

**EVALUATING PATIENT SATISFACTION
IN THE NEUROSCIENCE POPULATION**

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IN THE
NEUROSCIENCE PATIENT POPULATION**

By

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ABSTRACT

Patient satisfaction regarding health care has been recognized as an important variable for promoting effective and efficient utilization of health care services, improving compliance with treatment regimes, improving health outcomes for the patient, and eliciting patients for future care (Charles, Gauld, Chambers, O'Brien, Haynes & LaBelle, 1994, p.1814). Since the basic premise of health care is to improve the health of others, improving the level of satisfaction with care is essential. Also, with the cuts in financial support for Ontario health care, efficient utilization of health care resources and improved health outcomes are primary goals for hospital administrators, health professionals and politicians. The Neuroscience Program, at the Hamilton Health Science Corporation (HHSC), felt it necessary to evaluate the current level of patient satisfaction from the neurological patients and their family members, to identify opportunities for improvement in care, and to identify whether the neurological impaired patients and their families have unique care needs.

A review of the research on patient satisfaction revealed that neurological patient's had not been specifically studied for their level of satisfaction with their health care. In other bodies of research, the neuroscience patient population had been identified as needing frequent, current information and communications in understandable terms. For the patients who sustain cognitive, behavioural, and speech impairments, and those with a decreased level of consciousness, these patients and family members identified information and support as their highest needs. The need for hope was also identified as a priority. In the general patient population, the need for sufficient personal care, emotional support, and increased family involvement in the patient's care were acknowledged as additional areas for improvement. Discharge planning was also recognized as being an area in need of significant improvements.

In analyzing the information available to the Neuroscience Program regarding current level of patient satisfaction, there were only three main sources of information. These three sources were the letters from patients and families regarding care, the previous corporate discharge

questionnaire, and a focus group study. In reviewing these data, themes similar to those noted above were recognized. The need for timely, pertinent, understandable information and education was imperative. In addition, safety and personal care issues were identified, especially in the case of very ill or very confused patients. Finally, the greatest concern noted by the patients and families was the fear that their feedback might go back to the health care team, potentially jeopardizing their future care. These concerns were most pronounced in the case of patients with diagnostic conditions such as head injury, brain hemorrhage (vascular) and brain tumours (neoplasia), hydrocephalus and spinal cord injuries with impairment. These patients also tended to have the longest stays in hospital and the highest levels of disability.

The stakeholders of the Neuroscience Program were interviewed to examine the most relevant areas for study. Communication, information and education were identified as pivotal to improvement in all other aspects of care. A qualitative method of examination was felt to be the most appropriate to collect extensive information. Also, quantitative data would be collected on a patient satisfaction survey that was being implemented by the HHSC. The critical incident technique, by Flanagan (1954), was chosen as the preferred method of data, as it allowed for a consistent focus to the interviews while still collecting in-depth information.

In reviewing and utilizing all of the above information, the research project is outlined using Flanagan's framework and the cycle for improvement outlined by the Joint Commission on Accreditation of Healthcare Organizations. Each step of the process is outlined from the design phase, data collection, data analyses, interpretation and implementation of the improvements. The study, once implemented, should be viewed as a year-to-year process and as being an integral part of the overall quality plan for evaluating patient satisfaction. A database should be established bringing together both patient and family information in order to assess for changes over time.

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CHAPTER ONE

RATIONALE FOR THE PROJECT

Background

Quality care- the catchphrase of the 1990s in health and medical care- has two dimensions. One has to do with technical excellence: the skill and competence of professionals and the ability of the diagnostic or therapeutic equipment and procedures to accomplish what they are meant to accomplish, reliably and effectively (Gerteis, Edgman-Levitan, Daley & Delbanco, 1993,p.2). The other dimension is the subjective experience of the patients, which is their perception of illness or well being and their encounter with the health care professionals and the institution. What the patient experiences, and what they think about that experience is important to health care administrators and health professionals. For the most part, those who work in the health care field do not need to be convinced that what the patients think, feel, and experience is important. Health professionals, by nature, are a kind and sensitive lot, motivated to help people and ease their suffering. But in the past, recognizing and acknowledging patients' experiences with the health care system has not shaped the way in which health care services were developed. Why this has occurred is based on two main issues. The tension between the objective data relating to the scientific aspects of care and the less quantifiable, human aspects of patients' experiences. The second reason is the health care practitioner's belief that he/she knows what is best for the patient, thus giving the patient little say in planning for care.

