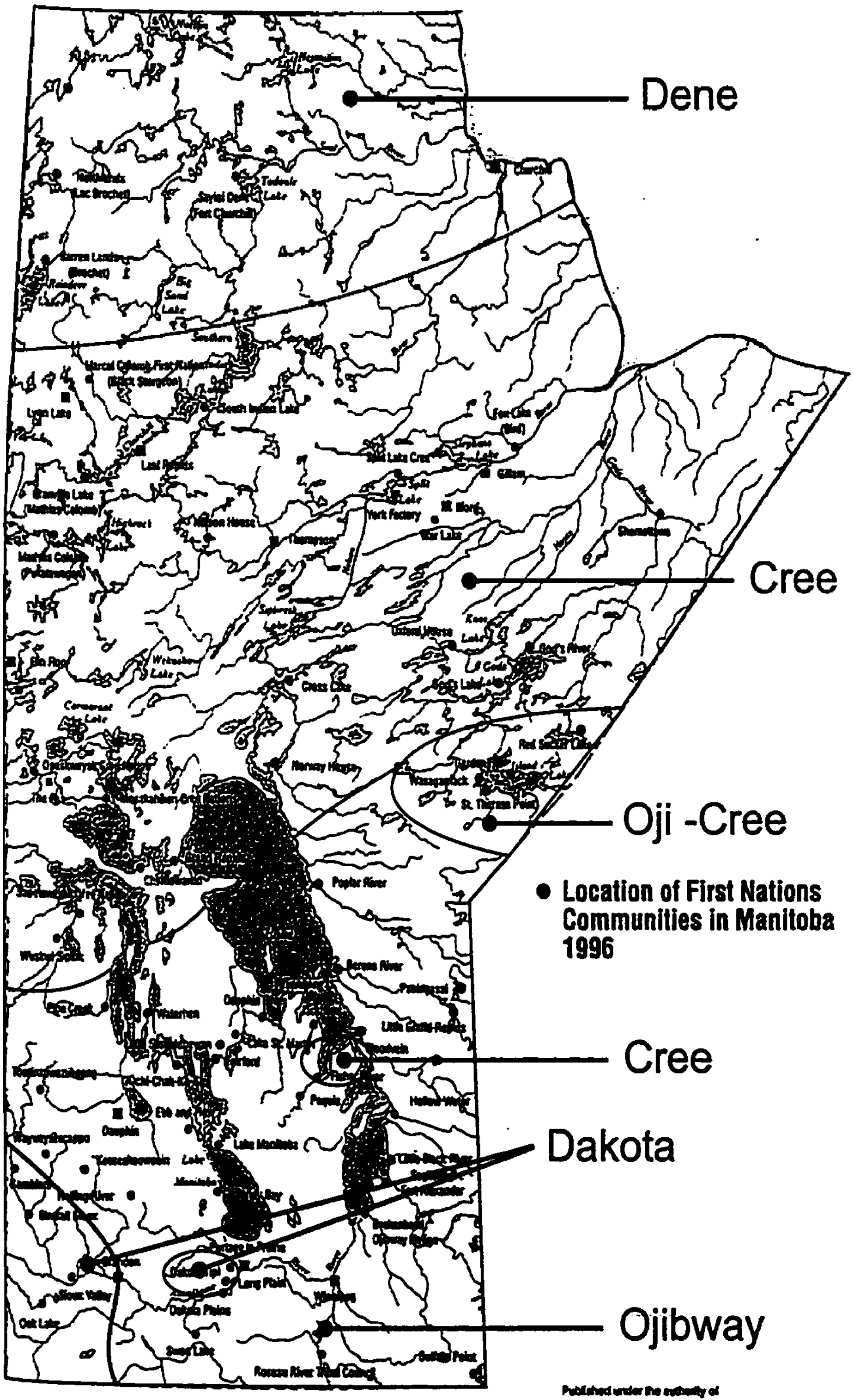

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Fig. 1

1.3 Summary of Literature Review

The literature suggests that the patient satisfaction areas of respect, communication, and involvement in care would be important to all hospitalized patients, Aboriginal and non-Aboriginal. These aspects go beyond physical healing. They are congruent with the Aboriginal belief that health encompasses spiritual, emotional, intellectual as well as physical dimensions of the individual (Brant, 1990; Canada Royal Commission on Aboriginal People, 1993).

There is little in the patient satisfaction and communication literature regarding Aboriginal and other minority patients' experiences in the health care system. Aboriginal patients admitted to hospital often must often deal with different interpretations of illness and may have different expectations of treatment. An appreciation by the reader for the diversity of beliefs of Aboriginal people and the expression of their cultures, values and languages will support this analysis of Aboriginal patients' perceptions of their care.

CHAPTER 2

STUDY METHODOLOGY

2.1 Choice of Methods

The purpose of this patient satisfaction study was to gain insight into Aboriginal patients' perception of their care in the context of Aboriginal participation at this particular hospital. Qualitative research is particularly suited to the study of health and social policies and program outcomes (Mays & Pope, 2000; Rist, 1994).

Aharony and Strasser (1993) reviewed the state of knowledge about patient satisfaction. They suggested the need for further qualitative research for information representing phenomena in a way that is ethnographically accurate, for increased understanding of cognitive and affective processes and for data enrichment. They promoted qualitative methods to avoid patients' tendency to answer closed survey questions more positively compared to open-ended questions. Qualitative research is considered a better tool to evaluate health care as it takes into account the macro and micro levels (Rist, 1994).

Case study and semi-structured interviews were the two qualitative methods chosen for this study. Case studies can be used for evaluation of health policies. Case studies are a tool used to explore phenomenon in institutions over a period of time (Creswell, 1994). Yin (1993) defines descriptive case studies as exploration of an organization or other subject within a defined scope and depth. Case study involves collection of multiple sources of detailed evidence. Using a variety of collection procedures and sources ensures verification and allows convergence of the data.

Qualitative interviews were chosen over survey methods of quantifying patient satisfaction to elicit patients' explanations rather than measurements and for more understanding than generalizability (Jones, 1995; Avis et al, 1997). Qualitative interview methods are sanctioned for health policy analysis because they reveal the patients' views and concerns about their care rather than providers' concerns as is frequent in health surveys (Aharony & Strasser, 1993; Calnan, 1988; Carr-Hill, 1992). Quantitative survey methods reduce their focus to the macro level, the whole population under study and obscure respondents' individual variability. Surveys limit validity because the opportunity to analyze the context of the responses is lost (Owens & Batchelor, 1996; Lupton, 1997).

Aharony & Strasser call patients' recounts of their own narratives situated truths, shaped in particular by the context in which they occur (1993). Owens and Batchelor state that context is particularly important when reviewing responses from other cultures, as their explanations will not always fit with those of the main culture. In Aboriginal teachings it is said that:

> Everything is related to everything else, that things can not be understood outside of their context and interactions, and that there are four aspects to the human condition - the physical, the emotional, the mental and the spiritual (First Nation and Inuit Regional Health Survey National Steering Committee, 1999: 190).

This reinforces the need to use qualitative methods to analyze Aboriginal patients' perspective. Regardless of what the concept of patient satisfaction means to Aboriginal people, their perceptions of care will be grounded in their everyday lives. Content analysis of the interviews could reinforce findings of survey method reports in the literature as well as uncover new themes of importance.

A case study of Aboriginal services and involvement in employment and governance at the hospital would give background information to assess patient interviews. Matching (triangulation) of patients' perceptions from interviews with detailed knowledge regarding the hospital situation would improve analysis of the interviews. The subjects' frame of reference would be better understood.

2.2 Case Study Method

This first section involves a descriptive case study. Various data sources were used to explore the hospital situation. Some of the data had been collected in previous research projects, related to this topic. In 1996, while I was participating in a course on Aboriginal Health, Dr B. Postl asked our class of four students to follow-up on the outcome of the Report of the Aboriginal Services Review Committee (1992) at the Health Sciences Centre. I researched the section of the paper on the history of Aboriginal services and the cultural awareness workshops. Our paper (Bruyere, Cooney, Marchessault & Riese, 1996) was circulated to Health Sciences Centre administration and board members.

The following year in a research methods course, students were required to perform an interview. The previous director of the Aboriginal Services Department was chosen for an 'exit' interview, as he had resigned from his position. (In our 1996 paper, we had recommended that any Aboriginal employee who left a position at the hospital should participate in an exit interview.) The recorded interview was transcribed and analyzed for the course work. The interviewee was promised that the material would be used only for the course work, unless permission was granted at a future date. This year the interviewee was contacted and written permission was received to use parts of the interview for this project.

Based on this early fieldwork, this patient satisfaction study required a detailed description of the past and current situation at the hospital to add context. Our previous review of the Aboriginal Services Review Committee's report identified issues of importance at the hospital. In particular the Aboriginal Services Department and Aboriginal representation in employment and governance at the hospital were sensitive areas. Cross-cultural issues were also significant. These issues were reviewed from 1971 when the Native Services program was started at the hospital to the current situation under the governance of the new Winnipeg Regional Health Authority.

Multiple sources were used to investigate the issues in addition to the field notes from the previous noted work. I researched in detail related 'non-technical' or 'gray' literature: hospital committee meeting minutes, reports, policies, memoranda, and letters (Strauss & Corbin, 1990). Key hospital informants in administrative positions at the hospital and health authority were interviewed to clarify my understanding of the information gathered, and to supply missing details. I participated in the hospital cultural awareness workshops to observe what was taught as well as to observe people's reactions to the teaching of Aboriginal culture. Many areas of concern in this research overlapped with my work for the Northern Medical Unit and the Aboriginal Health and Wellness Centre. I have participated in meetings and discussion groups on the patient issues through my employment and volunteer work. The Vice President of Human Resources at the Winnipeg Regional Health Authority invited me to join in a related meeting and a workshop, knowing my interest in Aboriginal employment issues. Participation in events such as this minimizes the distance between the research and informants (Creswell, 1994).

My interpretation of the data was reviewed with some of the key informants for feedback, further validating the details. This background description assisted interpretation of the patient interview results. Multi-dimensional data adds depth to the expressed experiences of patients (Aharony & Strasser, 1993).

2.3 Key Informants Interviews and Study Tool Development

The involvement of Aboriginal people and their endorsement of the study was important in planning this research. The Royal Commission on Aboriginal Peoples stressed the need for the community's consent in research (1996). Dr Pam Orr and I approached the Assembly of Manitoba Chiefs for their approval of the study. Their initial reaction to the study was negative, as the study was perceived to benefit the non-Aboriginal researchers more than the population being studied. The potential benefits of the study were discussed, as well as the uniqueness of the information to be gathered. The Assembly representative cautiously agreed, with the requirement that two specific Aboriginal people be involved in planning the study.

This provided an opportunity to involve informants from the Aboriginal community. Key informants are individuals with important knowledge (Mays & Pope, 1995). The two people specified by the Assembly worked in health planning in First Nation communities. Another recommended informant was the Aboriginal representative of a national disability association who worked extensively with Aboriginal patients on the rehabilitation wards of the Health Sciences Centre.

These three key informants are employed outside the hospital. The director of the Aboriginal Services Department and the Cultural Awareness Coordinator for the hospital were also approached to participate as internal informants. They both continue to work extensively with Health Sciences Centre staff and are aware of issues of concern to the Aboriginal community regarding care at the facility.

Interviews were set up with each of the five key informants separately. Consent was obtained and anonymity regarding their recorded comments in these interviews was promised (see Appendix 1). In discussion with these individuals, the writer was cautioned against further "victimization" of Aboriginal people. They stressed the need to present a positive image of the successes of Aboriginal people not just the negative results of repression. Research that reinforces an image of Aboriginal people as weak and different and in a negative light perpetuates their marginalization (O'Neil et al, 1998).

The five key informants agreed to participate in recorded interviews to help guide question development. Multicultural research should involve exploratory interviews and community participation to generate research questions (Kaufert, Commanda, Elias, Grey, Young & Masuzumi, 1999; First Nation and Inuit Regional Health Surveys, 1999). Appropriate questions were desired that would meet the approval of patients involved in semi-structured interviews.

The key informants described above were interviewed in person or by telephone, with audio-recording. They were asked the following five questions:

1. Do you think Aboriginal patients are willing to evaluate their hospital care?
2. On what basis will they evaluate their care? Would it be according to their perceived needs? desires? or expectations?
3. How can we elicit that information?
4. Are there any specific questions that you think we should ask?
5. What responses would you predict?

These questions were asked to verify the author's expectations after exploring the literature and to seek the key informants' opinions and recommendations regarding issues to explore with hospital patients. The five preliminary interviews were transcribed and analyzed to plan the patient interview questions.

Many issues were brought forth by the interviews. One key informant predicted frequent non-participation, either because of past oppression where

Aboriginal people were taught not to ask questions about Western institutions or as a stand against yet another study about Aboriginal people by outsiders. Another informant thought patient's satisfaction would depend on their personal history and experience.

One key informant predicted Aboriginal patients would be dissatisfied with their hospitalization if the hospital care did not fill the voids in their outpatient care. Patients from northern communities with limited health care resources might expect many of their health care needs to be addressed during their hospital stay, even if some of their needs were unrelated to the primary reason they were hospitalized. Another informant thought that societal influences would affect whether patients' evaluation of care was guided by what they needed versus what they wanted. They felt the cultural background of the research assistant-interpreter was important (as mentioned under Aboriginal culture).

Looking at areas of patient satisfaction to explore, most of the informants felt we should ask about family involvement. One informant was also concerned that some patients may not want their families involved in their care. She suggested asking patients whether anyone else should be included in discussions about their care.

The main recurring themes in the key informant interviews included communication, family and visitor involvement, and involvement of the patient and the family in discharge planning. Involvement of the Aboriginal Services Department in patients' care was also considered important. There was consensus to seek for incidents of differential or disrespectful care for Aboriginal patients. These were the areas that informants felt Aboriginal patients would regard as important. Another important question was felt to be a study in itself: "What does health mean to you?

What do you think needs to happen for you to reach that?"

It was proposed from the literature review that Aboriginal patients would evaluate their care based on expectation fulfillment. The key informants predicted the expectations would be related to patients' previous experience within the health care system, rather than based on desires or needs. Their expectations were predicted to differ from mainstream patients, and again to vary according to experiences.

Recurring themes from the key informant interviews were used to formulate questions. These draft questions were distributed back to the five key informants for their comments. Further editing refined the questions and they were returned to the informants a final time for approval.

A research assistant with previous hospital interpreter experience was hired to interview the patients in English and Ojibway. The study would be better accepted if an Aboriginal person was present at all interviews conducted in English as well as the Ojibway. The research assistant was trained for interviews during the pilot testing of the questions. Staff on the participating wards was asked to identify known Aboriginal patients who might be willing to participate. The pilot interviews involved both the author and the assistant asking questions with continual refinement of the interview questions for clarity with each interview (see Appendix 2). Pilot interviews were done until the assistant was confident in doing the interviews and until all of the questions were clarified. These seven pilot interviews were recorded and transcribed for later comparison with the study results.

2.4 Interview Process

All patients were interviewed either in an office room, a cafeteria, outdoors, or in the patient's room if they felt this was private enough. Most patients chose to stay in their room. The research assistant read the consent form with the paraphrase in English or Ojibway to the patients (see Appendix 3 & 4). The patients were encouraged to read the consent form if they so wished and all signed the consent form before participating. All the consent forms were stored securely away from the interview material. The Aboriginal research assistant was present at all interviews and conducted most of them with the author present. A few were done without the author present. Whether the non-Aboriginal author was present at the interviews was recorded to see if this influenced the responses especially to the questions regarding racism.

Another bilingual Ojibway research assistant translated the Ojibway interviews and these were then transcribed word for word. All the taped interviews, the English translations on paper and the transcribed interviews were labeled with only an identification code, to keep the interview material anonymous. Demographic characteristics of all Aboriginal patients approached for an interview were recorded in a journal kept secure and away from the tapes. The characteristics included age, gender, residence (urban, rural or remote), language group, number of admissions and ward of admission. Statistical analysis would be done comparing demographics of patients who did and did not fit the eligibility criteria and patients who refused versus those who did participate. The journal information will be destroyed at the end of this research project to protect patient confidentiality.

2.5 Sampling

2.5.1 Ward Selection:

Clinical teaching wards were used for the sampling, as typically there are high percentages of Aboriginal admissions on the three medical teaching wards, and two general surgical wards. The rehabilitation ward for amputees and spinal injuries was also chosen because of the large representation of Aboriginal patients. Sub-specialty medical and surgical wards were excluded, as their patient populations may not have reflected the general hospital population. Other specialty wards such as obstetrics, pediatrics and psychiatry were not chosen for sampling as we felt that there are different factors contributing to experiences on these wards (such as birthing experiences, parental involvement, and mental health issues).

I met with the unit managers from the involved wards for their input and to gain their cooperation. Nursing and support staff, and physicians admitting to these wards received written notification of the study as directed by the ethics committee (Appendix 5 & 6).

2.5.2 Patient Selection:

Starting on a randomly chosen date in July 1998, pamphlets with information about the study were distributed daily for over three weeks to medical, surgical and rehabilitation patients from the selected hospital wards. We approached all ward patients to participate regardless of perceived ethnicity. Patients missing from their rooms were left a study brochure with a telephone number to contact the researchers if interested.

Patients first were asked if they considered themselves to be Aboriginal. A few Aboriginal and non-Aboriginal patients or their visitors were offended with this question which they took as discriminatory. Most Aboriginal patients seemed interested when we explained that the study results might help improve services for Aboriginal patients in the future. Our recruitment resulted in a self-identified sample of Aboriginal patients. If Aboriginal patients were interested in the study, participation criteria were reviewed and the interview process was explained further. Eligibility to participate in the study required:

1) Ability to speak English or Ojibway fluently
2) Admission for greater than two days
3) Ability to participate not impaired by confusion
4) Ability to participate not impaired by severe illness

And again, signed consent was required. Those admitted for less than two days were excluded. This was determined to be too short an experience and too difficult for planning an interview time before discharge. Patients with more severe illnesses may not be capable of enduring even a brief interview. When possible, they were re-approached to participate if their condition improved. If the patient qualified to participate and was agreeable, a time for the interview was arranged when possible.

Patients were offered interviews in English and Ojibway. The researcher wanted to see if people who were able and willing to be interviewed in an Aboriginal language would have different concerns about their care than patients who chose to communicate in English. The researchers felt this language choice could generate a fairer representation of Aboriginal patients and their concerns from most of the catchment areas since Ojibway-speaking people live in urban, rural and remote areas of Manitoba (Figure 1). We decided to limit the interviews to the two languages, to control variation between groups and to limit costs of the study. People in either interview language group could be fluent in other languages.

Written consent was received from all eligible participants. Patients had the right to refuse the interview or to withdraw from the process even after the interview was recorded. Reasons for patients not participating were recorded. Some prospective interviewees were missed due to discharges, visitors, weekends, or hospital appointments, all of which had precedence over our study.

2.5.3 Participation Rates:

All patients on the selected wards were approached to participate if they considered themselves Aboriginal. After completing 23 interviews in English over four weeks beginning in July 1998, early analysis of the English interviews revealed multiple themes emerging repeatedly. There were few Ojibway speaking patients on the chosen wards. No Ojibway-speaking patients had yet agreed to do the interview in Ojibway with the assistant. Some people who spoke Ojibway had chosen to use English for the interviews; others had refused to participate.