Administrators and researchers, over the past ten years, have come to recognize the importance of providing care based on patients' needs. This has resulted in a change in philosophy for care from a provider-centered model towards a patient-centered model. Today, more than ever, the voice of the patient is crucial for promoting continuous improvement of health care processes and clinical outcomes. When patients' needs are met, they are satisfied with the care. A patient who is satisfied with his/her care has been shown

in the research to have improved health outcomes and to utilize the health care services more effectively and economically. As the health care system in Ontario currently has limited resources, the need to provide the most effective and efficient types of care that meet the needs of the patients and their families is essential.

The Neuroscience Program at the Hamilton Health Science Corporation was charged with the responsibility of evaluating the current level of patient satisfaction, of initiating methods for continuous monitoring, and of implementing changes in patient-care based on the patients' perceived needs, as able. A planning team was formed with a representative from administration and from each of the health care disciplines throughout the spectrum of care provided by the program. Satisfaction with care would be evaluated utilizing several methods. The planning team felt that it was important to build upon our current level of knowledge and evaluation processes, and to develop a quantitative patient satisfaction survey form and a qualitative interview approach to collecting information from patients and family members.

Outline of the Paper

The purpose of this paper is to provide the reader with the framework and process for evaluating patient satisfaction within the Neuroscience program. It results in an actual proposal for a qualitative approach to evaluating patient satisfaction. The intention is to implement the research study following approval by the planning team within the Neuroscience Program.

To begin the process of defining satisfaction for the Neuroscience patients and their family members, a framework was needed for evaluating the current patient care system. The primary framework utilized for this project is the "Cycle for Improving Performance" outlined by the Joint Commission of Healthcare Organizations (1995). A patient flowchart

was developed to outline the flow of care through the inpatient care areas in the Neuroscience Program. This flowchart will assist with identifying which aspects of care need improvement.

In the third chapter, an extensive literature review of relevant research studies on patient satisfaction are outlined and reviewed for their strengths and limitations. Very little Canadian research was available, so applicable pertinent research, primarily from the United States, will be outlined and critiqued, recognizing the similarities and differences in our health care systems.

Fourthly, the Neuroscience Program is described identifying the scope of practice, with an emphasis on the inpatient care areas. Data regarding the patient population served based on their diagnostic illnesses/categorization, lengths of stay and indicators of morbidity and mortality are noted. Unique characteristics and needs of the Neuroscience population are identified utilizing the Neuroscience Annual Report (1997) and applicable research.

Following this, current knowledge regarding patient satisfaction in the Neuroscience Program is presented. A review of the contributions of the focus group of Neuroscience patients is discussed. Next, major themes from letters of complaint and commendation, and data obtained from discharge evaluation forms are reviewed. Finally, an analysis of the results from the Hospital Corporation survey completed in 1995 of the general level of patient satisfaction is presented.

In Chapter six, a framework developed by Dull, Lansky and Davis (1994) outlines an approach to obtaining input from all stakeholders in evaluating patient satisfaction is presented. They outlined the importance of stakeholder input, even in the beginning stages of planning, for improved utilization of the research results. This framework is utilized to identify the stakeholders, outline their goals, the essential components of the study, the end

products required and the potential utilization of the results. The major themes in the interviews with the stakeholders are described.

The next chapter examines the corporate patient satisfaction survey that is currently being pilot tested in the Neuroscience Program. The survey questionnaire will be reviewed for the content covered, and identify gaps in the data that will be collected. Also, the advantages and disadvantages of a written questionnaire format will be discussed.