It was decided to recruit specifically for interviews to be conducted in Ojibway. We asked the Aboriginal Services Department for assistance identifying Ojibway speaking patients. The department was contacted on a regular basis in person or by telephone for names of Ojibway speaking in-patients. The department's referral clerk alerted us when they had received consultations for Ojibway speaking patients. My assistant would meet the patients and explain the study, translating the consent into Ojibway. It took a number of months to recruit willing participants. Five interviews in Ojibway were done. Analysis of these revealed many themes similar to the English interviews and some differences. Interviewing in Ojibway ended in March 1999.

Altogether 73 patients identified themselves as Aboriginal in the initial ward sampling. Fifty-two people (71%) from this group fit the participation criteria. Twelve

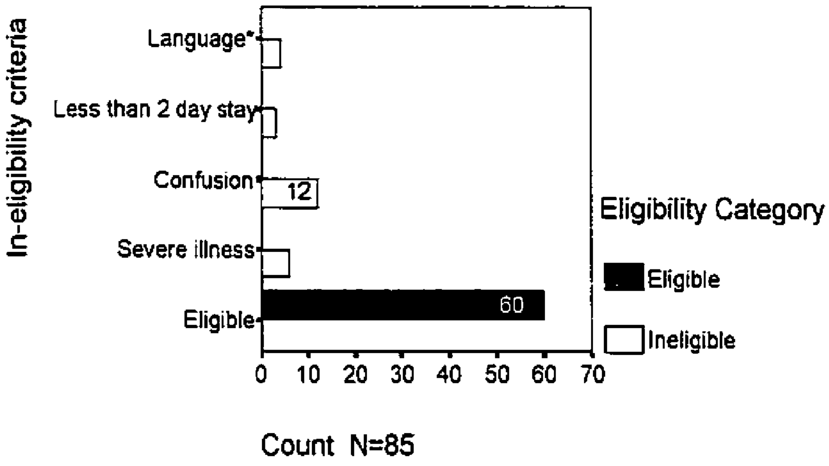
Ojibway speaking patients were approached for interviews specifically in Ojibway. Nine (75%) of the twelve Ojibway speaking people approached specifically to be interviewed in Ojibway were eligible to participate. This gave 85 potentially eligible participants in total. Overall, 71% (60 of 85) of the Aboriginal patients were eligible to participate, and 29% (15) were excluded (see Figure 2).

Demographics were compared for eligible and ineligible patients (Table 1). Eligible patients were significantly younger than those who were ineligible. The two categories of patients who were unable to participate due to confusion or due to severe illness were comprised of older patients (confusion: median age 55.5 years old [range 34-87]; severe illness: median age 53 years old [range 46-66]). Four patients who were ineligible were Oji-Cree from remote or rural communities and did not speak either English or Ojibway. They had a median age of 60.5 years old. There were similar patterns of distribution of gender, place of residence, and number of previous hospitalizations for participants and non-participants. Looking at distribution by ward service, more patients on the rehabilitation ward qualified to participate (none were too sick and no one had short admissions). No differences were statistically significant, as the numbers participating were too small to achieve a high statistical power.

Of the 60 people who were eligible, 44 (75%) agreed to be interviewed. Patients who refused were slightly younger and more often female (see Table 2). Patients who refused were less likely urban dwellers, and more likely to have had previous hospitalizations (for discussion of reasons why patients may have refused, see 2.8 Data trustworthiness). No differences between patients who refused and patients who agreed to participate were statistically significant.

Of the 44 who agreed to an interview, 16 (33%) were missed due to competing appointments, visitors or being discharged earlier than anticipated. Consequently, we conducted 28 interviews. Participating patients were 32% female, 68 % male, and had a median age of 39.5 years old. There was a higher percentage of surgical participants (medicine 9 [32%], surgery 12 [43%], and rehabilitation 7 [25%]). More interviewees were from remote areas (remote 16 [57%], rural 6 [21.5%], urban 6 [21.5%]).

Figure 3 shows the background cultural group of participants and the language used for the 28 interviews performed. Patients interviewed in English (n=23) were compared with those interviewed in Ojibway (n=5). They were similar in age (median 39 years old for English interviews vs. 41 years old for Ojibway interviews), and both had more male participants (English 65% males v. 80% Ojibway males). Both groups had representation from all three ward services. All five patients interviewed in Ojibway were from remote communities, and 11 of 23 patients interviewed in English were from remote areas (48% remote, 26% rural and 26% urban).



Eligibility Category**

of Potential Participants

*Unable to speak English or Ojibway

**See text for details of criteria

FIGURE 2

Table 1 Demographics of Self-Identified Aboriginal People

Category	Eligible		Ineligible*		P value
Number	60		25		
Mean age (years)	40.8 ± 14.9 Median 37 Range 17-79		55.4 ± 16.6 Median 54 Range 30-87		.001
Gender	Females	26 (43.3%)	Females	10 (40%)	.49
	Males	34 (56.7%)	Males	15 (60%)	
Residence	Urban	15 (25%)	Urban	7 (28%)	.46
	Rural	20 (33.3%)	Rural	5 (20%)	
	Remote	25 (41.7%)	Remote	13 (52%)	
Ward Service	Medicine	19 (31.7%)	Medicine	11 (44%)	.32
	Surgery	29 (48.3%)	Surgery	12 (48%)	
	Rehabilitation	12 (20%)	Rehabilitation	2 (8%)	
Previous Hospitalizations	Never	6 (10%)	Never	1 (4%)	.07
	Once	8 (13.3%)	Once	1 (4%)	
	Two or more	43 (71.7%)	Two or more	17 (72%)	
	Unknown	3 (5%)	Unknown	5 (20%)	

*Ineligible due to one of: 1) inability able to speak English or Ojibway; 2) less than 2-day stay; 3) confusion; 4) severe illness.

Table 2 Demographics of Eligible Patients by Participation Category

Category	Agreed to interview		Refused interview		P value
Number	44		16		
Mean age (years)	42.0 ± 15.8		39.8 ± 14.3		.57
	Median 39.5		Median 36.5		
	Range 17-79		Range 24-60		
Gender	Females	17 (38.6%)	Females	9 (56.3%)	.22
	Males	27 (61.4%)	Males	7 (43.8%)	
Residence	Urban	14 (31.8%)	Urban	1 (6.3%)	.09
	Rural	12 (27.3%)	Rural	8 (50.0%)	
	Remote	18 (40.9%)	Remote	7 (43.8%)	
Service	Medicine	15 (34.1%)	Medicine	4 (25.0%)	.74
	Surgery	20 (45.5%)	Surgery	9 (56.3%)	
	Rehabilitation	9 (20.5%)	Rehabilitation	3 (18.8%)	
Previous Hospitalizations	Never	5 (11.4%)	Never	1 (6.3%)	.05
	Once	6 (13.6%)	Once	2 (12.5%)	
	Two or more	33 (75.0%)	Two or more	10 (62.5%)	
	Unknown	1 (2.2%)	Unknown	3 (18.8%)	

Cultural Group of Participants

And Language of Interview

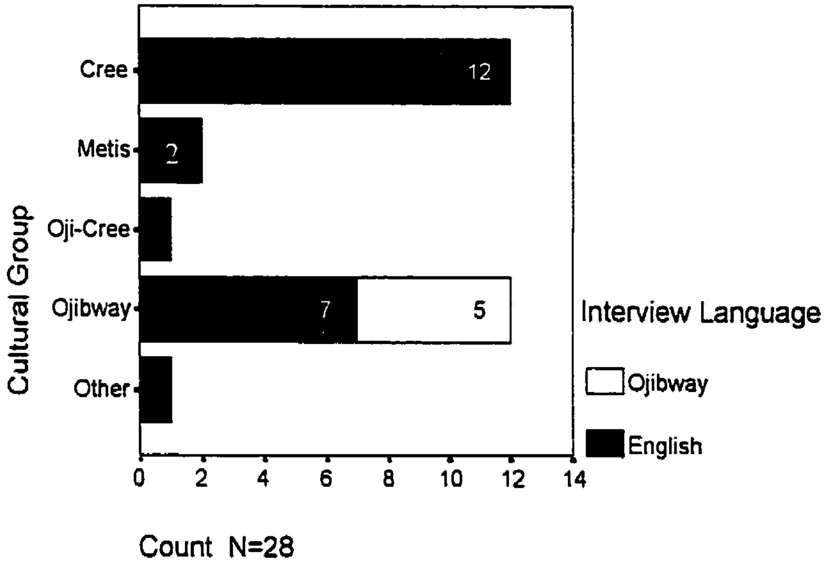


Figure 3

2.6 Interview Analysis

The recorded English interviews were transcribed word for word using MS Word^{TM} software. All audio-recordings of Ojibway interviews were translated into English by another Ojibway-speaking assistant and then transcribed word for word. The English audio-recordings were reviewed with the transcriptions for content, intonation, and possible meaning. All the patient interviews were analyzed together including the pilot interviews that were found to be similar to the others.

Qualitative methods based on grounded theory were utilized. The semi-structured interviews were analyzed using open and axial coding techniques. The interview material was categorized - initially by descriptive, then interpretative, and lastly analytical categories. The material was analyzed from various aspects, comparing theme categories generated, between age groups (<40 years old and 40 plus), gender, residence (urban, rural or remote), number of admissions and type of ward service (medical, surgical, rehabilitation) for patterns.

Results of the analysis were discussed with the key informants, to check for proper interpretation. Theme development resulted from merging categories, with the main themes to evolve after coding being *control and endurance*.

2.7 Biases and Limitations

2.7.1 Biases and Impact of Researcher:

Qualitative interviews always involve some level of participatory research. However, because of the nature of participation no one is value neutral. As author, my biases could impact on interactions with interviewees and on my interpretation of interview data.

I have worked with Aboriginal people in the medical field for over fifteen years beginning in medical school in the early 1980's in Winnipeg. I vividly remember the 'bead incident' at St. Boniface Hospital (see results section) when I was a first-year medical student. Many of my clinical rotations were at the Health Sciences Centre where many patients were Aboriginal people.

As a family-medicine resident I chose a two-month elective in the northern town of Sioux Lookout, which entailed travel to remote First Nation communities by floatplane to work in nursing stations. After my training, I worked with the James Bay Cree in Quebec in 1987-1988. This was a transferred health care system, meaning the Cree First Nation controlled the regional health and social service board. The James Bay Cree had maintained their traditional hunting culture and taught me much about their strong culture. I suffered some conflicts in my practice due to my ethno-centric upbringing and inexperience in cross-cultural work.

Two three-month blocks of work at a private charity clinic in Kingston, Jamaica in early 1987 and late 1988 showed me the similarity between health problems for Aboriginal people of the Canadian north and poor Jamaicans. The main factors in the health and social patterns of both populations were poverty and disempowerment from a colonial past.

I worked 6½ years in a northwestern Ontario town with a district hospital serving nine First Nations communities. I traveled monthly to one community. It was too close to the main populated area to maintain traditional hunting and fishing, and too far from the town for people to easily commute to sustain employment. These people taught me about disempowerment, lack of opportunity, poverty, and addictions. I returned to university to study Community Health Sciences out of frustrations with the Canadian health and social system and its paucity of services that would make a difference for these people.

In Manitoba, I have continued to work part-time in the north. I have worked at different urban community health centres in the core area of Winnipeg with underprivileged people, many of whom are Aboriginal. They share health and social problems with northerners. The existence of services in urban areas does not mean the services are accessible or appropriately designed for disadvantaged people.

Since 1993, I have participated in cultural awareness workshops for health care providers and now help with the organization of these workshops held in both urban areas and in First Nation communities. Through my work and volunteer activities, I have been exposed to ceremonies and interactions with elders.

I have personal biases after being a recent hospital patient. Due to orthopedic injuries, I endured two urgent admissions, and one urgent and two elective operations in the last six years. I was shocked at times to find how disempowered I felt as a result of the treatment by the staff. As an informed consumer being a provider myself, I was able to analyze more critically what was happening around me than would a less experienced patient. This made me concerned about other patients and their awareness of their rights.

From my personal life experience, I bring to this research knowledge about possible living conditions of patients, community politics, and knowledge of the Canadian health care system across provincial borders, and health jurisdictions. This will have affected the way I assessed the information from the interviews. My contextualization of the interview responses should be more accurate, knowing the conditions in which people may be living.

A situation came up during the interviews at which I felt I had to use my professional influence to intervene on behalf of a patient. An Ojibway patient from a remote community was approached for an interview by the researchers after along weekend. He told the bilingual research assistant that he had not been able to speak to anyone since before the weekend, because he only spoke Ojibway. He was unable to understand the ward staff and did not know why he was still in the hospital even though he felt well. We discovered his very sick wife was in an intensive care unit at an urban community hospital and his seven-year-old daughter was in the city at a boarding home alone since he had been admitted. He had not been able to communicate with either of them for a number of days.

We promised to translate for him after the interview. His nurse shared information and answered his questions. It was apparent the patient was not very sick and could have visited his wife if the hospital staff had been aware of his situation. I asked the nurse to request 'passes' for the patient to leave the hospital if a quick discharge could not be arranged. I contacted the transportation office of the First Nations and Inuit Health Branch to arrange a ride for him to visit his wife's hospital. This intervention in his care was outside of the role of a researcher, but I felt it was my duty to resolve his sad situation using my knowledge and influence as a physician with the assistance of the interpreter.

2.7.2 Limitations:

This patient satisfaction study focused on English and Ojibway speaking Aboriginal patients on medical, surgical and rehabilitation at the Health Sciences Centre. The semi-structured interviews have scope and depth and represent individuals' perceptions of their care. The main disadvantage of the qualitative interview method in comparison to surveys is the risk of non-representative sampling, since only a limited number of people can be interviewed.

The study was limited to certain wards as it was felt that patients would have comparatively similar experiences on these wards. The non-inclusion of pediatric, psychiatric, cancer and obstetrical patients served at the hospital reduces the generalizability of the study to all patient areas. The research planners felt that issues on these other wards could be quite dissimilar making comparison difficult. Many areas of concern to patients on the chosen wards would likely apply to patients on the non-included wards, but the reverse would not necessarily apply.

The omission of non-Aboriginal inpatients in this patient satisfaction study limits generalization to the broader patient population and prevents comparisons between the two groups. The results of this study may not apply to other minority groups. Comparison of satisfaction with Euro-Canadian patients or with patients from another minority group may have shown many similarities and also interesting differences.

The study was limited to one urban teaching hospital and may not be representative of the experience of Aboriginal people in urban community hospitals or rural hospitals. Anecdotal evidence suggests the situation may be similar if not worse in the community hospitals, which lack Aboriginal services. A uni-lingual Ojibway elder apparently spent months in 1999 at the Grace Hospital with no interpreters and no advocacy except by his visitors (G. Fulford, personal communication, May 22, 2000).

2.8 Data Trustworthiness

Reliability and validity are concepts commonly used in quantitative research. These concepts are more difficult to apply to qualitative research. Reliability refers to the reproducibility or transferability of a study method. Reliability in qualitative research is achieved in meticulous recording of interviews or observations and documentation of coding processes (Pope & Mays, 1995). Documented coding methods and the availability of audio-recordings should allow another researcher to reproduce similar findings with the same tool. The uniqueness of a study within one context would make replicating it exactly in another context not feasible (Creswell, 1994). Good documentation of central assumptions, choice of informants, biases and values of the researcher would make transferring to another setting more reliable.

Validity is the assessment of how closely a research tool measures the outcome it was intended to measure. Qualitative research methods are considered internally valid or credible since they describe real people's real experiences and perceptions (Pope & Mays, 1995). External validity is limited in qualitative research because findings are often specific to the group under study and not as easily applied outside of the particular circumstances of the group.

Although quantitative methods are considered more generalizable than qualitative methods, as mentioned previously, quantitative survey methods limit data validity because of context stripping with pooling of responses (Jones, 1995; Owens & Batchelor, 1996). Qualitative research findings could be used to help design a quantitative questionnaire for a later date; this would increase the validity of a survey. Qualitative methods can verify findings by checking results with sources of information, by triangulation (Creswell, 1994). In this study key informant interviews were done first to help design the research tool, the patient questions and to ensure that the questions were approved by the Aboriginal community. This approval by 'experts' increases the content validity of the research tool to be used interviewing patients from a culture other than the writer's (McDowell & Newell, 1987). The use of key informants, other hospital contacts and comparison with historical data sources helped ensure accurate interpretation of results ensuring that multiple perspectives were considered. Using multiple data sources improve the construct validity of the study.

Concepts such as satisfaction are not specific and not easily measurable. Hospital outcomes such as disease remittance or pain resolution are more specific endpoints and can be 'scientifically' measured more easily. Qualitative researchers rely on the ability of subjects to explain their reasoning, which may not be apparent, particularly in more complex decisions (Dunfield, 1996) or working with other cultures.

Timing of the interviews can affect credibility of results. In-hospital responses could be more favorable towards hospital than responses given post-discharge weeks later. Interviews done many months later tend to gather favorable results, compared to interviews completed soon after discharge (Ford et al, 1997). Post-discharge interviewing gives patients time to reflect on their experience and could result in selective recall. It was not feasible to do this study post-discharge due to the time and costs involved tracking out-of-town patients in particular. The researchers' attempts to time the interview close to discharge resulted in missing some interested patients. The discharge of some patients earlier than expected decreased participation rates.

Limiting this study to English speaking patients plus one Aboriginal language may affect how representative it was of all Aboriginal patients served by the hospital. Further credibility would have been lost if we had tried to compare interviews in more languages. Limiting the project to only patients of Ojibway culture, whether interviewed in that language or English would have made for a more defined cultural group but increased the difficulty obtaining interviews. The limited number of Ojibway speaking patients who participated in their mother tongue limits the validity of comparisons with the English interviews: there were only 5 Ojibway interviews and 23 English interviews.

The interviews in English were of patients from Cree, Metis or Ojibway cultural backgrounds (Figure 3). No Inuit patients were identified on these wards during the time of the study. We tried to ask all patients on the study wards whether they considered themselves Aboriginal. We left our brochures at the bedsides of patients who were absent from their rooms so they could contact us later. (No one did contact us later). Some Aboriginal patients may have denied Aboriginal identity if offended by the question "Do you consider yourself to be Aboriginal?" in our initial contact.

Another possible limitation is the research assistant's fluency and dialect of Ojibway. She may have spoken a different Ojibway dialect than the patients, as she was from a rural community and all the participants who agreed to interview in Ojibway were from a remote area of the province. The research assistant had worked previously in the hospital, as an interpreter caseworker, so was familiar working with different dialects. Translation of the interviews by another Ojibway speaking person may have affected accuracy of the interpretation of the responses. As the researcher was unfamiliar with the Ojibway language listening to the tapes did not add any further clarification of these interviews.

As inpatients can be discharged quickly, especially in these times of fiscal restraint, it was difficult to develop a good rapport with many of the patients through repeated encounters on the wards. This is particularly important in Aboriginal culture. More superficial or neutral responses or even refusal to participate may have occurred due to the lack of time to develop trust (see discussion on Aboriginal culture). Some of the interviews were very brief, others longer, depending on patients' responses to the semi-structured interview questions. More in-depth interviews would have been able to gather further details, but would have been much more challenging to arrange and only a limited number could have been performed. In-depth interviews are more costly and more difficult to obtain due to the time involved on the part of the interviewer and the patient.

All of the English interviews were completed over the months of July and August of 1998. Volunteers for interviews in Ojibway took months longer to recruit, so the interview period extended into the winter months. The types of admissions and ward staffing may be different during the summer season, when more replacement staff may be working.

Interviewing patients regarding their satisfaction with the system may bring out excessive negative comments, as patients may feel that this is the desired response. Alternatively, interviewees may give what they think are socially desirable positive responses. Open-ended questions tend to have less positive responses than survey methods. Careful wording of questions for semi-structured interviews is needed to look for a variety of experiences. Ford et al (1997) suggests that any non-response bias is towards less favorable evaluation. Because of this, we may have missed the people with the most concerns.