In chapter eight, the critical incident technique methodology developed by Flanagan (1954) is described. Research in the health care field utilizing the critical incident technique with patients is reviewed and critiqued. The advantages and disadvantages of these studies are discussed in the hope of improving on these issues in the current research proposal.

Finally, in chapter nine, the information from the previous chapters is utilized in developing the research proposal. The framework from the initial chapter and Flanagan's theoretical methodology guides the process. The study population and the sampling techniques are discussed. Methods for organizing, analyzing and utilizing the data relating to improvements in patient care are summarized.

In the conclusion, I will reflect on the process and on the potential usefulness of this study proposal to the Neuroscience Program. I base my conclusions on the information provided and on my many years of caring for Neuroscience patients and their families. We need to address the subjective needs of the patients and their family members if we are ever going to improve the quality of care. This matter is of importance to the health care practitioner, to health care service, and to the future consumers of care.

CHAPTER TWO

PATIENT SATISFACTION: A FRAMEWORK FOR DEVELOPING AN EVALUATION TOOL

Measuring the quality of care from the client's perspective within the health care industry has become a major challenge for health care clinicians and administrators. Although manufactures can develop quality control methods to ensure that their products meets quality specifications before the customer ever see or use them, the service providers does not usually have that luxury. Accurately measuring how the patients and their families feel about hospital stays are far more a challenge than is determining the durability of a product or the quality of workmanship.

The diagnosis and treatment of medical illness has become even more complicated as a result of advanced technologies and the subspecialization of caregivers. The result is that ever more caregivers are involved in the care of a single patient. The front-line caregivers are increasingly focused on the specific problems that they are trained to deal with, as well as the advances in their particular discipline and the standards that they are required to uphold. In addition, health care organizations have evolved into complex systems with variety of additional goals and interests. These include patient care, education, research, and mediating political, regulatory, financial, and community interests (Niles, Tarbox, Schults, Swartz, Wolf, Robb, Plume, Nelson & Nugent, 1996). These competing agendas can result in competition for financial and administrative support, and in decreases in commitment to patient care. "Consequently, as the technical and scientific quality of care has achieved excellence, the humanitarian aspects of care have been neglected and the service rendered to the patient is increasingly depersonalized. The result has been an erosion in the patient's confidence and the public's trust in the health care system and its providers" (Niles, et.al.1996, p.324). To deal with this problem. health care organizations are changing the care delivery process and making it a patient-centered model of

care. This model of care utilizes the patients' and families' inputs when developing and evaluating the care process and planning for the future. The goal of patient-centered care is to gain the confidence and trust of the public, and to provide, from the patient's perspective, a high-quality care.

Health care administrators need feedback from patients and their families as part of the total quality plan and as a means of evaluating in a patient-centered care model. Patient satisfaction is one of the components of a quality plan. Other important components are: employee satisfaction, cost utilization, clinical outcomes, clinical benchmarks, research and education. Health care administrators utilize this information, together with the hospital vision statement, in order to link structures, processes, outcomes, value, quality and costs (Castañeda-Méndez, Mangan & Lavery, 1988). The key measures identified from these linkages are utilizing this information for planning, evaluating and improving patient care.

Data relating to patient and family satisfaction can be generated using a variety of methods and processes. Health care clinicians and administrators need to find and select appropriate methods for measuring overall patient satisfaction and its various components within the context of a patient-centered model of care. This challenge is made even more complex by the fact that each individual patient has his/her own beliefs, past experiences and values and these opinions affect how the service is evaluated. Consequently, service that one person perceives as merely acceptable may be viewed as excellent by a second person, and as totally unacceptable by a third person. The subjective nature of definitions of quality and the value of the service experience makes identifying and implementing the appropriate measurement techniques particularly challenging (Fottler, Ford & Bach, 1997). Various researchers have developed frameworks for evaluating patient satisfaction. Relevant frameworks and methodologies for evaluating patient satisfaction within the Neuroscience patient population will be presented.