Aboriginal culture may affect participation and responses. The group of people whom Longclaws (1996) describes as anomic may have been represented in the people who refused to participate in this study. They may have felt they have no voice, no control. Non-participation in this study may also be more common in the group Longclaws refers to as traditionalists. Consider the James Bay Cree tradition:

> Reticence, for instance, may serve as a protective function until mutual knowledge allows more confident communications (although reticence is not the only possible response). At the other extreme, where mutual knowledge is well developed, interpersonal relationships are quite different, for the threat is no longer due to the lack of knowledge of each other, but rather the presence of this knowledge. Each individual's privacy is at stake, and now reticence allows appropriate disclosure, so that each individual may maintain his autonomy (Preston, 1976: 451).

Interviews and survey methods (which are used to probe patients' satisfaction with care) expect patients to relate their perceptions. Talking about one's self is discouraged in many Aboriginal cultures, as is positive or negative criticism or judgments about others (Black, 1973 & 1982; Henderson & Primeaux, 1981; Brant, 1990). These values promote equality within a group, as opposed to the competitiveness of mainstream North American society. The teaching of non-interference may restrict people with traditional values from voicing any critical analysis of their hospital care. This may have affected recruitment to participate in the study, as well as responses to questions.

Younger people living between the two cultures may adopt some of more forthright styles typical of Euro-Canadians, and relay their dissatisfaction, especially with incidents of perceived racist treatment (Longclaws, 1996). Some may refuse participation to resist more research by the dominant Caucasian group. It was hoped the presence of the Ojibway research assistant would allay some of this attitude.

The researchers may have been perceived as hospital employees since we performed the interviews with inpatients at the hospital. If we were seen as representing the institution, the patients may have hesitated criticizing their care and discussing their true experience. The social distance between researchers and the patient can affect interactions (Britten, 1995). Studies assessing patient interactions with interpreters found that some patients were uncomfortable discussing health issues using hospital interpreters, and were concerned the information shared may become gossip (Fitzpatrick, 1991; Kaufert Koolage, Kaufert, O'Neil, 1984). The community and members of the interpreter's own family may hear stories regarding their role in advocacy or assistance to patients (Kaufert and Koolage, 1984). If the patient and the Aboriginal research assistant are from the same community, the patient may be more or less open, depending on their interpersonal connections.

In Aboriginal culture, the interpreter's age and gender is also important (Ellerby, 1999; Kaufert, 1999). An example of this possible influence on the study was one older male Ojibway patient who repeatedly refused to participate in an interview. He spoke only Ojibway and spent months on the rehabilitation ward, so his views on his experience would have been valuable. Discussion with the hospital elder suggested that this refusal to participate might have been related to the age and gender of the younger female researcher and assistant.

2.9 Ethical Considerations

This research proposal was approved in 1997 by the University of Manitoba - Faculty of Medicine Committee on the Use of Human Subjects in Research, chaired at that time by Dr. G. Grahame. This qualitative study is part of a larger study at the Health Sciences Centre, titled "Aboriginal Patients at the Winnipeg Health Sciences Centre: Utilization of Services and Perceptions of Care" (see acknowledgements). Support from the administration of the Health Sciences Centre itself was obtained for the study to proceed in the facility and for the results to be published. This will allow the information to be discussed and used by external health planners, by Aboriginal groups, health care workers and researchers.

All research with human subjects must have informed consent. In this study, informed consent was obtained from all individuals participating in interviews. Information about the purpose of the research, confidentially, and freedom to withdraw from the study was given. Consent was always received in writing before participating. A sample consent and paraphrase are attached (see appendices 3 & 6). The interview data was aggregated with no identifying information (such as name, hospital number, community, and diagnosis). The demographic information collected during the interview process was always stored separately from the recorded tapes, which had only numerical identification. This data will be destroyed upon completion of the research, and the tapes erased.

Cross-cultural research brings up many ethical issues. Patients from different cultures will analyze information using their own explanatory models. Knowledge development from research of other cultures should fit the models of the minority groups involved, not the assumptions of the dominant society.

The problems of Aboriginal people have been well studied, sometimes without benefit to the group. Research to document problems must be outcome focused, and avoid stigmatization (First Nation and Inuit Regional Health Survey, 1999; O'Neil et al, 1998). Aboriginal people want to control research activities in their communities and they want research to generate useful information for their communities to negotiate for resources and services with different levels of government and private businesses.

The Royal Commission on Aboriginal Peoples recommended that consultation on all stages of any study must be sought from the people who will be affected by the results (Royal Commission on Aboriginal Peoples, 1993). Cultural informants should always be involved in an advisory role in the development, conduction and analysis of a study (Jacobson, 1994).

As noted earlier, in accordance with these recommendations the project proposal was discussed with the Health Advisor for the Assembly of Manitoba Chiefs. An outline was submitted to the Chiefs' Health Committee and the Regional Advisory Committee for First Nations Health Research. Their written support was obtained January 1998. This was contingent on the involvement of two Aboriginal health care workers. These two informants and three Aboriginal employees at the Health Sciences Centre were involved in planning interviews and formulation of patient questions for the interviews. The patient interview results and analysis were shared with these informants for their comments and direction.

CHAPTER 3

RESULTS

In this chapter, the findings of the case study of the Health Sciences Centre will be presented first. This will set the 'stage' for the interview results. I will describe Aboriginal services at the hospital since their initiation and mention a pivotal event in 1980 at the St. Boniface General Hospital in Winnipeg. The process involved in the 1992 Report of the Aboriginal Services Review Committee will be reviewed. I will examine the outcome of several recommendations from this report regarding governance, the Aboriginal Services Department, cultural awareness issues, and employment issues. I will describe the restructuring of health services in Winnipeg as they affect Aboriginal hospital patients. Later I will present the interview results.

3.1 Overview of Aboriginal Services at the Health Sciences Centre

Patient advocacy services for ethnic minorities only exist in some hospitals in Canada, and these are directed at specific groups. Programs exist specifically for Aboriginal patients in some provincial hospitals in Canada. With the growth of the Aboriginal population in Canada, there is an increasing need to provide culturally appropriate health services, to satisfy the needs of this unique group of people.

3.1.1 Early Native Services at the Health Sciences Centre:

The Native Services Department came into existence in 1971 as one of the first such programs in Canada (Aboriginal Services Review Committee, 1992). The initial need for services at the hospital was identified from communication and cultural barriers on interacting with children of Aboriginal families, in particular families from the north. The training of the first interpreters was initially funded by federal and provincial employment training grants. In 1974, the positions were accepted for permanent funding by Manitoba Health. Four positions were funded for the Children's Hospital at that time and in 1976, three additional positions were created so the program could service the entire hospital (Native Services Department, 1995). The department offered interpreter services, liaison, and advocacy services for all Aboriginal patients and their families.

Similar interpreter services at St. Boniface Hospital in Winnipeg were made available in 1978. In November 1980, an incident at this other teaching hospital brought services for Aboriginal patients at both Winnipeg hospitals to national media attention. A young surgeon had strung glass beads on the ends of suture material closing a chest incision on a 52 year old woman from a remote Cree community. The woman was upset when she realized there were beads hanging from her incision.

The patient and family involved the Four Nations Confederacy (the former Manitoba Indian Brotherhood and a political advocacy organization for First Nations people in Manitoba) as their representative regarding the complaint against the hospital. The hospital commissioned Justice Emmett Hall to investigate the situation. He reviewed the long detailed brief by the Four Nations Confederacy, commending them for "dealing with problems of Indian Health Services generally as well as the ... incident and for not focusing entirely on that incident (1981: 12)." Their brief to Justice Hall expressed concerns regarding the treatment of Aboriginal people in the provincial hospital system and the lack of involvement of Aboriginal people in planning hospital and community programs. Their final recommendations included: ongoing cultural awareness training (including the role of interpreters) for all hospital employees including professional staff and the expansion of the interpreter/advocacy program to allow 24 hour coverage and city-wide service. They also had recommendations for the hospital administration regarding the need for ward staff to understand their responsibility to speak out when any patients may be mistreated and for administration to hold formal inquiries into any patient grievances.

Justice Emmett Hall supported the Confederacy's recommendations fully. He commended the hospital on early efforts to address problems with communication channels within the hospital. He commented that the woman had felt insulted and humiliated by what the doctor did. Hall felt the physician had no racist or prejudiced intent towards the patient and recommended no loss of hospital privileges, as the physician had already suffered from the national media attention. The surgeon had spoken to the patient without the use of an interpreter and had thought her roommate had explained the surgery.

Justice Hall noted that the hospital planned to identify the needs of Aboriginal patients and families. The hospital wanted to work towards meeting the needs without replicating existing community services. Hall recommended that the hospital should ensure trained interpreters were available to avoid recurrences of lack of informed consent by non-English speaking patients. He concluded that much would:

> depend to a great extent on the co-operation of the Medical Staff and all hospital personnel and particularly on the determination of hospital management in overseeing that communication is monitored at all levels and between all levels (1981: 14).

A decade later, the Health Sciences Centre was dealing with issues related to these recommendations. The sole Aboriginal member on the hospital Board of Directors had pushed the other Board members to focus on Aboriginal patients' concerns at a strategic planning meeting. In 1990, an ad hoc subcommittee was created to deal with these concerns as well as recommendations following a chaplaincy survey on Aboriginal patients' spiritual needs (Aboriginal Services Review Committee, 1992). This subcommittee created by the Board executive was mandated to study services provided to Aboriginal patients at the Centre.

This subcommittee went on to become the Aboriginal Services Review Committee, made up of members of the Aboriginal community, including the Assembly of Manitoba Chiefs, the Manitoba Metis Federation, the Indigenous Women's Collective (Health Sciences Centre, 1991). Later, representatives from the Aboriginal Council of Winnipeg, the Aboriginal Women's Collective and the Keewatin Regional Health Board were added. Their mandate was expanded to include a needs-assessment of patients and the educational needs of Health Sciences Centre employees and trainees regarding traditional Aboriginal beliefs and healing practices. The committee was accountable directly to the executive staff of the hospital board.

The Report of the Aboriginal Services Review Committee was finalized in June 1992. It concluded with nine recommendations that the committee felt were consistent with mission statement of the institution (see Appendix 10). The internal review found:

> That all patients have a right to expect personalized and continuous care is recognized in the Mission Statement of the Health Sciences Centre. The reality of the situation for Aboriginal patients is often very different. *It is not only the depersonalization that takes place, for this is a common complaint of many hospitalized patients* [italics added]. What makes the experience more acute for Aboriginal clients is that Western medicine generates isolation and impersonal care due to the different cultural values of the Aboriginal and non-Aboriginal societies. *The root cause of the discomfort felt by Aboriginal clients is the wide-spread perception of systemic and individual discrimination against Aboriginal people within the Health Sciences Centre* [italics added] (1992: 18).

The initial report of the Aboriginal Services Review Committee was given to another ad hoc committee of the board for a review. This committee endorsed most of the recommendations with some modifications and made their own recommendations to the Board as to how to approach the issues (Health Sciences Centre, 1992). The Board of Directors approved the ad hoc committee's recommendations entirely, including the above statement (see Appendix 7).

Concurrent with changes happening at the hospital coming out of the report, there was a complaint at the Health Sciences Centre about the care of a patient who died in late 1992. The family complained to the former manager of the Native Services Department, Margaret Lavallee, who arranged a meeting with the Patient Representative, Ms. Catheryn Martens (Health Sciences Centre, 1993). Mr. James Rogers, Assistant to the President, agreed to a request that they visit the home community of the patient and the three individuals traveled to the community. The hospital personnel toured around and visited patients at home and listened to many community members' concerns. The community presented their problems with the health system in general, and did not focus on the one case. Their concerns included many of the things covered in the Report of the Aboriginal Services Review Committee to the Board. The visitors summarized the community's recommendations and advised the hospital president of the concerns (Health Sciences Centre, 1993). They also recommended further "site visits to reservations (sic) around Manitoba be undertaken by the Centre. Such visits should be done by members of the Board of Directors, senior managers and line staff whose job performance affects the treatment of Aboriginal patients in this institution (1993:5)." They realized the need to gain community trust and insisted that visits must be two days in length at the absolute minimum to appreciate a community's situation.

3.1.2 A Review of the 1992 Recommendations:

The 1992 Report of the Aboriginal Services Review Committee recommended many things to improving services and participation of Aboriginal patients at the hospital. This document will look at six of the nine recommendations that are considered germane to this patient satisfaction study. Progress was limited in the early and mid 1990's environment of health care reform and fiscal reductions (Bruyere et al, 1996). The first recommendation was increased representation of Aboriginal people on the Health Sciences Centre's Board (see list of recommendations in Appendix 7). Instead, the Aboriginal Affairs Committee was struck in February 1993 as a standing committee reporting directly to the Board of Directors. The committee was made up of five members of the Board one of which one was the chair. Also included was one appointee from each of: the Assembly of Manitoba Chiefs, the Keewatin Regional Board of Health, the Manitoba Metis Federation, and the Indigenous Women's Collective (Health Sciences Centre, 1995a). Three non-voting members were the Vice President Human Resources, the Director of the Native Services Department and the Corporate Secretary. The committee was advisory to the board and was responsible to make recommendations on issues of patient contact, education and employment related to Aboriginal peoples.

The Aboriginal Affairs Committee was assisted and supported by an advisory committee, made up of various hospital management and staff area representatives, three Aboriginal community members, and three Aboriginal employees at the hospital. Three subcommittees to the advisory committee were set up to work on the first objective of the main Aboriginal Affairs Committee "to identify opportunities for expanded roles for Aboriginal people in (hospital) activities and recommend thereon

(Health Sciences Centre, 1995b:1)." These were the Staff Education Subcommittee, the Training and Employment Subcommittee and the Services and Evaluation Subcommittee. The director of the Native Services Department sat as a member on each subcommittee.

The 1992 Report of the Aboriginal Services Review Committee recommended an increase to five Aboriginal representatives on the Board of Directors for equitable representation, but the ad hoc committee of the Board rejected quotas (Health Sciences Centre, 1992). The Assembly of Manitoba Chiefs had passed a resolution in 1991 that the Minister of Health should ensure First Nations people had equitable representation on all hospital boards (Assembly of Manitoba Chiefs, 1991). They described the exclusion of Aboriginal people from board participation as irrational, intolerable and racist. The 1991 Northern Health Services Task Force had also recommended increased Aboriginal representation on hospital boards and an increase in employment at hospitals for Aboriginal people (Manitoba Health, 1991).

The ad hoc committee felt the Aboriginal Affairs Advisory Committee would fulfill the role of increased Aboriginal representation at the Board level (Health Sciences Centre, 1992). Aboriginal representation on the hospital Board remained at one in twenty positions for years after the 1992 request for increased representation was made, yet many Board vacancies were filled in that time. In 1996, the previous sole Aboriginal Board member left the board. The number of Aboriginal board members has never risen above two since the 1992 report.

The second recommendation from the 1992 report was for improved links between the Health Sciences Centre's Board with the Aboriginal community by having Board meetings outside the institution, in Aboriginal communities. The

Aboriginal Affairs Committee of the Board held a meeting at Sagkeeng First Nation, northeast of the city in 1997. Gerald Courchene, the director of the local health centre describes how he welcomed the urban delegates "with their cultures" to the community (personal communication, April 2000). He told committee members that Aboriginal people are asked "to leave their culture at the door of the hospital." At this meeting, many local community members came out and told stories of their experiences as patients in the hospital.

The Aboriginal Affairs Committee and the Aboriginal Affairs Advisory Committee held a joint meeting in 1998 at the Aboriginal Centre located in the core area of the Winnipeg (Aboriginal Affairs Committee & Aboriginal Affairs Advisory Committee, 1998). The Board of Directors never held a meeting outside of the hospital since the 1992 report. The 1992 report also called for improved links for the hospital with Aboriginal leaders in Manitoba, Northwest Ontario and the Keewatin District of the Northwest Territories (Nunavut). Further progress in the area of community connections or Aboriginal representation on the Health Sciences Centre Board has halted since provincial regionalization of health services resulted in dissolution of the board in the late 1990's. This will be discussed under the current situation of Aboriginal services.

The Aboriginal Services Review Committee's third recommendation called for greater autonomy and expanded financing for the Native Services Department (1992). To this end, the department was removed from the Nursing portfolio at the Health Sciences Centre with the director reported directly to the Corporate Secretary (J. Rogers, personal communication, March 2, 2001). This alteration in reporting lines effectively re-created the Native Services Department as a freestanding department. The director participates on many hospital committees and with

Aboriginal organizations outside the hospital.

In 1995, there was an evaluation of the Children's Hospital, including services for Aboriginal families (McLaren, 1995). Focus groups pointed out the need for increased use of the Native Services Department. Many families expressed concern that hospital staff only referred patients to the Native Services Department for interpreter services while families felt their role was more encompassing. Families described the need for the emotional and cultural support by the department staff as well as their varied assistance such as finding housing. Increased staffing was recommended in the 1995 evaluation.

The department's name was changed in 1995 to the Aboriginal Services Department. The Aboriginal Services Department is recognized at the level with other clinical departments (Health Sciences Centre, 1998). The entire department was moved in April 1999 to a larger space. Previously the administrative staff were housed in a separate hospital building from the case workers because of lack of space. The intent of the move was to centralize services and to have space available for large families of sick patients to gather, and for large group meetings, fulfilling another recommendation from the 1992 report. A sacred ceremonial room is located near the department offices. This room is used for smudges, sharing circles and other ceremonies as requested (G. Berthelette, personal communication, December 13, 2000). The space for the department itself and for family group meetings is in a building across the street from the hospital (connected by tunnels). However, visiting families find the room is too far away from patients' wards so the department often reserves a room for gatherings within the main hospital cafeteria that is more central (G. Berthelette, personal communication, April 2000).

3.1.2.1 Employment Issues:

The Aboriginal Services Review Committee had criticized the Health Sciences Centre for the inadequate representation of Aboriginal people in the hospital workforce (1992). The review recommended that the workforce at the hospital should be more reflective of the patient population served. Aboriginal people are over-represented in hospitals as patients and under-represented as health care workers (MacMillan, MacMillan, Offord & Dingle, 1996). The committee recommended the use of employment equity for expanding the numbers of Aboriginal employees at the hospital. Low numbers of Aboriginal employees suggests systematic discrimination in employment and " it inhibits the Health Sciences Centre's ability to deliver culturally appropriate health services to Aboriginal clients (Aboriginal Services Review Committee, 1992: 11)."

The former director of the Aboriginal Services Department felt it was hard "to get people to transfer the skill and the technology, the knowledge to Aboriginal people." Non-Aboriginal employees may have felt the Aboriginal trainees and employees might threaten their jobs (L. Longclaws, personal communication, February 18, 1997). He noted many non-Aboriginal health care workers are suburban residents who drive to work at the hospital that is located in the core area that has a large Aboriginal population. This pattern resembles the Caucasian health professionals who work temporarily in the north. Neither group lives as 'equals' with the local Aboriginal people. They are perceived by some to earn their income "on the backs of Aboriginal people" while giving little back to the community (L. Longclaws, personal communication, February 18, 1997).

In 1994, the hospital implemented an "Aboriginal preference" hiring policy for wards with 25% or more Aboriginal patients (Aboriginal Affairs Advisory Committee, 1994). Knowledge of Aboriginal culture and language were considered bona fide qualifications to work on these wards. Managers of these wards with high counts of Aboriginal patients were to recruit for openings with this preference in mind, and the postings were marked as such.

The first cultural diversity/employment equity coordinator was concerned that the 'Aboriginal preference' for hiring staff was based solely on knowledge of the culture and languages (L. Spillett, personal communication, February 10, 1997). This gave non-Aboriginal applicants equity or preference over Aboriginal applicants if they had either of these qualities without an Aboriginal background. Attendance at the cultural awareness workshop was considered a qualification.

Previously the five unions at the hospital wanted only a full equity program (Aboriginal Affairs Advisory Committee, 1994). Unions wanted involvement, fair recruitment practices, and for employees on the redeployment list to maintain preference for vacancies. Across Canada in the mid-1990's hospitals were reducing staffing in times of fiscal restraints and the unions were looking out for deployed colleagues. Today with ongoing hiring, the hospital unions are supportive of full equity programs directed at all minorities (W. Byron, personal communication, May 29, 2000).

Currently new openings at the hospital are first posted for internal applicants only. This greatly decreases the chance of increasing Aboriginal representation at the hospital. If the positions are not union-directed or have no suitable internal applicants, then efforts are made to attract Aboriginal or other minority applicants. The preferential hiring clause for Aboriginal people has had little effective in raising the number of Aboriginal employees at the Centre (Aboriginal Affairs Advisory Committee, 1999).

The cultural diversity coordinator ensures that external postings go to organizations such as the Assembly of Manitoba Chiefs, and the Manitoba Metis Federation, as well as Aboriginal employment agencies including 'Partners in Careers' (K. Morriseau-Sinclair, personal communication, August 16, 2000). Obtaining employment at the Health Sciences Centre is complicated by the fact that no applications are kept on file for future reference. A new application must be completed for each new job posting. This process is frustrating for all external applicants. Aboriginal employees have been frustrated with the need to reapply frequently before obtaining a position at the hospital (G. Berthelette, personal communication, 1997).

The percentage of Aboriginal employees in 1996 was less than .5% of the 5000 employees at the hospital (Bruyere et al, 1996), and probably remains as low as 1% (K. Morriseau-Sinclair, personal communication, August 16, 2000). The hospital has no system to determine exactly how many Aboriginal people are employed. New applicants are offered a form to self identify as Aboriginal when they apply in person, but this is not circulated to people applying by e-mail or fax.

At a recent Aboriginal Affairs Committee meeting, some Aboriginal committee members stated that the hospital's track record retaining Aboriginal staff was poor (Aboriginal Affairs Committee, 2000a). Retention of Aboriginal staff was explored in our class paper (Bruyere, Cooney, Marchessault & Riese, 1996). Former employees were interviewed in 1996. Their reasons for leaving the hospital included questioning of their competence by non-Aboriginal people, a hostile work environment, and subtle discrimination. Some felt very isolated. The former director of Aboriginal Services also perceived his competence was questioned (L. Longclaws, personal communication, February 18, 1997). These issues contributed to the departure of the former employees we interviewed.

The Aboriginal Staff Network started in November 1998 to address some of these retention issues (K. Morriseau-Sinclair, personal communication, August 16, 2000). All Aboriginal staff are invited to join the network and attend monthly meetings. These meetings involve making acquaintance with other Aboriginal employees, professional development, participation in cultural awareness promotion, information sharing and peer support. Approximately 63 Aboriginal employees have been attending these network meetings. Some staff hesitate to ask managers for the two hours off work a month to be able to attend, as they worry they are imposing on others to cover the work in their absence.

In discussions with Aboriginal employees at the hospital there are some Aboriginal people employed at the Health Sciences Centre who choose to refrain from openly identifying themselves as Aboriginal to avoid perceived discriminatory treatment. These Aboriginal workers may be concerned that other staff will interact with them as equals until the staff become aware that they are Aboriginal. Members of minority groups who do not 'come out' in the workforce may feel caught in some situations. Risdon (2000) found that gay and lesbian physicians in training in Canadian hospitals were stressed by the attitudes of other staff towards gay patients, and were not always able to challenge their negative assumptions. However, this group of physicians felt that they had an enhanced ability to connect with other minority groups, sharing the outsider experience.

The present milieu may be stressful for Aboriginal workers. If Aboriginal staff perceives no real benefit of being identified by their ethnicity, the hospital employment goals will be harder to attain. However, having more Aboriginal employees disclosed or otherwise could still benefit Aboriginal clients, and hopefully increase cultural sensitivity amongst the staff. Increased Aboriginal employment would help prevent Aboriginal staff and patients feeling isolated in the hospital.

The Winnipeg Regional Health Authority needs to hire more nurses, licensed practical nurses and health care aids as well as other hospital staff. New health care positions have been created at many facilities in Manitoba as well as previously deleted positions reinstated with increases in provincial health funding in recent years. The Winnipeg Regional Health Authority has developed an Aboriginal Employment Strategy to address the need for more Aboriginal employees at urban hospitals (Winnipeg Regional Health Authority, 2000a). The strategy acknowledges the large Aboriginal patient population served by the hospitals.

The Health Authority plans to support the principles of improved opportunities for education, training and employment by Aboriginal people in health care as described in the provincial document Applying Manitoba's Policies for Aboriginal people living in Winnipeg (Manitoba, 1999). An Aboriginal recruitment coordinator will be involved in recruitment and retention, developing networks with other agencies and outreach. This person will be involved with Human Resources at all the urban hospitals, to promote hiring vacancies to Aboriginal agencies. The Aboriginal awareness/cultural diversity coordinator at the Health Sciences Centre has been working with this project.

Across Canada, there is a shortage of health care workers. The Winnipeg Regional Health Authority has sponsored the training of Metis health care aids to assist in alleviating the problem (Winnipeg Regional Health Authority, 2000b). The students were recruited by the Manitoba Metis Federation provincial recruitment initiative, and trained at the Winnipeg Technical College. Fifteen of twenty students have graduated and they will hopefully all find placements in Winnipeg health care institutions (W. Byron, personal communication, November 30, 2000). The Health Authority has been recruiting overseas for nurses, as other training initiatives for professional staff will take years (W. Byron, personal communication, September 2000). The Health Authority would prefer to focus on preparing Manitobans and especially Aboriginal people for these positions.

The Winnipeg Regional Health Authority has met with the Assembly of Manitoba Chiefs to discuss the Health Authority's interest in hiring more Aboriginal staff. The Health Authority wanted to connect with the human resource people of Aboriginal organizations to assist their employment plan. A suggestion that emerged from one of these meetings was for an Aboriginal employee to be on the interviewing committee of the Health Authority (Sheila Lewinski, personal communication, June 23, 2000). The presence of an Aboriginal person may increase confidence of Aboriginal interviewees and add more culturally appropriate input into assessment of their skills.

The Winnipeg Regional Health Authority hosted an Aboriginal Employment Equity Session on August 29, 2000, with a keynote speaker from Saskatchewan. Provincial representatives of many different departments including Health, Aboriginal and Northern Affairs, Culture and Heritage, and Employment and Training attended this workshop. Other regional health authorities, union leaders and human resources professionals also attended.

The Metis presenter stressed the need to employ Aboriginal workers not only in low end, low skill and low pay jobs, but also with equal representation in technical, professional and managerial occupations (McKenzie, 2000). Counseling Aboriginal youth towards stereotypical jobs of doctors, nurses, social workers and interpreters was criticized, because it implies there is nothing between the bottom and top positions in institutions. After the workshop, comments to the Vice President Human Resources of the Health Authority suggest unions would be more willing to support representative participation by Aboriginal people (W. Byron, personal communication, September 2000). Unions will participate on a Winnipeg Regional Health Authority steering committee for this purpose.

On December 11, 2000, the Winnipeg Regional Health Authority had a signing ceremony with the provincial ministry of Aboriginal & Northern Affairs, committing both sides to increase and improve Aboriginal employment in health care (Winnipeg Regional Health Authority, 2000c). The Health Authority plans to also enter a similar agreement with the Assembly of Manitoba Chiefs. Each and every health care union in Manitoba wants to participate in these new initiatives. The Winnipeg Regional Health Authority has established an Aboriginal Human Resources Stakeholders Circle. The Circle will comprise of many different groups and the chief executive officers of other regional health authorities in the province.

3.1.2.2 Cultural Awareness Training:

The next recommendation of the Report of the Aboriginal Services Review Committee was the development of orientation and continuing education programs in cultural awareness training for Health Sciences Centre staff, trainees, students and volunteers (Aboriginal Services Review Committee, 1992). "These activities should be incorporated into the Total Quality Management Program being considered at the Health Sciences Centre (1992:15)." Paternalistic, racist and 'blame the victim' attitudes had been identified in the review. The report commented on the need for awareness regarding the health problems of Aboriginal people, and the historical and social context of Aboriginal issues. Awareness of traditional values and of variability in cultural practices to avoid stereotypes was stressed in the report, as was the importance of family and visitors in patients' care.

An example of cultural insensitivity in the past involved a reaction to the burning of sweet grass for ceremonies. A worker across the hall from the Aboriginal Services Department had arranged for environmental assessments to be done due to her exposure to sweet grass smoke and wanted to outlaw the traditional practice. The worker had gone to the extent of circulating a petition against the burning of sweet grass. "To have a petition signed, that totally has no respect for traditional Aboriginal ways ... (L. Longclaws, personal communication, February 18, 1997)." This former director of Aboriginal services found the organizational culture of the hospital willing to tolerate certain changes in the system for the benefit of Aboriginal people but only up to a certain point. Some changes that would empower Aboriginal people were perceived as too threatening by the non-Aboriginal administrators.

Cultural awareness workshops were designed to promote increased understanding of Aboriginal culture. The first Aboriginal woman hired as the Aboriginal awareness/cultural diversity coordinator started in June 1996 (L. Spillett, personal communication, February 10, 1997). Workshops offered to people employed in social work, security, and renal dialysis areas of the hospital as a pilot project. The coordinator position became a full-time contract with funding from human resources and the 'Vision Fund' within the hospital and externally from the Canadian Council for Aboriginal Business. This program has been able to accommodate 20 people per two-day workshop since October 1996. An optional third day to go out of town for exposure to traditional healing methods and a sweatlodge ceremony has been possible.

The coordinator position has had permanent funding since March 1999 (K.

Morriseau-Sinclair, personal communication, 2000). Currently, the team of eight facilitators has three Aboriginal members. Workshops are held weekly if registration is adequate. The workshops are offered to all staff as part of professional development. Over 2400 people have participated as of September 2000 including employees of Aboriginal descent who sign up because they feel they have lost much of their culture.

An evaluation of the Cultural Awareness training program occurred in 1998 (Leskiw and Associates, 1998). Informants within the hospital and in outside organizations who often deal with the Health Sciences Centre participated in three focus groups with the evaluators. The three groups had the impression that staff who had participated in the workshops have attained a higher degree of awareness. Informants perceived a reduction in the level of negative behaviors, inappropriate assumptions, and frustrations dealing with patients. Aboriginal employees were acknowledged as specialists on-site, who could assess patients' needs and be a resource to staff. The evaluators called for an Aboriginal support network to assist with retention of Aboriginal staff.

The hospital was commended in the review for the provision of back-fill staffing relieving staff of their duties to attend the two-day workshops (Leskiw et al, 1998). The participation of physicians and hospital managers, executives and supervisors in the workshops was considered essential to reinforce the position that the workshops are valued and would change the corporate culture. No physicians had yet participated at that time (with the exception of myself in the role of researcher). Further sessions to cover pertinent questions arising out of the workshops and to teach practical application of the knowledge was thought to be useful. More in-depth repeat sessions would comply with the recommendation of the

Aboriginal Services Review committee's report for continuing cultural education programs (1992).

As part of offering more culturally appropriate hospital care, Aboriginal language courses have been offered at the hospital since 1996. These are considered self-development and must be taken on the employee's own time. This consists of ten evening classes on one of the two main languages used in Manitoba - Cree and Ojibway. These classes are offered on a cost recovery basis through Educational Services at the Health Sciences Centre; non-hospital employees may also attend (K. Morriseau-Sinclair, personal communication, May 2000). Completion of either or both of these courses would help gain 'points' for a hospital employee to use when applying for another internal position. Union members can apply to their union to have the costs of these courses covered by their dues.

3.1.3 Current Situation of Aboriginal Services in Winnipeg:

The hospitals in the city of Winnipeg were brought under the direction of the Winnipeg Hospital Authority in 1997, with a separate Winnipeg Community and Long-term Care Authority for community services. The urban hospitals retained individual boards, but all were covered under the operating agreement of the Winnipeg Hospital Authority. The Winnipeg Hospital Authority board had one Aboriginal representative (Winnie Giesbrecht), who also chaired the regional Aboriginal Affairs Committee.

The two city regional authorities were amalgamated into the single Winnipeg Regional Health Authority after a provincial election resulted in a change of government late in 1999. On April 1, 2000, the Health Sciences Centre Board disbanded and came under the direct control of the Winnipeg Regional Health

Authority. The new single regional board now has two Aboriginal representatives, out of thirteen board members.

With these changes, the Health Sciences Centre's Aboriginal Affairs Advisory Committee no longer exists. The Aboriginal Affairs Committee still meets but no longer reports to a hospital board of directors as in the past. The hospital's Chief Operating Officer, Dr. John Horne, now chairs the committee. The Winnipeg Regional Health Authority has recently hired a Regional Director for Aboriginal Services, Dr. Catherine Cook. Dr. Cook will collaborate with the directors of the two teaching hospitals' Aboriginal Services Department. Local site issues will still be under each institution's direct-reporting corporate structure (W. Byron, personal communication, May 29, 2000).

Specific budget increases in the late nineties were reflected in an improved work environment for the Aboriginal Services Department, with more equipment, supplies, and staffing. Currently at the Health Sciences Centre there are thirteen employees of the Aboriginal Services Department, including the director, administrative assistant, discharge nurse, full-time elder and a coordinator for the five full-time, one part-time and two casual interpreter-case workers. Their funding is permanent departmental funding within the hospital.

Only the nurse's position is unionized. The current staff put in frequent overtime due to workload demands (G. Berthelette, personal communication, March 2000). The part-time discharge-planning nurse often worked full-time hours. The hours for the discharge-planning nurse were increased recently from .5 to .7 full time effective, but the employee resigned in November (G. Berthelette, personal communication, December 13, 2000). She was interviewed about her resignation, which was related to a desire for guaranteed full-time hours.

Current services provided by the Aboriginal Services Department include interpretation, liaison, advocacy, support, and cultural services for Aboriginal inpatients and outpatients at the hospital. Sharing circles and smudges are held weekly for patients, families and even some staff have been attending (G. Berthelette, personal communication, December 13, 2000). There is no dedicated social worker. There has been a full-time Elder since 1997. The Spiritual Care Department has had a Spiritual Care chaplain who is Aboriginal since 1997. She was ordained in the Anglican Church over a year ago. Interpreter services are available in Cree, Ojibway, Oji-Cree and the Island Lake dialect of Oji-Cree. There is no interpreter service for Dene-speaking people from northwest Manitoba. Two Dene people living in Winnipeg provide this service on a volunteer basis when possible.

The Winnipeg Regional Health Authority plans to increase funding to expand the teaching hospitals' Aboriginal services departments (R. Cloutier, personal communication, February 23, 2000). Each department would benefit from a dedicated Aboriginal social worker, and full-time discharge nurse. Expansion in the numbers of interpreter caseworkers appears to be needed to enable the two existing departments to respond to current demands for services. Currently, the Winnipeg Regional Health Authority is evaluating the current Aboriginal Services Department at both teaching hospitals and may identify efficiencies to improve service output and may need to enrich services. The review will include assessing the efficiency and effectiveness of current services, development of long-term strategies, and stakeholder consultations.

Expansion of services to the community hospitals would need even further staffing. If service demands are greater at one peripheral site, such as the proposed dialysis site at Seven Oaks Hospital, a new onsite service may be developed.

Funding for greater availability of services after hours and on weekends is wanted as well as increased density and distribution of daytime services. Expansion of the hospital's cultural awareness workshops is probably also needed. The Winnipeg Regional Health Authority has started to offer participation in the Health Sciences Centre's cultural awareness workshops to other health care organizations (Health Sciences Centre, 2000b).

3.1.4 Summary of Case Study:

This section presented the historical background of the hospital's Aboriginal services to assist in the analysis of the patient interview results. There has been progress in fulfilling some of the recommendations of the Report of the Aboriginal Services Review Committee. Aboriginal services have expanded and cultural awareness training is offered to all employees, with thousands of people attending the workshops over the past five years. There is a perception that the workshops are increasing awareness amongst participants. However review sessions for the cultural awareness workshops are not yet held and hospital physicians are not participating as recommended. This will limit the level of cultural competency that health care workers can attain through their work.

Thus progress on the recommendations in the areas of employment and governance has been limited. The Winnipeg hospital system has had significant restructuring since 1998. The shortage of health care workers across Canada especially Aboriginal health care workers is limiting Aboriginal employment increases. The Health Authority's cooperation with Aboriginal groups for training and recruiting workers has commenced with the partnerships with the Manitoba Metis Federation and the provincial department of Aboriginal and Northern Affairs.

3.2 Results from Patient Interviews

This section will present the data from the semi-structured interviews and will discuss the emerging themes. Analysis of the interviews found two main themes, *control* and *endurance*. First, I will present the five areas of concern to the key informants, which the interview questions were designed to explore. The themes to be presented are the patients' perceptions of communication problems, family and visitor involvement, patients' involvement in discharge planning and perceptions of racism. Involvement of the Aboriginal Services Department in patients' care and patients' general satisfaction will follow.

The interview results to these questions will paint a picture of the patients' concerns. Control and endurance as the main themes flowing through these proceeding areas will be described last.

Quotes from the patient interviews will be followed by codes to indicate the different participants. Quotes from interviews done in English end with an alphabetical code (A-W); quotes from interviews done in Ojibway end with the codes O1-O5. The pilot interview results were quite similar to the other interviews and so were included in the analysis; they are coded (P1-P5).

3.2.1 Patient Perceptions of Communication Issues:

The key informants involved with planning the research questions stressed their concern about communication difficulties experienced by Aboriginal patients. Various aspects of communication were explored. Initially, we asked patients if they knew why they were in the hospital and what was going to happen to them, to determine whether information the staff had shared had been understood.

Some were confident they understood all the information provided to them. Most interviewees stated that they knew why they had been hospitalized, but many did not know what might happen to them in the hospital:

> Respondent: I understand why I'm in the hospital but I don't know what is going to happen to me.
>
> Interviewer: Did you have a chance to ask what was planned?
>
> Respondent: No, I'm pretty sure they will come around and tell me what is going to happen (F).

Younger respondents more frequently stated they knew what was planned during their hospitalization. To inquire more specifically about problems understanding information, we also asked "Could you tell us about any problems you had understanding the hospital staff? Or any problems you had being understood by them?" Many reported they had no problems. Some stated they were sure to ask staff to repeat explanations so they would understand.

> No, I always ask over and over what's going on to make sure I understand it (R)

Another said:

> For most of it yes [I do understand]. But most of the time I ask for explanation on things or to see things like my x-rays or to see my file. But they tell me "You aren't supposed to look at your file, only the doctor can" and I ask "Who's file is it?" It's my medical information and lots of times I never get to see it. But in most cases I understand. I ask them questions about what they are doing (B).

A patient interviewed in Ojibway (who switched back and forth into English) stated in English:

> Yeah, cause I don't know nothing about ... you know, I always ask "can you go through" "like I don't really understand this and that" tell me what" (O5).

A patient participating in a pilot interview explained how she ensures that the staff understands her information:

> Not really, it may take me a couple of times to explain what it is I want to do or say but I really have no problems (P4).