FRAMEWORKS

The Joint Commission on Accreditation of Health Care Organizations (1995) outlined a cycle or stages for “using patient input in a cycle for performance improvement” (Chapter 2 – Understanding the Patient’s Perspective: A Tool for Improving Performance). The cycle consists of four stages – *design, measurement, assessment, and improvement* – in terms of the patient care (see below). The *design* stages requires the outlining of the patient group served, the acknowledgement of the relevant clinical and organizational functions that affect the patient, the identification of factors which affect patients within these functions, and the determination of possible methods for gathering and utilizing patient input. Patient groups can be determined by diagnostic categories, age and current or former status as a patient. In addition, priority patient populations can be identified as needing improvements in the care process or as being priority patient populations for the individual clinical programs and/or the health care organizations.

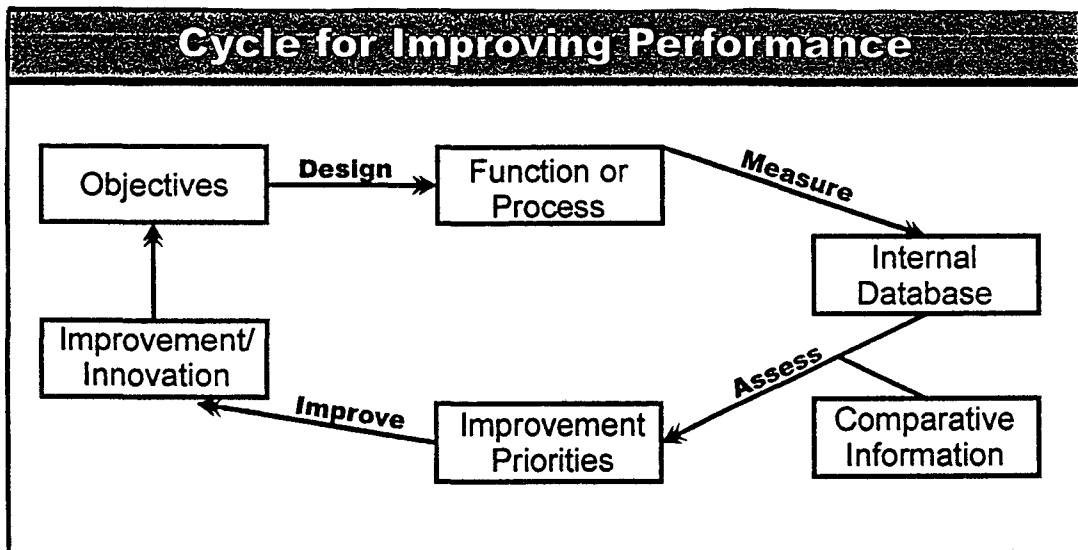


Figure 1: Cycle for Performance Improvement

(Joint Commission on Accreditation for Health Care Organizations, 1995,p.33)

The Joint Commission (1995) has identified several important functions that affect patient care. These include patient-focused functions are related to assessment, personal care, patient education, and the continuum of care provided for patients. Organizational functions refer to the leadership, to the structure of the organization, to its mission and values, and to the management of the physical environment and human resources. Structures with functions are the professional bodies within the organization, and the organizational regulations that determine the manner in which these professionals provide patient care. An example of a professional structure within an organization is the registered nurse. The College of Nurses has regulations, which governs the nurse's practice, but it also has regulations, which guide practice and serve to protect the public consumer. The regulation of the professional bodies within an organization needs only to be considered if a proposed change would affect their professional standards and practices.

The particular methods that is chosen for measuring patient satisfaction should take into account the priorities of the organization and each clinical program, the information needs, the available resources, and other criteria such as patient groups with high-cost, problem-prone or high-volume patient populations. Fottler and colleagues (1997) have argued that the initial stage of data collection should utilize a qualitative approach and should result in the formulation of themes and in the development of priorities. Once this stage has been completed, quantitative measures should be developed in order to measure patient responses. A literature review should also be undertaken in order to document areas of patient satisfaction/dissatisfaction and to examine methodologies that have yielded useful results. Niles and colleagues (1996) suggest the development of a flow chart depicting the continuum of care from the patient's perspective. This approach examines the care as the patient views it, and also targets areas within the care continuum that need special attention. Below is an example of a patient flow chart outlined in Niles and colleagues article (1996,p.325). This is followed by a patient-experience flow chart for urgent and elective admissions into the Neuroscience Program's inpatient care unit.