Like the first patient example above, many patients who denied they had any problems with communication expressed concerns about others:

> I haven't had a problem really, but I could see other people from out of town, who speak tongue, their tongue languages, I could see them having problems, because the staff here all speak English. I am fluent in English (H)

Worrying about other patients came up many times:

> If I didn't understand English I would be in big trouble but I understand English pretty well. It's pretty good for me though. I don't know what it is like for older patients. They must have trouble. *They should have employees who speak Cree* [italics added] (F).

The respondent wanted the interviewers to be aware of other Aboriginal patients' problems with communication. Many Aboriginal people, especially patients from rural and remote areas and older Aboriginal people in general, have maintained their first language, and may not speak or understand English as well.

Health care workers who assume that patients understand more than they actually do are at risk of creating situations of conflict and not obtaining true informed consent for treatments (see 3.1.1 regarding 'the bead incident'). A young woman whose name was given to the researchers by the Aboriginal Services Department for a possible interview in Ojibway had the ward staff believing that she understood English quite well. They suggested we could have interviewed her in English. She had been able to answer the staff's basic questions, and make simple requests.

When asked in Ojibway if she understood why she had been hospitalized, she was unsure and she had no clear idea what was going to happen during the remainder of her stay. She hoped for homemaker assistance when she would be discharged.

The staff may misunderstand Aboriginal patients from remote communities who speak English as a second language. Another patient interviewed during the pilot testing of questions stated:

> I know there have been some problems with the Aboriginal people that can't speak very good English. *We have a lot of problems here you know!* [italics added] I always offer to help when I see people don't understand what they are trying to say when the nurses or doctors are talking. (P2)

The interpreter caseworkers are not always available to translate (or are not called) and other patients or visitors may assist as described above. There are no interpreters for patients from other ethnic groups who do not speak English well (outside of the three main Aboriginal languages of Manitoba). Assistance to translate is requested from any staff or visitor in the hospital who happens to speak the patient's language.

One respondent commented that he had difficulty understanding the English spoken by hospital staff from the Philippines. Foreign accents in English are an additional barrier to good communication between patients and health care workers. The different accents of a multicultural hospital workforce would make comprehension more difficult, especially for patients who speak English as a second language.

A few interviewees suggested that sometimes Aboriginal patients claimed to have understood the staff when in fact they had not. One stated:

> It may take me a couple of times to explain what it is I want to do or

> say but I really have no problems. When you ask questions you learn things and *when you pretend to understand* [italics added] you don't learn anything (P5).

Another respondent described communication between Aboriginal and Caucasian people as:

> Well, people like the whites don't understand us. And we say we understand the white people but a lot of the time we don't. I'm afraid to ask. *We're being looked down upon. I wish there were more Aboriginal people working in this area* [italics added]. I wish they would sit down more with us and talk. (T)

Instead of just a language problem, this respondent's comments suggest that the different communication styles of the cultures cause problems. He may have been referring to the use of ambiguity and avoidance of directness for questioning and answering in some Aboriginal cultures (Black Rogers, 1973). These etiquette rules are very different from the directness of Euro-Canadians.

The respondent also described the feeling of disempowerment common to Aboriginal patients. He considered these ongoing problems at the hospital, commenting:

> Every ward should have a counselor or someone we could talk to and get our feelings out to; that's what we need. I just want to talk and talk. These nurses and doctors don't understand that (T).

A second respondent was lacking information in order to access a counselor:

> Yes there was this woman but she doesn't come around anymore. I would like to see her more often; I would like to see someone like that (R).

Apparently, a social worker had visited him early in his hospitalization when he had been too sick or too medicated to benefit. He was dealing with lots of anger after a severe assault. The Aboriginal Services Department is not staffed to provide ongoing counseling during hospitalization. The department at this time has no social worker on staff and the interpreter caseworkers may not have the time for support when needed.

Patients wanting information can also have problems with access to their physicians or the appropriate nursing staff:

> Respondent: Actually no, you get the head nurse, and the doctor. If you can't get any where with (the nurses) go to the head nurse or go to the doctor. With the nurse, you usually have to explain things a couple of times, and she usually walks out the door on you. With the doctor, he will listen for a while, but he just usually just tries to pop his head in and out the door.
>
> Interviewer: No one has the time, or no one makes the time?
>
> Respondent: You have to catch them at the desk. Usually I do (Q).

This rehabilitation patient was bedridden for months due to pressure sores and described how he would hang around the nurses' desk area on his self-propelled stretcher to catch the physician. Another respondent had difficulty speaking to his physician.

> There are so many doctors here you can't really tell who is who. It's hard to tell, but they are good people (P3).

3.2.1.1 Discussion of Patient Perceptions of Communication Issues

The respondents' comments above show that communication problems do exist. Dissatisfaction with health care often results from poor communication and inadequate sharing of information with the patient (Stewart, 1995). Many respondents were concerned that communication problems would be much worse for those patients who are not fluent in English.

Health care workers gather information about hospital patients through observations and investigations, yet the sharing of information with the patient is carefully controlled. Health care can be disease-oriented, with workers forgetting about the individual patient's personal life circumstances, and right to participate in their care. In past models of Western care and sometimes still today, physicians focus on persuading the patient to do something by giving them limited information and advice and with little input from the patient. The patient was expected to take a submissive role and trust the physician without question. The communication was largely one way. The patients' comments suggest this remains a problem in hospitals. With this beneficence model, patients have less responsibility for their health and less ability to control events affecting their lives. This lack of negotiation between the patient and health care worker may affect compliance and patient satisfaction (Butler et al, 1996). Patients may have a sense of devaluation when providers are not interested in listening to their illness story (Morse et al, 1991).

Patients have become more interested in being a partner in their care. They want to negotiate the treatment plan keeping some control. Communication skills and patient-centred clinical approaches are now being taught to medical students and physicians. In the patient-centred approach, it is acknowledged that the patient is the expert on their own *illness* in knowing the implications of their illness on the different facets of their lives (McWhinney, 1997). Patients are encouraged to make their own assessment of their problems and solutions. Patients who feel they are able to control events may have enhanced motivation to participate in the proposed treatment. Patient-centred care looks at the patient's illness in their life situation, not just their medical problem. This model of care delivery is more congruent with

Aboriginal values of holistic healing, looking at spiritual, emotional, and mental as well as physical aspects of health.

Many patients tell healthcare workers they understand something when they do not, simply out of social embarrassment (Cole & Bird, 2000). Medical staff cannot be sure the patient understands unless they check in a positive non-threatening way. To teach future physicians how to handle this situation better, the medical school at the University of Manitoba has a communication program for first year students. They are teaching students to assume that patients do not understand all the information given to them and to make the patients feel at ease about asking questions (G. Schnabel, personal communication, July 2000). Students are taught to tell patients some variation of: "What I have said to you can be difficult to understand and I could explain it again to you another way if you want." This approach normalizes *not understanding* with a non-threatening statement and will make most patients more comfortable to ask more questions.

What a patient will understand about information relayed is unpredictable. A possible way to determine what a person understands is to ask the patient to explain what the caregiver said in the patient's own words, as described in a patient brochure on doctor-patient communication (Health Canada, 1999). This brochure was part of a national campaign to improve doctor-patient communication especially for cancer patients who often feel overwhelmed after their encounters with physicians, although they speak the same language. This brochure also instructs patients "if you do not understand, say so (Health Canada, 1999)." Non-English speaking patients should also be asked to describe what they understood through an interpreter, to ensure translation and cultural understandings are congruent with the physician's explanation (Kaufert & O'Neil, 1989).

Training in health care equips workers with a new medical language that separates them from lay people. Hospital personnel use this new language with complex terminology and create an information barrier. This medical *jargon* is especially problematic with less experienced patients or for those who speak English as a second language. The Canadian Public Health Association has a program to address this issue, particularly when literacy is a problem (Canadian Public Health Association, 1999). Their campaign aims to teach physicians to use 'Plain Words' to communicate with patients and to provide plain language health information.

Communication problems can occur even when patients and healers use the same language and disease terms because of the different meanings each hold for these terms. Patients may use the same terms but have a very different understanding of the disease process and may not understand fully the medical terminology. A patient's understanding and expectations regarding his illness and its treatment is described as the patient's explanatory model (Katon & Kleinman, 1978). Patients' interpretations of their medical illnesses seek to unify their symptoms with their lives, not like clinical explanations (Williams & Wood, 1986). The physician's understanding of a patient's problem can improve by asking about the patient's interpretation of their illness or explanatory model. The patient's social, occupational and family circumstances all influence their illness. Deducing the entire picture of the patient's illness can make a physician more effective (Veith, 1949/72).

Medical interpreters are needed to assist patients who do not speak English. Medical interpreters need training in medical terminology to ensure they understand the hospital staff. They must have a thorough understanding of the cultural perspective of the disease process, as well as the medical concepts (Kaufert, Lavallee, Koolage, O'Neil, 1996). Using medical interpreters may introduce into the clinician-patient interaction a third personal explanatory framework, which may be different from the other two parties involved.

Foreign accents in English can be problematic even for Aboriginal patients who grew up speaking English. The shortages of professional health care workers in Manitoba have necessitated recruiting nursing staff from the Philippines (R. Cloutier, personal communication, February 27, 2000). Physician shortages have increased recruitment of graduates from South Africa and other commonwealth countries to work in under-serviced areas that tend to have large Aboriginal populations. The importation of health care professionals creates even greater distances between the culture of the workers and the Aboriginal patients. Nurses and physicians from overseas may be less informed of the socio-political history and current situation of Aboriginal people. Ninety percent of the Northern Medical Unit physicians staffing the two federal hospitals in Manitoba at this time are foreign trained. As Medical Program Coordinator for the Unit, I deal with patient complaints in these communities. The complaints are often communication problems between patients and physicians; some are cross-cultural issues.

A more thorough ward orientation for patients on admission could prevent some problems for those who are unfamiliar with the hospital system. Uncertainty about the hospital routines and lack of access to information regarding services is part of the depersonalization felt by some inpatients (as described in 1.2.4). Difficulty accessing physicians to ask questions and confusion over the numbers of health care workers and students involved in one's care in a teaching hospital are also disempowering. Patients hospitalized in rural hospitals after urban hospitalizations often have commented on how the care is much more personal.

3.2.2 Patient Perceptions of Family and Visitor Involvement:

> To be poor in the Indian world is to be without relatives (Henderson & Primeaux, 1981: 242)

Family and visitor involvement in the patient's hospitalization was an issue of importance to the key informants. One key informant stressed the need to inquire whether the patient wanted their family or someone else to be more involved in their care. We also wanted to ask patients if their visiting family had had any concerns with their care or other problems at the hospital as problems were noted in the 1992 report (Aboriginal Services Review Committee, 1992).

Many respondents stated their families were involved in their care; some wanted even more involvement to prepare for their up-coming discharge. Older respondents voiced this more often. When asked what visitors thought of her care, an older respondent interviewed with her daughter stated:

> Respondent: Not too bad I guess. Whatever the nurses do not do she does.
>
> Interviewer: Do you think the nurses should be doing more?
>
> Daughter: Some of them. I have to look after her at home; I have to know that experience, so I don't mind (E).

The daughter went on, denying any concerns:

> Nothing, no but now their visitors can be more involved in her care, they do not hold back information.

Another respondent felt her family was interfering:

> My daughter is very fast in commenting. She was going to phone my doctor and I said "No, you are not. I'm the one that goes there [to see him], not you." She wants to criticize him. I'm the one that goes there. She should not be so fast to blurt something out (V).

Concerns regarding visitors were explored. There were complaints from rehabilitation patients who may be hospitalized for months. Hospital staff sometime frown upon visiting outside of the allowed hours. A rehabilitation patient interviewed in Ojibway stated:

> The only thing is ... the only thing is visiting hours, so early. They should change it up to 10:30 (O5).

Another complained, having missed his visitors:

> One thing though, you don't get your messages from your visitors (Q).

The rehabilitation patients were often off the wards at physiotherapy or occupational therapy sessions. They may have gone to smoke or to socialize with other patients. Missing visitors or messages could be more upsetting for longer stay patients.

Another respondent described a situation:

> At one point, there were four people here. One of the nurses said only two people at a time are allowed here and my daughter said we are from out of town and we should be able to visit whenever and the nurse agreed. She didn't argue with that (O).

This demonstration of flexibility and appreciation of the individual patient's family and life circumstance helps avoid unnecessary conflicts that can occur with over-zealous enforcement of visitor hour restrictions. Northern family members who travel to be with a patient in Winnipeg can incur great expense.

Another important issue was access to information for the patient's family:

> Sometimes she just gets really upset because they won't tell her anything. She says " I'm right here. Why won't you tell me anything?" She got really upset because she is next of kin and they won't tell her anything. Nobody tells me anything (R).

The respondent's spouse was visiting from their remote community. Although she was available when the staff came around, her desire for more information was not heeded.

Some remote residents expressed frustration with the inability to involve family in their care from a distance. Out-of-town patients often lacked funds and some even admitted not knowing how to telephone their family while in hospital because of the charges.

Respondents from out-of-town voiced complaints of separation and loneliness more often. An older rural respondent thought that urban Aboriginal people could "have something for the (out-of-town) patients" who often feel isolated when in the hospital. In fact, the hospital does have some Aboriginal volunteers, but they may not be able to visit all the Aboriginal inpatients.

3.2.2.1 Discussion of Patient Perceptions of Family and Visitor Involvement

Patients desire family involvement during their hospitalization and this is especially beneficial in these times of early discharge of patients to convalesce at home. Aboriginal culture emphasizes the importance of the extended family. Aboriginal patients are often visited by large groups of family members. Hospital staff denying access to visitors because of a facility policy has created problems in the past (Kaufert, 1999). Rigid enforcement of visitor hours can be frustrating for anyone when a family member is sick.

The hospital's cultural awareness workshops try to increase the sensitivity of staff to Aboriginal culture values, including the importance of family. Some Aboriginal people have a different concept of use of time from Euro-Canadians and prefer to do things 'when the time is right' (Brant, 1990). The wards are not well suited to large groups of family and other visitors. The staff of the Aboriginal Services Department will arrange to provide space for large families to congregate. The department's elder is available to provide healing ceremonies for the patient and family in a designated room.

For the patients from out-of-town, the financial costs for family members to visit from remote areas can be prohibitive. Anyone who has incurred travel expenses to visit a hospitalized relative might complain about visitor restrictions. In this study, 57% of the 28 participants were from remote areas (11 English interviewees and 5 Ojibway interviewees), and 21% were from rural areas (6 English interviewees). Recent research showed at least 60% of First Nation patients on medical, surgical and rehabilitation wards at this hospital are from rural and remote communities far from Winnipeg (Riese, Orr, Nicolle & Cheang, 2000). For family members unable to come to the city, the hospital has been able to organize video teleconferencing with some communities in the past.

All families want access to information regarding the maladies of their sick relatives. The 1999 Personal Health Information Act in Manitoba may cause increasing difficulty for families to obtain information (Health Sciences Centre, 1999). Unless family members are with the patient when information is being relayed, the new privacy policies in health institutions may make obtaining information more difficult. In the past, Aboriginal leaders have been known to contact hospitals and physicians, on behalf of families to obtain missing information or to intervene for further services.

3.2.3 Patient Perceptions of Involvement in Discharge Planning:

Involvement of the patient and their family in discharge planning was explored in this study. Patients often stated that they had no idea what the plans were for the remainder of their admission or for discharge. Interviews for this study could not always be arranged close to the discharge of the patients. More information might have been available to some of the patients later in their stay. One wheelchair bound patient fought to delay his discharge:

> I had to get the doctor to understand I had nobody to look after me. It was a good thing I understood English, or else, they would have discharged me (P2).

The respondent implied that if he was not fluent in English, he might have misunderstood the immediacy of his (untimely) discharge, illustrating what could happen to other patients. He went on to say:

> Especially when you're very weak ... they don't keep you in the hospital for that long anymore, they haven't any orderlies to help on the reserves. Maybe that's what they should have on the reserve - some home care (P2).

Another respondent said he was involved in the planning of his discharge:

> To some degree, yes (I am involved) ... but I think they should let me know about my medication. I really don't get told any of that (B).

Some other respondents stated they had been involved in their discharge planning. Discharge case conferences are more common for rehabilitation or other patients in the hospital with complex needs. We asked all patients who had responded that they were involved in their discharge planning whether they felt the plans were appropriate for where they lived. Most answered in the affirmative. Some northerners had relocated to Winnipeg in the past because of the complexity of their medical problems and follow-up. Others stated they planned to stay in the city with relatives.

The rural respondent quoted above had concerns regarding newly confined wheelchair patients. He knew from the past that some non-urban patients had been discharged with wheelchairs equipped with only small diameter tires. People from rural and remote communities generally require large diameter wheels for their wheelchair because of road conditions. The respondent was aware that rehabilitation patients were not always informed of issues regarding wheelchair repair:

> They have a problem with wheelchairs, especially in the isolated reserves. I don't know how much funds are available now. But, I know [about the funding] from years ago when I was first in my wheelchair. If anything went wrong with it, they had to wait a whole month before they could use [the chair] again. There were no spare ones. That's like being without legs for a whole month! Even if they didn't have a spare wheelchair at least they could have one spare wheel (P2).

He felt the lack of awareness regarding the different sources of funding for various medical needs caused unnecessary problems:

> I was working so I have an insurance plan. That's another thing ... Aboriginal people don't know that there is insurance available, especially if they are working. These insurance plans also have funds for equipment to make you independent at work. A lot of them didn't realize that the heritage [sic] association will come to your work, or your house and make it wheelchair accessible (P2).

3.2.3.1 Discussion of Patient Perceptions of Involvement in Discharge Planning

Some urban health care workers have little insight into the realities of northern living, from lack of infrastructure to lack of health services. The Winnipeg hospital system has become known for having 'perimeter-itis', not appreciating the differences in availability of outpatient or community supports beyond the city limits. Health care providers in rural communities complain patients have been discharged home with little or no communication from the Health Sciences Centre (Leskiw et al, 1998). Urban workers often lack sufficient understanding of rural patients' home situation to consider the limited community conditions and local health care capacities.

Isolated Aboriginal and Inuit communities often lack paved roads and most have no sidewalks. Poor overcrowded houses exist and some have no running water or indoor toilets. There is a limited variety of goods available at the local stores. Health care services often consist of an understaffed nursing station, physician services only on an itinerant basis, and little or no homecare nursing. Some communities are developing newly funded homecare programs (Cochrane, 2000). Rehabilitation services are itinerant or do not exist at all. The organization of specialized medical supplies should occur before patients leave the city, as they may not be available locally and ordering supplies from the city takes time. Northern patients who do require outpatient services, such as physiotherapy or homecare, can stay at boarding homes in the city. Patients staying at boarding homes may receive homecare services as any Winnipeg resident.

Many wards at the Health Sciences Centre have large wall maps of the province of Manitoba with rural townships and First Nation communities marked on them. These could help orient the staff to the location where patients live, and issues of distance and remoteness. The cultural awareness workshops try to cover issues of lack of infrastructure in remote communities, which would also affect non-Aboriginal patients living in these areas.

Urban Aboriginal people have more outpatient health services available than do rural and remote residents. In practice, their use of services are sometimes inconsistent and inadequate (Waldram, 1995; Gudmundson, 1993). High levels of poverty and lack of experience and education make negotiating the complex urban health care system challenging. Ward staff must not make assumptions about a patient's knowledge about the system or abilities for self-care without adequate exploration of the individual patient's situation.

The hospital initially had only one discharge planning nurse, but since 1997 there has been a second part-time discharge planning nurse who is part of the Aboriginal Services Department. This Aboriginal nurse assists the ward staff and physicians to arrange complex discharges. She works with the ward case-managers to see that supplies, services, and information are organized and prepared before discharge of the patients from the hospital. Her role, and that of the interpreter caseworkers, is to advocate on behalf of patients, assisting healthcare workers to understand the patient's home situation.

In the current economic situation in health care, there are increasing demands for families to provide care after early discharges. Especially when patients are discharged early to convalesce at home, the family must be aware of factors affecting their care. Information provided should be in a form that is understandable and acceptable to the family. Bull (1994) found that effective communication was critical for quality discharge planning and consistent information from all health care workers is necessary. More recently, Bull (2000) advises that communication regarding discharge-planning goes beyond giving out information. Information must be delivered in a culturally sensitive way and be responsive to the different literacy levels of patients. Practitioners must allow for negotiation with families and patients about the prescribed treatment to avoid conflicts with their values and beliefs (Anderson, 1986).

Respondents with previous hospitalizations were more knowledgeable about the health care system and their rights to access their own health information. Some rehabilitation respondents with years of repeated and often prolonged hospitalizations voiced concerns that new wheelchair-bound patients would have to struggle as they had done lacking sufficient information. Patients and their families adjusting to non-ambulatory status may have been overwhelmed with the amount of new information given to them in a stressful time. Cleary et al (1991) state that if patients do not remember being given information, then communication has failed, regardless what the patient was told.

Treaty status patients are entitled to coverage of medication or medical supplies through the federal 'Non-insured health benefits' program; non-registered patients who are not working would have some coverage of medical needs by provincial income assistance. Patients with less experience rely on the ward staff and interpreter caseworkers to inform them of these issues.

3.2.4 Patient Perceptions of Respect and Racism:

Key informants suggested that questions should probe for issues of perceived racism or lack of respect, given the history of discrimination at the hospital. Generally, people responded positively when asked whether they felt they had been treated with respect. Only one respondent from the rehabilitation ward commented otherwise about this aspect of care:

> Kind of like Rodney Dangerfield " You get no respect." The old nurses are really cranky; the younger ones are pretty good (Q).

A few respondents described a not infrequent situation at a teaching hospital. Hospital physicians use individual inpatients to teach students about clinical examination and care of medical diseases. One respondent annoyed with being 'spoken about' by medical people involved in teaching rounds stated:

> Just to talk to me more and more, instead of them just talking around me. I know there are a bunch of students and that, but I don't really appreciate him. Just that one doctor, I never really did from day one. He is so rude to the nurses and everyone. He's really ignorant, I kinda tell him myself .... I just want to know more about what's going to happen to me and (for them) to fill me in more often (J).

Another example of this:

> Well yesterday, there was two doctors and nurse that came to see me and they were scratching away and they were talking amongst themselves. I says (sic) "what to you think it is?" and they were talking amongst themselves. The three of them looked at me and I said "are you guys just guessing?" (C)

Discussion about a patient, in front of the patient but not with them as a participant in the information sharing, is rude and disrespectful. This is an example of the depersonalization that patients experience in hospitals.

We specifically asked whether patients ever felt they were treated differently because they were Aboriginal. We asked those who denied any difference in their treatment if they saw other Aboriginal people mistreated. Many respondents commented that all people were treated the same on their wards. A rehabilitation respondent denied differential treatment:

> No, she treats everyone like that, I know for a fact. Everyone is treated the same way (Q).

The treatment may have been less than satisfactory, but the respondent felt it was consistent with the way others were treated. Other rehabilitation respondents stated that their ward treated patients all the same way. However, they felt that on the general hospital wards, in particular surgical wards, the staff did not always treat

Aboriginal people as equals.

> Some of the staff wouldn't talk to me. I told them " I don't know why you guys treat me differently, because I'm Native." I told them (S).

In our sample, respondents with previous hospitalization experiences had no greater likelihood of perceiving racism, though some individuals observed discrimination during more than one hospitalization:

> Respondent: Just recently ... on my last visit [to the emergency room] one of the nurses just said "Mr. X - *not you again* [italics added]." I said "I heard what you said and what you did was wrong." And the doctor came in later and said "now that you made enough noise and you have everybody's attention what would you like?" I turned around and said "why don't you get rid of your god-complex and go away until you can come back with a better bed side manner. I'm the one who is sick here." ... I do understand how busy emergency is.
>
> Interviewer: Do you think you were treated like this because you are Aboriginal?
>
> Respondent: I think I am being treated like this because I am Aboriginal and mixed [black] as well. I have seen people being wheeled in and there has been times I have sitting out there for 6-8 hours in the emergency room (B).

Many respondents reported no differences in how they were treated. While questioning patients about communication problems, a few respondents had suggested that people who do not speak English (or do not comprehend it well) were treated differently.

> I think people who can't talk for themselves get treated different (P3).

Older respondents related less dissatisfaction, reporting differential treatment less often than younger respondents. One explanation for this point of view is explained:

> 15 years ago I was treated as a nobody but now it is different. Nurses and doctors used to treat Indians differently. When I wanted something or requested something they treated me as if they didn't even hear anything. There is no racism involved anymore... I was in the Grace hospital about 20 years ago and you were treated like you were second class (P).

This shocking statement reveals the ways of the past, which make the current situation appear more positive in contrast. However, an elderly woman had a different experience when asked if she ever felt she was treated differently:

> I don't know, you're in the room with all Natives and some of the nurses don't even want to touch you because you are an Indian. And some patients want to get out of here because we were all Natives. *That did not bother me* [italics added] (E).

This older woman shows how resilient Aboriginal people have had to be, enduring racist behaviors and attitudes. Another respondent stated:

> Yes, in a lot of ways, a lot of these people that work here don't even want to deal with you (U).

A rehabilitation respondent described an incident on another ward where the nurses did not heed his calls for help. They did not believe his complaint that his back was burning from the heat of a hot water bottle, possibly because of his neurological disease. He had to endure the burning sensation and later the treatments for his skin burn afterward as he was too disabled to remove the bottle himself. His family was very upset with this neglect, and they perceived racism was the cause.

Another respondent whom we interviewed in Ojibway felt that the other patients in his room had received surgery before him because they were Caucasian. The reasons for other patients having their surgery before his could be multifold (e.g. their physical condition may have been more favorable than his condition). However, for a patient whose procedure or appointment is delayed, it is disconcerting to see others not waiting as long. Patients may wonder about explanations for the differences in service, and some may perceive discriminatory treatment.

A young woman stated that she felt comfortable at the Health Sciences Centre because of the high number of Aboriginal patients. Some Aboriginal patients were pleased that we were inquiring about problems for Aboriginal people and were willing to listen to their concerns:

> I wanted ... I always wanted to tell something like this to... like we're doing right now (O5).

They were not sure how things could be improved:

> I don't know how you are going to accomplish anything here because you have to be in the ward all the time (P2).

3.2.4.1 Discussion of Patient Perceptions of Respect and Racism

The examples of poor bedside manner with medical people talking over patients are disturbing. The medical staff is guilty of objectifying patients as a diseased entity for discussion on their rounds. All patients desire personalized care that respects all aspects of a person, physical, mental, spiritual, and emotional health. The depersonalized disease-centered approach is the antithesis to the holistic view of health. Foucault described this medicalization of people and their problems as part of the 'clinical gaze' (Foucault, 1994).

Conflicts over cultural differences like the situations described by patients above are not new for health institutions in Manitoba (see Kaufert, Koolage, Kaufert & O'Neil, 1984; Hall, 1981). The perception of systemic racism and individual discrimination at the Health Sciences Centre was identified in the Report of the

Aboriginal Services Review Committee (1992) and was described previously in section 3.1.1 Early Native Services at the Health Sciences Centre. Systemic racism refers to hospital policies that systematically repress or disregard Aboriginal people, such as non-acceptance of Aboriginal values and ceremonies in the past. Individual discrimination refers to behaviors or attitudes of people based on ignorance.

Cultural differences are magnified by inappropriate perceptions that Western values are superior to other cultures, by personality conflicts, and by ignorance of other cultures (Ellerby, 1999). Ethno-centricity, when someone interprets the behavior of another person from a different culture, assuming it is based on the same values, leads to misinterpretations, labeling and miscommunication (Sanchez, Plawecki & Plawecki, 1996). Health care workers need to avoid this ethnocentric professional-model to be opened to patients' explanatory models (Waxler-Morrison, 1990). O'Neil found communication problems between Inuit patients and healthcare workers were often based on inappropriate assumptions on the part of southerners (1989). Establishing rapport and trust between health care workers and Aboriginal people can be difficult, as false assumptions and inappropriate behaviors on the part of non-Aboriginal workers can result in perceptions of racism by Aboriginal people.

The Aboriginal Service Department's interpreter-caseworkers assist Aboriginal patients and ward staff to resolve cross-cultural conflicts. Preferably they would become involved with orienting Aboriginal patients on admission and thereby would prevent some misconceptions that cause these forms of cross-cultural conflicts. In an ideal situation, the ward staff would be culturally competent and would not need the services of the Aboriginal Services Department.

The hospital has had cultural awareness workshops for staff since 1996 to address past problems of racism and insensitivity to Aboriginal values. The

University of Manitoba medical school is also addressing the need for cultural sensitivity. In the first-year curriculum of the medical school, Aboriginal elders introduce medical students to traditional ceremonies and values. Professors use case studies of past cross-cultural conflicts at the urban hospitals to teach cross-cultural communication to medical students, also reviewing the impact of socio-political factors (Kaufert, Koolage, Kaufert & O'Neil, 1984). It is assumed that future graduating medical students will have an increased sensitivity to difficulties of Aboriginal peoples, though they may need access to the ongoing workshops to reinforce previous teachings.

The evaluation of the Aboriginal Cultural Awareness training program in 1998 found fewer complaints of racism from Aboriginal staff, though focus group participants cautioned that some of the behaviors might have gone underground (Leskiw et al, 1998). Prejudice amongst the patient population is beyond the control of the hospital. However, a mixture of cultures in both the workforce and patient population will help normalize diversity. Keeping patients of Aboriginal culture in separate rooms from non-Aboriginal patients continues social isolation, reinforcing the different perspectives and realities of each culture (Dreachslin, Hunt & Sprainer, 2000). "Fewer occasions for interaction due to social isolation results in diminished opportunities to develop shared beliefs and a common social reality across racial groups (2000:1410)."

When health care workers and patients are from the same ethnic group, there are still class and personal differences so generalizations and assumptions can be dangerous (Katon & Kleinman, 1978; Kaufert and Putsch, 1997). Kaufert and Putsch describe the distance between physicians and patients (even when the patient is a physician) as a gap greater than that between any two ethnic groups. All patients are disempowered as they are reliant on others with knowledge and control.

Young Aboriginal people may perceive racism in the current hospital situation more often than would older patients. Older patients who have past personal experience of extremes of discrimination may feel the current situation looks good. Young people in general may voice dissatisfaction and may perceive racism more often (Brant, 1990; Longclaws, 1996).

The reporting of stories of differential care as Aboriginals did not seem to vary with the presence or absence of the Caucasian researcher present (I was absent for five interviews in English and the interviews in Ojibway). The numbers are too small to be significant. I met all interviewees, and all were informed of my participation in the study, so comments regarding racism may have been limited. Most of the interviews of inpatients were done without a chance to establish trusting relationships over a period of time. Thus comments may have been limited regardless of the writer not being Aboriginal (see discussion in section 2.8 Data Trustworthiness).

3.2.5 Aboriginal Services Department Involvement:

All respondents were asked whether the Aboriginal Services Department had been involved in their care. Many respondents had not heard of the department, when asked if an interpreter-caseworker was involved in their care. Some respondents referred to the interpreter caseworkers only as interpreters for people who do not speak English. Some did not seem to know that the service they had received was from the department's interpreter-caseworkers:

> No, I still don't know what you mean [by the Aboriginal Services Department]. There is a native guy that comes here once in awhile. ...

> He works on getting help for my family, he got paid from the government. They have had some success with that. He paid for their room here in town and everything (R).

Another respondent was seeking help from the department:

> No, I was trying to get a hold of them, I went to Native Services to get some help. I asked that guy to send some stuff, but I never heard anything yet. My family doesn't know that I'm here. No, I don't know who is involved right now. I was trying to get my home town to get me some stuff (F)

At the time of the interview, some remembered being visited at least once during their hospitalization. One northern respondent indicated he had asked the nurses to contact the staff:

> I took advantage of the Cree interpreter to help me get around. [The nurses] asked why I needed an interpreter... but I did not want to get lost here (P4).

Previous quotes revealed problems that may have been avoided with the involvement of the interpreter-caseworkers. Few English-speaking respondents received advocacy services from the department. The five respondents whom we interviewed in Ojibway had the assistance of the interpreter-caseworkers. One bilingual respondent stated in Ojibway:

> Yes, They come to see if I have any problems. Their job is to interpret but they are involved (O2).

Some respondents were helped with financial and family support services by the caseworkers, but no one described this as one of the department's functions. A northern respondent who worked in the health-field felt that financial barriers associated with being hospitalized out of town were major concerns for people from remote areas. Urban respondents did not mention financial problems with hospitalization, but northern respondents brought up this topic repeatedly, especially when family and visitor involvement was discussed. Some respondents had be assisted by the Aboriginal Services Department staff to obtain needed supplies, or help for their family to be able to visit in Winnipeg.

3.2.5.1 Discussion of Involvement of Aboriginal Department

From these stories, patients and hospital staff do not appear to be aware of the broad service mandate of the Aboriginal Services Department's staff. The interpreter caseworkers try to assist patients in any way possible. Cross-cultural advocacy and discharge planning services were discussed in the previous sections. Interpreter caseworkers often need to advocate on behalf of the patient alerting the health care worker to the realities of the patient's life and put the patient's story into proper context. The interpreters' role is described as middleman or cultural broker, informing health workers about Aboriginal culture and the patient's community (Kaufert and Koolage, 1984).

Interpreters and other Aboriginal health care workers gain an elite status among their community members. The research assistant in this study had previously heard complaints that some Aboriginal employees at the Health Sciences Centre were felt to have taken on part of the 'culture' of the institution. At the same time, other Aboriginal people inside or outside the hospital system might question the interpreter-caseworkers' loyalty to the patient versus the work place (Kaufert & Koolage, 1984). Outside agencies may call to advocate for the patient and want the caseworkers to work harder on behalf of the patient, even in opposition to the system that employs them (L. Longclaws, personal communication, February 18, 1997). Their job as advocates puts them in conflict between helping the patient cope in the system and helping the system relate to the patient.

To address financial problems of the patients, the Aboriginal Services Department holds fundraising events periodically and collects donations of clothing. They often communicate with home communities on behalf of patients or family for financial assistance and other supports. They provide cultural and emotional support to many patients.

3.2.6 General Satisfaction:

Discussions about hospital care brought up many concerns and desires. Many respondents described the overall care as acceptable or voiced concerns. When asked what the hospital could do to improve their stay, few would identify what would help make their stay better. Some respondents commented on the 'house-keeping' aspects of the hospital, including suggestions of bigger rooms, free telephone calls and:

> I don't know. They could provide some black and white TV for us instead of color TV for the rich people. Basically, it is okay. They make you feel like you are at home (F).

We asked respondents who had previous admissions if they had noticed any changes at the hospital. Some noted a decrease in staffing compared to the past. The loss of choice of meals was cited as unsatisfactory, especially for the long stay patients on rehabilitation. Respondents also spoke of the 'No smoking' policy. Some wards had staff or volunteers accompany patients outside to smoke. On the rehabilitation ward, assistance to go outside is not always available. Even disabled patients must go outdoors to smoke in any weather.

3.2.7 Main Themes: Control and Endurance:

The main themes identified when analyzing the patient interview material were *control* and *endurance*. Grounded theory techniques were used to analyze the interview data. The material was categorized - initially by descriptive, then interpretative, and lastly analytical categories, with these two main themes emerging (Strauss & Corbin, 1990). I will discuss each of these two themes separately. There is much overlap between these themes as when people perceive they are not in control of a situation, they feel they are being subjected to someone else's control, and have to endure that loss of power.

3.2.7.1 Control

Aboriginal inpatients described many situations regarding control issues in the hospital. The theme of control refers to a continuum from lack of control to maintaining a sense of control in a situation. Many patients cited problems accessing information and described situations of feeling out of control. Responding to our question regarding how his care might be improved, a respondent stated:

> Just to know more about what's going to happen to me and to fill me in more often (R).

Many respondents expressed concern that other Aboriginal patients told the ward staff they understood what the staff said; when these observers felt the other patients had not understood the information. Perhaps the other patients were trying to prevent the ward staff from sensing their lack of understanding in order to 'save face'. This may have given the patient a sense of control over the immediate situation when in fact they had not understand the information, and later would feel less in control. A previous quote summed up this situation:

> And we say we understand the white people but a lot of the time we don't. *I'm afraid to ask. We're being looked down upon* [italics added] (T).

He describes a sense of powerlessness as an Aboriginal patient in a Western institution. The feeling of lack of control from lack of information sharing could increase patients' perceptions of racism, if they perceive that other non-Aboriginal patients receive better communication. Another respondent noted changes at the hospital, which would have affected his sense of control:

> Health Sciences has more patients now so they don't have as much time. You don't get the opportunity to get to know the nurses. Don't get a chance to ask questions (P4).

Patients would feel less in control and less able to participate in their care when they do not have a chance to interact with familiar ward staff and develop trust. The respondent's statement implies that in the past there were more nurses per patient and one could become more acquainted with the staff. Another respondent was bilingual and did his interview in Ojibway. He demonstrated his knowledge of bureaucracies and his ability to express himself in English:

> Yes, I speak for myself. If I see something not right, I don't bother the nurses. I go speak directly to their bosses. That's if I see something. I know nurses just work here and they have bosses. They're not their own bosses- they have someone they work for. That's how jobs are (O2).

The patient was able to use his knowledge to maintain control of his care.

Patients' inability to access information could contribute to their perceptions of vulnerability and racist treatment. Vulnerability for these inpatients is "related to an *inability to retain control* [italics added] of life situations and or protect themselves against threats to their integrity (physical and emotional wholeness, intactness) (Irurita, 1999)." The Aboriginal Services Department caseworkers support and empower patients. Some patients appeared unaware of this support service. In addition, some patients who were involved with the service were unsure how to reach the interpreter-caseworkers. Patients' control of their situation in the hospital was decreased by inaccessible advocacy services designed to empower the patients!

3.2.7.2 Endurance

Respondents suggested the need and the ability of Aboriginal patients to endure situations. In this study, respondents described how they endured problems and even helped each other endure the hospitalization experience.

> I know there have been some problems with Aboriginal people that can't speak very good English. *We have a lot of problems here you know!* [italics added] I always offer to help when I see people don't understand what they are trying to say when the nurses or doctors are talking (T).

Another respondent previously quoted under the section on Respect and Racism described how a non-Aboriginal nurse seemed reluctant to touch her as an Aboriginal person. In addition, she felt that non-Aboriginal patients were reluctant to share a room with Aboriginal patients. She ended her statement with "That did not bother me." Her final words show her ability to endure differential behavior without allowing herself to feel disempowered.

Respondents described how they endured a great deal of waiting:

> Not really. No. The only comment I have about the hospital is that when you need them they don't come. Sometimes you wait 20-25

> minutes for someone to come (E).

Respondents commented on waiting for information, waiting for pain medication, or waiting for other assistance. The patients' uncertainty while waiting to have their expectations fulfilled would increase their sense of vulnerability. Patients may feel less important when they are waiting. One handicapped respondent reported he had endured a skin burn in the hospital in the past while waiting for someone to heed his calls for help to remove a very hot water bottle.

A teenager expressed anger at the nurses. Unaware of the other demands on the ward, the respondent perceived the nurses had deliberately made her endure the pain longer:

> ... I asked the nurse for some Tylenol because my leg was hurting and I had to wait 20 minutes to half an hour. Nobody came. So I went to ask them again. They said I had to talk to my nurse. So I took off, because they never came back (C).