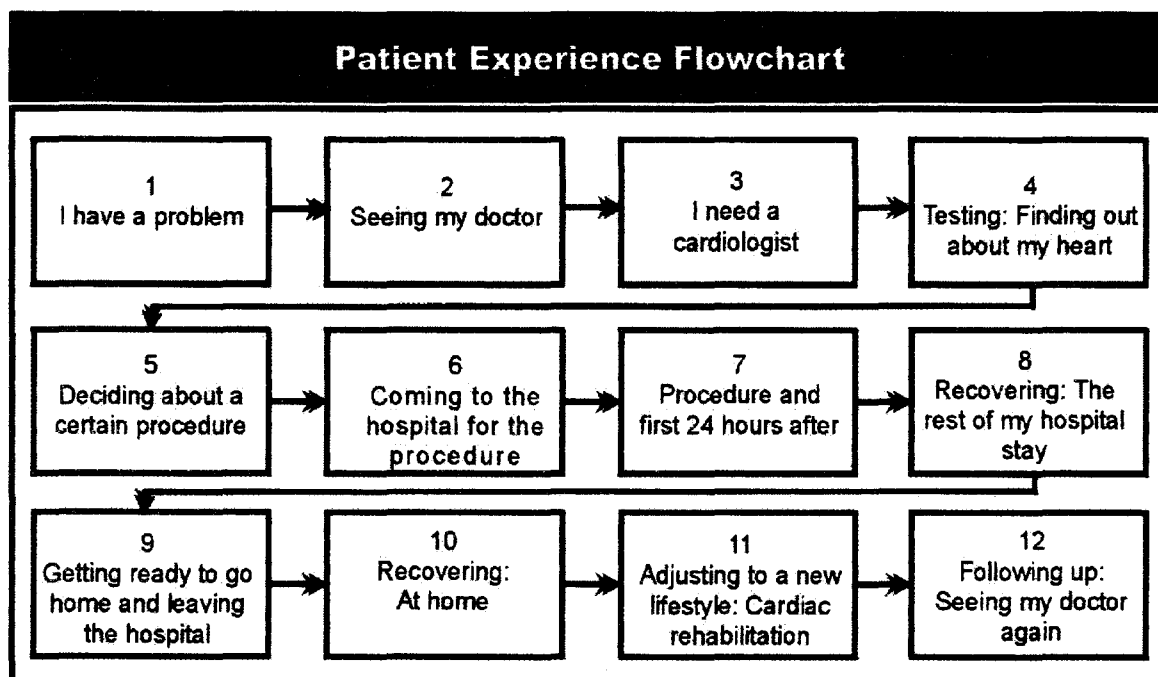
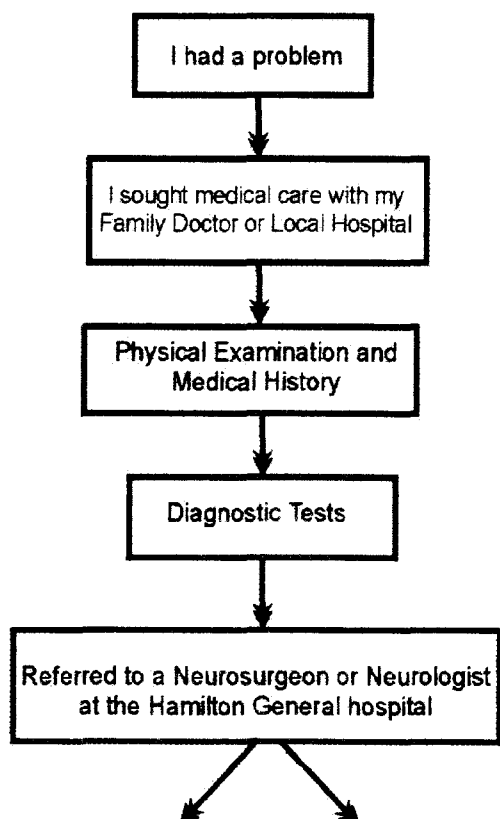