She had eloped from the hospital, as she was fed up with waiting on the ward. Friends had convinced her to return, as her diagnosis was serious. Afterwards she found the nurses came in to her room often "just to make sure I won't take off" and they offered her something for the pain more often. Her visitors had expressed concern about how long she had waited for assistance.

One respondent suggested that waiting was related to cutbacks:

> At the Health Sciences Centre, there aren't as much nurses on the ward. You almost have to have your family there to look after you (P2).

Patients are following the hospital's 'No Smoking' policy. On the rehabilitation ward, patients in wheelchairs and even on self-propelled stretchers also must go outdoors to smoke in any weather and face a core area street. A respondent described worrying about his own and other patients' safety:

> Now you're almost scared to go outside the hospital. There are a lot of drunks on the street. Someone almost got mugged one time (Q).

He had witnessed another patient being harassed, while he was outside on a self-propelled stretcher. He was unable to intervene on her behalf. He felt the 'No Smoking' policy should allow smoking in the courtyard of the Rehabilitation Hospital. This would protect patients from having to endure unwanted attention from other people as well as poor weather conditions out on the street. This courtyard is currently a 'No smoking' area.

An incredible and hopefully uncommon example of endurance and lack of control was the uni-lingual Ojibway patient who had not spoken to anyone in his language for four days, since admission. He was physically better and had no idea why he was still in the hospital. The respondent told the researchers that he preferred to go to "the Anishinaabe hospital" rather than to be at this hospital. The Health Sciences Centre usually has many Aboriginal patients and visitors, and may be "the Anishinaabe hospital" to which he was referring. Possibly he had not interacted with other Aboriginal people that weekend on his ward, and so he thought that he in a different hospital.

His language handicap was worsened by lack of support services on the long weekend and his lack of familiarity with Winnipeg. The respondent had endured a lack of real communication, with resulting lack of informed consent. He was unable to leave the hospital due to his vulnerability, being unable to communicate. His wife was hospitalized at another city hospital which never has Aboriginal services, and she was unable make contact also. These two individuals had no control regarding events in their hospitalizations. The research associate was able to interpret and we intervened on his behalf.

These are some examples of control and endurance issues found in this research. The previous sections on communication, family involvement, discharge planning, and racism cited concerns that overlap with these overall themes of control and endurance, which is how these themes developed.

Many of the problems experienced by the Aboriginal participants could happen to any patient in the hospital. Patients are often disempowered in the culture of large hospitals. Members of minority groups may encounter racist attitudes. Patients with repeated hospitalizations more often denied being treated differently from others. This may be related to their experience with the hospital system. Patients' perceptions of having to endure racism may relate to their past experiences (Kravitz, 1996) as well as their sense of control of a situation. Aboriginal people have historically been disempowered by mainstream society in Canada (O'Neil, 1989; York, 1990).

One of the key informants reviewing the results of this project sent me the following statement:

> We will continue to accept racism as our way of life. And we are teaching our children to be strong and "walk with your heads up and stick together."

She warned me that Aboriginal patients would not have given us their whole story as they do not trust the non-Aboriginal people because of the past and:

> (We) need to keep it to ourselves, otherwise we will not have anything left, to ourselves. The non-Aboriginal has taken everything from us. We need to do this to maintain some dignity.

These last two statements reflect the themes of control and endurance.

CHAPTER 4

CONCLUSION

In this section, I will first summarize the study results and compare the interview findings to the literature, and discuss the study limitations. Following this, possible future research to overcome these limitations and address other areas of concern will be suggested. I will conclude with recommendations to address the issues identified in this research.

This study examined Aboriginal patients' perception of care at the Health Sciences Centre through qualitative methods. Using case study methods, I reviewed the history of inpatient services for Aboriginal patients since Native Services started in 1971. I followed the recommendations of a 1992 report exploring Aboriginal employment in the hospital system, the involvement of Aboriginal people in governance and the evolution of the hospital's cultural awareness workshops. Finally I examined the current services at the HSC and the plan of the new Winnipeg Regional Health Authority for services to Aboriginal people.

This review of services provided a background for semi-structured interviews with Aboriginal inpatients regarding their satisfaction with their care. In this study, a patient interview tool was developed with five Aboriginal key informants interviewed separately. Their recommendations were directed towards exploring patient concerns in the areas of communication, family involvement, discharge planning, racism and involvement of the caseworkers from the Aboriginal Services Department in patients' care. Any changes in the hospital care noted by patients since previous admissions and suggestions to improve the care were sought. An Ojibway-speaking research assistant and I completed twenty-three interviews in English and five interviews in Ojibway with medical, surgical and rehabilitation patients who fit the participation criteria. These two languages were used to be able to compare English responses with those of people who were still able to speak their native language. The interview material was analyzed for important themes using grounded theory techniques (Strauss & Corbin, 1990).

The main themes identified in the patient interviews were control and endurance. Patients described a range of control issues; from situations where they felt they had little control regarding what was happening to them, to other events when they felt that they were in control. A common concern related to lack of control was the lack of patient involvement in their inpatient care and planning for their discharge. Poor patient access to information about their care including poor information sharing about the advocacy services of the Aboriginal Services Department contributed to the theme of lack of control. More experienced patients understood the medical system and could speak for themselves. Patient control and autonomy have been related to increased patient satisfaction in the literature (Butler et al, 1996; Carr-Hill, 1992). Patients who feel they are able to control events may have enhanced motivation to participate in the proposed treatment (Butler et al, 1996: Laine & Davidoff, 1996).

Patients described issues of endurance, related to perceived differential or disrespectful treatment, insufficient communication and waiting. They described their difficulties as inpatients and their ability to cope. Many patients expressed concern for others who did not speak English well and who would likely have to tolerate uncertainty about their care. Other significant problems endured by patients were the lack of emotional support and separation from family and community. As suggested in the literature, patients with more experience and knowledge about their rights as hospital patients reported enduring fewer problems (Sitzia & Wood, 1997; Webb et al, 1999; Williams et al, 1995; Nelson, 1990).

Communication problems identified were often related to insufficient sharing of information with patients and their families about their medical problems, treatment and discharge plans. These findings are consistent with general research in patient satisfaction: improved communication allows for increased patient participation and increases their satisfaction (Stewart, 1995; Golin et al, 1996; Speedling & Rose, 1995; DiMatteo, 1994; Brody, 1980; Hayes-Bautista, 1976; Laine & Davidoff, 1996). Unfulfilled expectations of sharing information can contribute to patient dissatisfaction. Many patients denied communication problems themselves but expressed concern for people who do not speak English fluently. They described looking out for other Aboriginal patients and noted the lack of Aboriginal employees on the wards. Ward staff may incorrectly assume that a patient understands their explanations (Cole & Bird, 2000; Katon & Kleinman, 1984; Kleinman & Eisenberg, 1978). Misinterpretation or miscommunication may occur and not be noted. This can be especially problematic when the patients speak English as a second language and may be less fluent. Some patients complained that the foreign accents of other minority groups represented in the hospital workforce made it difficult to understand the information being shared.

Patients' perceptions of family and visitor involvement varied. Some patients, especially older patients, wanted more family involvement to prepare for their upcoming discharge. Emotional support and family participation in a patient's care can benefit the patient and are related to patient satisfaction (Cleary et al, 1991). A few patients wanted less family involvement. A number of patients complained about insufficient access to information for families. Patients from remote communities cited separation from family more often. A few patients had concerns regarding the enforcement of visiting hours that limited their access to social support.

Many patients had little knowledge regarding the plans for their discharge, as in other reported studies (Bull, 2000; Bull, 1994; Bruster et al, 1994; Charles et al, 1994). The interviews may have taken place too early during the admission for some of these patients to assess this knowledge properly. Rehabilitation patients with multiple previous hospitalizations worried about less experienced patients. They described how wheelchair patients had suffered in the past from insufficient or inaccurate information regarding wheelchair choices and repair issues on their discharge. They hoped patients would be better informed than they had been. Information regarding funding for wheelchairs, their repairs and other expenses related to their disability had not been communicated adequately.

The cross-cultural issues identified included differences in communication styles between cultures, lack of cultural awareness and negative attitudes towards Aboriginal people. Some respondents in this study did perceive racist treatment at the Health Sciences Centre. Some patients thought things had improved compared to past experiences of racism in urban hospitals. Patient perceptions of racism may relate to past experiences (Kravitz, 1996) and the historical context of Aboriginal people's lives in mainstream society (O'Neil, 1989; Anderson, 1986). Individual health care workers did not cause the historical wrongs however their interactions with Aboriginal patients may have been perceived as racist because of history.

A feeling of depersonalization is common for hospital inpatients because of the broad context of lack of control for hospitalized patients, as cited in the Report of the Aboriginal Services Review Committee (1992). The key informants had predicted patients would base their expectations for their care on their past experiences within the health care system.

Patients were asked what changes they had noticed since any previous admissions and what would have improved their stay. Many respondents noted there were fewer nurses on the wards and that the staff appeared busier than during past hospitalization experiences. Many long-stay rehabilitation respondents cited the loss of choice of meals as unsatisfactory. Patients' need to go outdoors to smoke raised safety concerns for those without visitor or staff accompaniment. Telephone and television costs were a problem for some patients. Financial assistance was a common need for non-urban respondents. Few suggestions were given regarding what improvements could be made to improve patients' hospital stay.

These findings demonstrate the need for increased use of the interpreter-caseworkers from the Aboriginal Services Department. Few patients were receiving these services. Some patients thought the department staff were only available for interpretation needs. The respondents who had interpreter-caseworkers involved in their care were unsure of how to reach them. One patient had gone four days with no communication in his only language, Ojibway (see page 41). Interpreter-caseworkers working as cultural brokers could reduce the number of communication problems and cross-cultural misunderstandings between patients, families and staff. They also can advise patients and staff in discharge planning. Interpreter services should be mandatory for non-English speaking patients to ensure standards of professional communication and true patient consent.

Overall, many patients in this study reported that their hospitalization experience was positive, with no changes needed; others had much less favorable experiences including some reports of serious breaches in communication. In-patient satisfaction studies often have fairly positive responses, as compared to post-discharge studies, partially due to patient concerns that responses could affect their care (Ford et al, 1997). Conversely, another possible reason for the positive interviews in this study may be the Hawthorne effect. Informing the ward staff of the study may have influenced the staff's performance and hence more patients truly had positive hospital experiences. In this study as in others, older respondents and females tended to be more positive in their responses, while younger respondents and males responded negatively more often (Fox et al, 1981; Carmel, 1985; Cleary et al, 1988).

The five areas that the key informants felt should be explored because of past patient problems were still areas of concern to many of the Aboriginal respondents (communication, family and visitor involvement, discharge planning, respect and racism, and involvement of the Aboriginal Services Department). Many of their concerns could apply to other patients, as supported by the literature. Patients from other ethnic minorities may have similar problems with communication and cross-cultural issues, and do not have formal access to interpreters or advocates in the hospital. They too may benefit from cross-cultural training of hospital staff.

Research on patient satisfaction for minority groups, especially Aboriginal people, has been limited. The hospital should continue to monitor patient satisfaction through research using in-depth post-discharge patient interviews. Post-discharge studies avoid patient reluctance to criticize their hospital care, lest it be affected. In-depth interviews with more time spent developing rapport could establish more trust than we achieved in this study. Research could also be done on other areas suggested by my key informants. Some had suggested asking: "What does health mean to you? What do you think needs to happen for you to reach that [goal for your health]?" The use of traditional healers in hospital care is an area needing exploration. Access to traditional healers was another recommendation of the Report of the Aboriginal Services Review Committee (1992), but this issue was not explored in this study.

The study has limitations, related to method, site, sample, researcher bias and research in general. The Aboriginal participants may have limited their comments for many reasons. The interview results need to be examined with an appreciation of Aboriginal culture. The Aboriginal teachings of non-interference may restrict people with traditional values from voicing any critical analysis of their hospital care, positive or negative (Brant, 1990; Preston, 1975). This may have affected recruitment to participate in the study and also may have influenced responses to many questions.

The study results suggest that previously identified problems persist at the hospital (Aboriginal Services Review Committee, 1992). There has been some progress towards fulfilling the recommendations of the Report of the Aboriginal Services Review Committee to address these longstanding problems. There are striking similarities between the 1992 recommendations for the Health Sciences Centre (Appendix 10), the recommendations by the Four Nations Confederacy after the 1980 'bead incident' at St. Boniface General Hospital (Hall, 1981), the recommendations from a St. Theresa Point community visit and some of the health recommendations of the Royal Commission on Aboriginal Peoples (1993). The Aboriginal Health Issues Committee of the Society of Obstetricians and Gynecologists of Canada has just published similar recommendations (Smylie, Lessard, Bailey, Couchie, Driedger, Eason et al, 2001). Many of the recommendations from these reports relate to the findings in this study. Although there is congruence about the issues, implementing reform seems to be difficult and was not accomplished at the Health Sciences Centre since the 1992 report.

To address the issues identified by the respondents, I will first discuss some general recommendations. Increased access to advocacy and support services for Aboriginal patients from the Aboriginal Services Department could help prevent problems with communication, discharge planning, family and visitors concerns and cross-cultural issues. Aboriginal patients may benefit from a more thorough orientation on admission to the wards and other services. Patients who become familiar with the changing hospital system would have more of their expectations met and may be more satisfied with their care. Written information on how to access support such as social work, spiritual care and the Aboriginal Services Department could make patients feel more in control of what is happening to them in the hospital.

Patients noted the lack of Aboriginal employees on the wards. The 'normalization' of Aboriginal culture within the hospital requires increased representation of Aboriginal people in the staffing. Increased representation of Aboriginal people in the ward staffing including professional groups could increase advocacy for patients and decrease patient perceptions of racism if the new staff are sympathetic to Aboriginal patients' concerns. The Winnipeg Regional Health Authority is working towards increasing Aboriginal employment at health care facilities in Winnipeg through training and recruitment strategies.

The nation-wide shortage of health care workers has necessitated recruitment overseas. Some patients complained that the accents of foreign staff in the hospital workforce made it difficult to understand information being shared. In particular, employees who are recruited from overseas need cultural awareness training in order to appreciate the unique culture and life circumstances of Aboriginal Canadians.

Increased participation by all hospital employees in the cultural awareness program would prevent some of the cross-cultural problems identified. Enhanced awareness of Aboriginal culture would decrease the need for patient advocacy by the interpreter-caseworkers. The two-day workshops offered on a one-time basis need follow-up sessions to continue to increase understanding and help prevent future patient dissatisfaction. Participation by physicians and administrators in the workshops is needed to reinforce the position that the workshops are valued in order to change the culture of the institution (Leskiw, 1998).

Many Aboriginal patients in this study described their ability to endure problems and to maintain a sense of control as patients. The traditional doctor-patient relationship is one of dependency on the part of the patient towards the doctor. The Royal Commission on Aboriginal Peoples developed a Health Strategy with four core elements (1993). These include *holism, equity, control, and diversity.* In models of holistic health, nothing can be understood without looking at the context of people's lives (First Nation and Inuit Regional Health Surveys, 1999). Aboriginal people want a health delivery system responsive to their needs, which is culturally appropriate. Many of the problems identified in this study could apply to patients of all backgrounds. All patients are asserting their rights in the current health care system.

Aboriginal people are seeking equal participation in decision making as individuals in society, and in governance of public institutions. Increasing Aboriginal participation in institutional services and providing culturally appropriate holistic care could increase trust and bring greater healing of Aboriginal people. The Winnipeg Regional Health Authority has influence over services and employment at all Winnipeg hospitals. The progress of fulfillment of the 1992 recommendations should be built into the Health Sciences Centre's quality improvement program. Across the Winnipeg hospital system there is a need to improve the delivery of patient care for Aboriginal people.

Aboriginal participants in this project shared many concerns with the interviewers. Some are common concerns for all patients, such as the lack of access to information, loss of meal choices, and the effect of the 'No smoking' policy. Others are unique and must be addressed, such as real and perceived discrimination. The following recommendations arise from this research. Rather than deal with concerns at the individual patient level, I shall end with the following recommendations to the Health Sciences Centre and the Winnipeg Regional Health Authority, which look at the wide determinants affecting Aboriginal patients.

4.1 RECOMMENDATIONS

Monitoring progress:

1. To ensure the problems identified in this study and previous reviews are addressed:

The Winnipeg Regional Health Authority at its highest corporate level must ensure that systemic and individual discrimination is eliminated. It should monitor the progress of the Health Sciences Centre's implementation of the 1992 recommendations of the Aboriginal Services Review Committee and other identified needs to better serve Aboriginal people. This should be built in to the institution's quality improvement program. Other urban institutions should work towards these same goals.

The hospital should continue following all areas explored in this study, to ensure that longstanding concerns are addressed. The recommendations from the Report of the Aboriginal Services Review Committee of 1992, the report on the trip to St. Theresa Point (Health Sciences Centre, 1993) and the related recommendations of the Report of the Royal Commission on Aboriginal Peoples

(1996) should be built into the hospital's quality improvement program. The 1992 report did recommend that orientation and continuing education programs to increase understanding of Aboriginal culture be incorporated into the quality management programs of the Health Sciences Centre (Appendix 10).

Services at the Health Sciences Centre:

2. To increase Aboriginal patients' sense of control in their care:

a) The Health Sciences Centre should advise nursing and physician staff to consult the Aboriginal Services Department more often. The interpreter-caseworkers can help orient patients to the hospital system, assess potential communication issues, language problems, and assist in discharge planning in their role as advocates and support workers for Aboriginal patients.

b) The Winnipeg Regional Health Authority and Health Sciences Centre should assess the Aboriginal Services Department's funding resources to handle unmet patient needs at the Health Sciences Centre.

c) The Health Sciences Centre needs to support family involvement in the course of patient care.

The Aboriginal Services Review Committee Report (1992) and the Four Nations Confederacy (Hall, 1981) recommended increased staffing of the Aboriginal Services departments at each of the two teaching hospitals in Winnipeg. The Family Feedback Report (McLaren, 1995) found parents of children who are hospitalized at the Health Sciences Centre wanted more referrals to Aboriginal Services for advocacy services, not just interpreter service.

In this study, most of the patients interviewed in English denied communication problems that may have required interpretation services. From the patients' stories, physician and nursing staff do not appear to involve the interpreter-caseworkers outside the need for interpretation, and appear to be underestimating the number of patients with difficulties understanding English. The health care workers and patients appear unaware of broad services available. The availability of these services should be included in patient's orientation to the ward on admission, with written information on how to access the department staff, social workers and spiritual care workers.

The importance of good communication with patients needs to be reinforced.

Cross-cultural training

3. To address cross-cultural issues:

a) Mandatory orientation of new staff and ongoing cultural awareness training sessions for all staff are needed at the Health Sciences Centre. Sessions should include a review of the historical context of Aboriginal people's lives in mainstream society and Aboriginal values of family and community involvement in patient care. Periodic review sessions with more in-depth presentations will possibly increase cultural competency. Case reviews to demonstrate practical application may be beneficial.

b) Governing bodies such as the College of Physicians and Surgeons of Manitoba and the Manitoba Association of Registered Nurses should ensure that professional standards of communication are met by physicians and nursing staff at all health institutions.

c) The Winnipeg Regional Health Authority with Aboriginal organizations, the University of Manitoba Continuing Medical Education Department, the Faculty of Nursing, the J.A. Hildes Northern Medical Unit, and the Aboriginal Health Committee of the Manitoba Medical Association should work together to establish accredited workshops as an incentive for physicians and nurses.

A number of patients in this study perceived that they were treated differently from other patients because they were Aboriginal. General communication problems were found and some concerns were expressed for Aboriginal people who do not speak English fluently who have important communication problems.

Twenty years ago, the Four Nations Confederacy requested that cultural awareness training be mandatory and ongoing for St. Boniface Hospital employees (Hall, 1981). Cultural training was recommended also in the <u>Report of the Aboriginal</u>

Services Review Committee (1992), the report on the trip to St. Theresa Point (Health Sciences Centre, 1993) and the Report of the Royal Commission on Aboriginal Peoples (1996) also recommended cultural training. Recommendation 3.3.17 from the Royal Commission states:

> Post-secondary educational institutions and professional associations collaborate with Aboriginal organizations to ensure that professionals already in the field have access to programs of continuing professional education that emphasize cultural issues associated with the provision of health and social services (1996: 283).

More cultural awareness training, including an appreciation of living conditions and existing health care services for rural and remote people could have prevented some of the problems identified in this study. Increased cultural awareness could improve patient satisfaction by providing the hospital staff with enhanced skills.

Physicians need to be relieved of their duties in order to attend the hospital's cultural awareness workshops. Participation in cultural awareness training by physicians and hospital leadership is considered essential to reinforce the position that the workshops are valued, to change the corporate culture (Leskiw et al, 1998) and to improve patients' care and discharge planning. Small group workshops with the highest level of accreditation possible for continuing medical education would attract more physicians, as all physicians require these credits to maintain their certification.[3]

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[3] A physician workshop on Aboriginal culture and health issues has been developed in Alberta and accredited for Mainpro-C credits with the College of Family Physicians of Canada. The Northern Medical Unit and the Manitoba Medical Association Aboriginal Health Committee are interested in adapting this workshop to Manitoba Aboriginal cultures and obtaining accreditation for specialists also.

Hospital employment:

4. To help increase patients' sense of control at the hospital:

The Winnipeg Regional Health Authority should continue to implement its Aboriginal Employment Strategy to increase representation of Aboriginal people in the health care workforce at the Health Sciences Centre and elsewhere in Winnipeg. Aboriginal representation on hiring committees and exit interviews for all Aboriginal employees are needed. Greater Aboriginal representation should decrease perceptions of racism and improve communication.

Patients in this study commented on the lack of Aboriginal staff on the wards. The Report of the Royal Commission on Aboriginal Peoples and the Report of the Aboriginal Services Review Committee recommended increased employment of Aboriginal people in health care.

The Health Authority's adoption of the "Aboriginal Representative Workforce Strategy" will help to guide the employment process (McKenzie, 2000). Aboriginal representation on interview committees may help the hiring process. Aboriginal employees leaving or changing their positions at the hospitals should have an exit interview. The 'normalization' of the culture of Aboriginal people in the hospital through increased exposure to Aboriginal co-workers would benefit non-Aboriginal staff by breaking down stereotypes of dependency.

The Winnipeg Regional Health Authority and the Health Sciences Centre are commended for their employment equity initiatives, which require work with the unions and educational institutions to make the workforce at the hospitals reflective of the populations they serve. As recommended in the Aboriginal Representative Workforce Strategy:

> The extent to which the strategy achieves its goal of a representative workforce will directly reduce the demand and need for health services and in particular crisis health services for the Aboriginal community. This should free up resources for specialized mainstream services... (McKenzie, 2000:15).

Community Relations:

5. To improve communication at the governance, corporate and administrative level and increase Aboriginal peoples' sense of control:

The Winnipeg Regional Health Authority and urban hospitals need to increase communication with Aboriginal organizations. Community site visits and Aboriginal representation on the Winnipeg Regional Health Authority Board and hospital boards must be considered.

The 1992 Aboriginal Services Review Committee report and the St. Theresa Point trip report (Aboriginal Services Review Committee, 1992; Health Sciences Centre, 1993) recommended increased interactions. Both reports recommended that members of the Board of Directors and senior hospital managers do site visits to Aboriginal communities around Manitoba, Northwest Ontario and Nunavut. The Health Sciences Centre Board has previously been requested to hold board meetings every year in an Aboriginal community.

The Winnipeg Regional Health Authority recognizes its role with rural and northern communities, Aboriginal organizations in Manitoba, Northwest Ontario and Nunavut, and Aboriginal political, health and social service groups served by the hospital. Trust between the communities and the Health Authority needs to be built. The Regional Director of Aboriginal Services is charged with ensuring that the needs of Aboriginal patients are met. The Aboriginal Services Review Committee (1992) and other groups have stressed the need for the increased role for Aboriginal people in the governance of hospitals (Assembly of Manitoba Chiefs, 1991; Manitoba Health, 1991).

Regional Services:

6. The Winnipeg Regional Health Authority should ensure that Aboriginal services are universally available and appropriate at all Winnipeg hospitals.

Aboriginal patients at the non-teaching hospitals in Winnipeg likely have concerns similar to Aboriginal patients at the Health Sciences Centre. When the Health Sciences Centre has had bed shortages in the past, the Northern Medical Unit was asked to divert northern patients requiring hospitalization to urban community hospitals (B. Martin, personal communication, November 1999). This could result in inadequate care in the absence of Aboriginal services. Patients from northern communities are more likely to need interpretation and advocacy services.

Physicians in Winnipeg perceive that the two teaching hospitals are unable to care for all Aboriginal patients requiring urban secondary and tertiary care (P. Orr, personal communication, October 2000). Urgent provision of interpreters at the community hospitals is needed with the continued diversion of patients away from the teaching hospitals on an acute and elective basis. Expanding Aboriginal services to community hospitals must not divert existing resources from the teaching hospitals. Rather new staff must be hired specifically for this work.

Many issues explored in this study have been longstanding concerns for Aboriginal people in the Health Sciences Centre. This study has documented progress addressing the 1992 recommendations, but more change is needed. Changing the culture of institutions is a slow process. Support of change must come from the governance and corporate leaders. Increasing Aboriginal representation in governance and employment and increasing cultural awareness of non-Aboriginal staff within health institutions are required. These will be steps towards amelioration of the power imbalance and lack of control that Aboriginal patients currently face in the health care system. Trust will only be built on action.

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APPENDICES

APPENDIX 1

Sample Key Informant Consent Form

Consent to participate in the study

The Health Sciences Centre and the University of Manitoba are asking you to take part in a study to better understand the health care needs of Aboriginal patients. We are interested in your experience as a health planner/care giver/patient. This study will involve interviews of Aboriginal key informants and patients. We are interested in the concerns you have for Aboriginal patients or experiences you have had yourself in hospital.

Any information we receive from you will be kept anonymous, so that other people cannot identify you from the information. You may be identified by a pseudonym when the results are reported. The study is voluntary, and there is no payment for participating. You do not have to participate in the study, and you may withdraw from the study at any point. (It will not affect your care in the hospital.)

The interview will take approximately 30 minutes of your time. The interview will be taped. Later it will be typed up and you may see the information after to be sure that you were understood.

If you have any questions about this study you can ask Nichole Riese or Dr Pamela Orr. They both work at the Health Sciences Centre and are the main study investigators. They can be reached through calling 787-3391. If you agree to participate in this study, and have read and understand the information above, please sign below:

Signature	Date	Witness	Date

APPENDIX 2

Patient Questions

Communication:

Do you understand why you are in the hospital and what is going to happen to you here?

Can you tell us about any problems that you had understanding the staff?

Did you have any problems with others not understanding what you wanted to tell them?

Family:

Has your family been involved in your care here? Would they like to be more involved?

(Optional: Is there anyone else the hospital should talk with about your health?)

How did your visitors feel while they were here? What do your visitors think about your care?

Discharge plans:

Have you or your family been involved with planning your discharge?

Have you been told what to expect when you go home?

Do you think the discharge plan is right for where you live?

Do you understand what you have to do when you go home to look after yourself?

HSC experience:

If you have been in this hospital before, how have things here changed? What is better about it? What else could be done to make your stay better at the hospital?

Do you feel that you were treated with respect while in the hospital?

Did you ever feel that you were treated differently than other patients because you are Aboriginal? How was it different?

Was Aboriginal Patient Services involved in your care?

APPENDIX 3

Sample Patient Consent Form

The Health Sciences Centre would like you to take part in a study to better understand the health care needs of Aboriginal patients. We are interested in your experience as an Aboriginal patient at this hospital. We are interested in the positive and negative experiences you may have had during your time here.

The interview will be for approximately 45 minutes. The interview will be conducted by Olga Houle or Nichole Riese. You can be interviewed in English or Ojibway. You will be asked a few questions to describe your experience staying in the hospital. The interview will be taped. Later the interview will be typed and the tapes will be destroyed. Any information we receive from you will be kept anonymous, so that other people cannot identify you from the information. You will not be identified when the results are discussed. The study is voluntary. You do not have to participate in the study, and you may withdraw from the study at any point. It will not affect your care in the hospital. There is no pay for participating in the study.

If you have any questions about this study you can talk to Olga Houle, or to Nichole Riese who is the main study investigator. They can be reached through calling 787-3633 or through hospital paging 787-2071. If you agree to participate in this study, and have read and understand the information above, please sign below:

Signature Date Witness Date

APPENDIX 4

Paraphrase of Patient Consent Form

Aboriginal Patients at the Winnipeg Health Sciences Centre: Perceptions of Care

The Health Sciences Centre has many Aboriginal patients. Doctors, nurses and other Health Sciences Centre workers want to learn more about your experience as an Aboriginal patient at the hospital, and how they can make that experience better.

Researchers at the hospital are interested in talking to Aboriginal patients on certain wards. You will be asked if you want to talk to an interviewer about your hospital experience. The interviewer is Cree person, and the interview can be in English or Cree.

The Chiefs Health Committee of the Assembly of Manitoba Chiefs has approved this study.

Your identity will not be recorded with the survey or interview, so that no one knows who made the comments. Only information about your age, cultural group and area of residence will be included.

Your answers to the questions will be confidential (kept private).

The study is voluntary. You do not have to participate if you do not want to; your care will be the same whether or not you participate in the study.

You may change your mind at any time if you decide you do not want to finish the interview. You may listen to the recording to be sure we will understand your story.

There is no payment for the interview.

If you have questions about the interview, you can contact Nichole Riese at 787-3633 or Dr Pam Orr at 787-3391 in the hospital, or by paging us.

We will ask you to sign a consent form if you agree to participate in this study.

APPENDIX 5

Sample Notification to Physician Staff of Research Project

Health Sciences Centre Physicians June 1998

Dear Physician,

The departments of Medicine and Surgery are conducting a study involving Aboriginal patients. Graduate student, Dr. Nichole Riese, and an Aboriginal research assistant, Olga Houle are interviewing Aboriginal patients about their perceptions of care at the Health Sciences Centre. Aboriginal patients from the wards will be asked to participate in an interview, if they speak Ojibway. All responses will be confidential. We will book the interviews when patients are not busy with tests.

We hope this does not cause any inconvenience to you or your patients. If there are reasons why you do not want your patients to participate, please contact either Dr. Riese (935-6500) or Dr. Pam Orr (787-3391).

We are hoping to use the information gained in this study to improve the care that we provide to our Aboriginal patients. This study has the approval of the Health Sciences Centre administration, University of Manitoba Ethics Committee, and the Assembly of Manitoba Chiefs.

Nichole Riese and Pam Orr

APPENDIX 6

Sample Notification to Ward Nurses and Ward Aids of Research Project

June 1998

The departments of Medicine and Surgery are conducting a study involving Aboriginal patients. Graduate student, Dr. Nichole Riese, and an Aboriginal research assistant, Olga Houle will be interviewing consenting Aboriginal patients about their perceptions of care at the Health Sciences Centre. Patients from the selected wards will be asked to participate in an interview, if they consider themselves Aboriginal. All responses will be confidential.

Every patient admitted to the ward will receive our brochure advertising the study. We will be on the ward daily to see which patients are willing to participate. We will check with the patient and the unit clerk to see when the estimated discharge date is planned, and do the interviews when patients are not busy with tests. We may interview patients off the ward for privacy. If patients are not mobile, and they consent, we will interview them in their rooms. We want to try to interview the patient closer to their discharge date. Admissions of under 3 days will not qualify, and the patients must be fluent in English or Ojibway.

We hope this does not cause any inconvenience to you or your patients. If there are reasons why you do not want your patients to participate, please contact either Dr. Riese (935-6500) or Dr. Pam Orr (787-3391). We are hoping to use the information gained in this study to improve the care that we provide to our Aboriginal patients. This study has the approval of the Health Sciences Centre administration, University of Manitoba Ethics Committee, and the Assembly of Manitoba Chiefs.

Nichole Riese and Pam Orr

APPENDIX 7

ABORIGINAL SERVICES REVIEW COMMITTEE RECOMMENDATIONS	AD HOC COMMITTEE COMMENTS OR CAVEATS	AD HOC COMMITTEE RECOMMENDATIONS
#1 Aboriginal Peoples must be given a greater voice in the affairs of the Health Sciences Centre. Therefore, the Committee recommends increasing the number of Aboriginal people on the Board of Directors to at least five members to ensure "equitable representation" of Aboriginal people.	- The establishment of a standing committee at the Board level would give aboriginal people a greater voice in the affairs of the Centre as well as serving as a pool of possible Board appointees as future vacancies occur. - Appointments to the Board of Directors should be based on the abilities and interests of individual appointees rather than quotas. - It is likely that aboriginal representation on the Board of Directors will follow an evolutionary process not unlike the path that has led in recent years to significant increase in the proportion of Board members who are women.	That the Board of Directors emphatically endorse the principle that the aboriginal people be given a greater voice in the affairs of the Health Sciences Centre and that the establishment of a standing committee of the Board on aboriginal issues be viewed as a significant step to that end.
#2 To enhance cultural awareness, and to promote dialogue with Aboriginal peoples, the Committee recommends that the Board of Directors seek an invitation to hold one Board meeting a year in an Aboriginal community.	- Rather than hold a meeting a year, per se, of the Board in an aboriginal community, it would probably be more useful to hold a retreat in which cultural exchanges could take place rather than the transaction of routine Board business. - If established, the standing committee of the Board of Directors and the Aboriginal Services Advisory Committee at the staff level could also be encouraged to take part in cultural exchange retreats.	That the Board of Directors and any committees dealing with aboriginal issues seek opportunities to visit aboriginal communities periodically in order that the level of cultural awareness be increased.
#3 To increase the autonomy, authority and capacity of the Native Services Department, the Committee recommends a freestanding department reporting directly to the President, coupled with an increase in budgetary resources.	- Consideration needs to be given to how best to fit the department into the overall structure of the hospital and how to relate it both to management and the Board of Directors. - A reporting relationship to a Vice-President would serve the dual purpose of raising the profile of the department and simultaneously keeping it closely involved in the day-to-day workings of the institution.	That the Board of Directors approve the intent of this recommendation and assign it to management to develop cost estimates and action plans for approval, taking into consideration the comments made regarding reporting relationships and committees.

APPENDIX 7

ABORIGINAL SERVICES REVIEW COMMITTEE RECOMMENDATIONS	AD HOC COMMITTEE COMMENTS OR CAVEATS	AD HOC COMMITTEE RECOMMENDATIONS
	- In order to recognize the Board's deep and abiding interest in aboriginal issues, it is felt that a standing committee of the Board should be established to monitor progress in meeting those issues. Such a committee could include representatives from the aboriginal community, thus strengthening communication links between the HSC and aboriginal leaders, as well as providing a strengthened voice for aboriginal peoples at the Board level. Aboriginal representatives on such a committee could also serve as a pool of talent from which future Board members could be drawn, as vacancies become available. (A standing committee of the Board, if established, would be for the purposes of recommending policy and monitoring implementation. - An Aboriginal Services Advisory Committee at the management level would also be required as a day-to-day working committee. Aboriginal representatives could serve on both committees. (The current organization of quality assurance into Board and staff committees is perhaps a useful model to consider in this context).	
#4 The committee recommends that the Board of Directors commit resources to ensure that the services of traditional healers are available to Aboriginal patients.	- Clarity is needed on the risks and potential liabilities that might be created if traditional healers were encouraged to practice in the hospital. - The details need to be worked out concerning the integration of traditional healers with the standard practice of western medicine by physicians, nurses and other health professionals. - The Center should contact other hospitals where traditional	That the Board of Directors approve this recommendation in principle and assign it to management to develop cost estimates and action plans for Board approval.

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ABORIGINAL SERVICES REVIEW COMMITTEE RECOMMENDATIONS	AD HOC COMMITTEE COMMENTS OR CAVEATS	AD HOC COMMITTEE RECOMMENDATIONS
	healers are used in order that we may benefit from their experience.	
#5 The committee recommended that the Health Sciences Centre promote employer equity for Aboriginal peoples by developing and implementing policies to correct the significant under-representation of Aboriginal peoples among the Centre's employees.	- A baseline survey of staff should be undertaken in order that we may later measure changes in the numbers of aboriginal persons employed by the Centre - The Board should recognize the Centre's significant positive efforts to be an equal opportunity employer.	That the Board of Directors approve this recommendation in principle and assign it to management to develop cost estimates and action plans for Board approval.
#6 To increase cultural awareness, the committee recommends that the Health Sciences Centre develop orientation and continuing education programs for employees, trainees, students and volunteers to increase understanding of aboriginal culture. These activities should be incorporated into the Total Quality Management Program being considered at the Health Sciences Centre.	- The recommendation should include "members of the medical staff" among the listing of groups which would benefit from cross-cultural awareness. - Periodic reports should be made to the Board of Directors about activities which have taken place to increase cross-cultural awareness.	That the Board of Directors approve this recommendation in principle and assign it to management to develop cost estimates and action plans for Board approval.
#7 To increase educational opportunities both internally and externally, the Committee	- This recommendation in particular needs to be fleshed out and given focus, lest it be bypassed due to its generality. - Funding could be sought from federal agencies, private	That the Board of Directors approve this recommendation in principle and assign it to management to develop cost

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ABORIGINAL SERVICES REVIEW COMMITTEE RECOMMENDATIONS	AD HOC COMMITTEE COMMENTS OR CAVEATS	AD HOC COMMITTEE RECOMMENDATIONS
recommends that the Health Sciences Centre implement initiatives to increase the number of Aboriginal students participating in Health Sciences Centre based programs for health professionals and technologies.	foundations, etc. - Volunteer programs could give valuable work experience and job exposure to potential aboriginal employees.	estimates to explore external funding sources and to examine ways and means by which some of the proposed steps in the Report might be realized.
#8 Enhancement of outreach educational activities will improve the relationship between the Health Sciences Centre and Aboriginal communities. Therefore, the Committee recommends that this component of health-care service be explicitly acknowledged and adequately supported.	- The future role of the Health Sciences Centre in the provincial health care system is not clear at present. Outreach programs may be better designed and managed by community agencies or groups. - Ways of cooperating and complementing community agencies' activities should be fully explored and strengthened as appropriate. - Improvements to discharge planning requires change and cooperation by all parties.	That the Board of Directors approve this recommendation in principle and assign it to management to develop cost estimates and action plans for Board approval.
#9 The committee recommends that the Health Sciences Centre establish continuing links to the Aboriginal leaders in Manitoba, the Keewatin District of Northwest Territories and Northwestern Ontario.	- The recommendation in many ways represents a self-evident truth. - It will be necessary to determine the mechanism whereby this communication may be established and continued from the HSC side. The creation of an Aboriginal Services Advisory Committee at either the Board or management level might be one mechanism. - This recommendation needs to be viewed in the context of recommendation #3 (Native Services Department).	That the Board of Directors approve this recommendation in principle and assign it to management to develop cost estimates and action plans for Board approval.