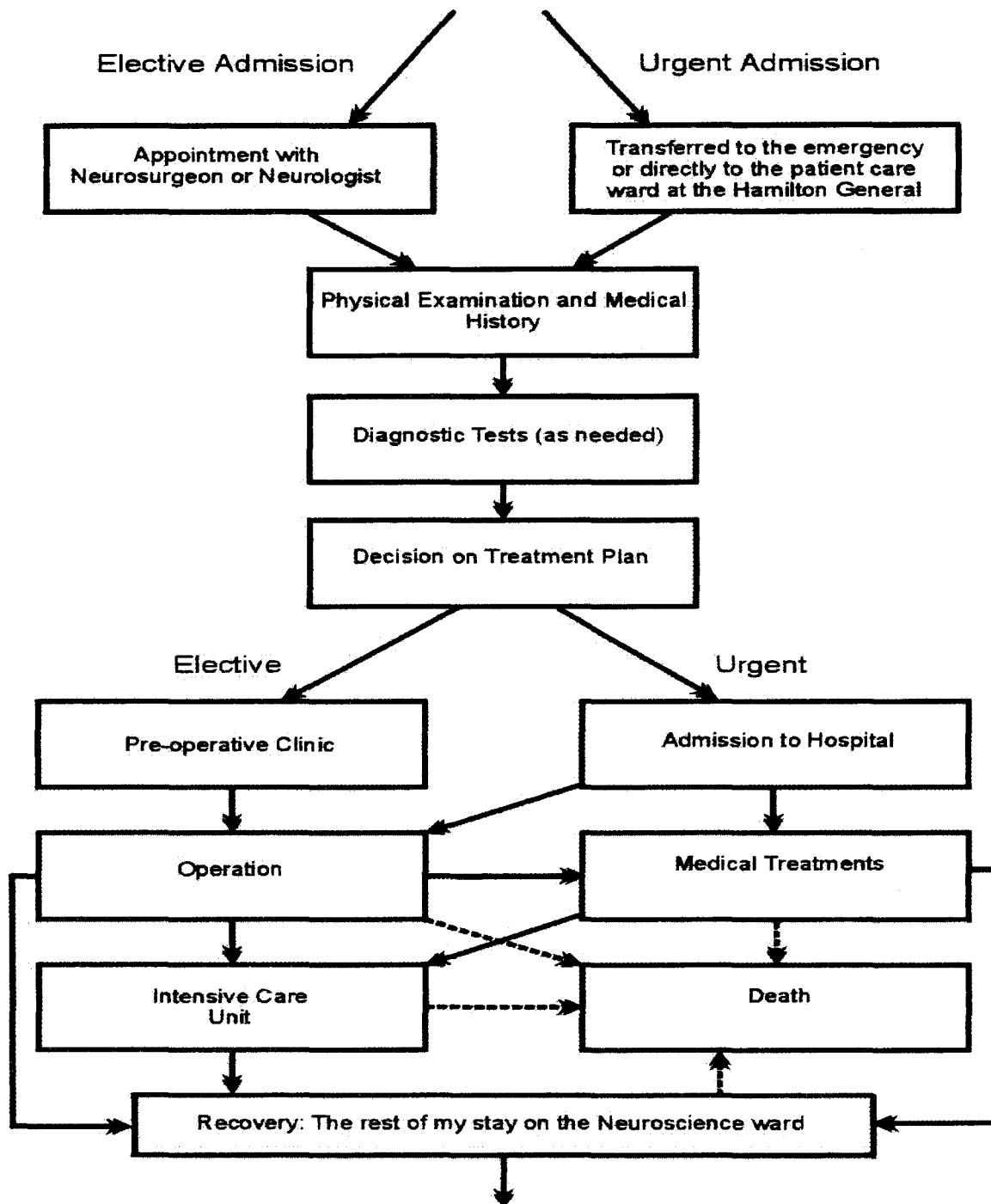
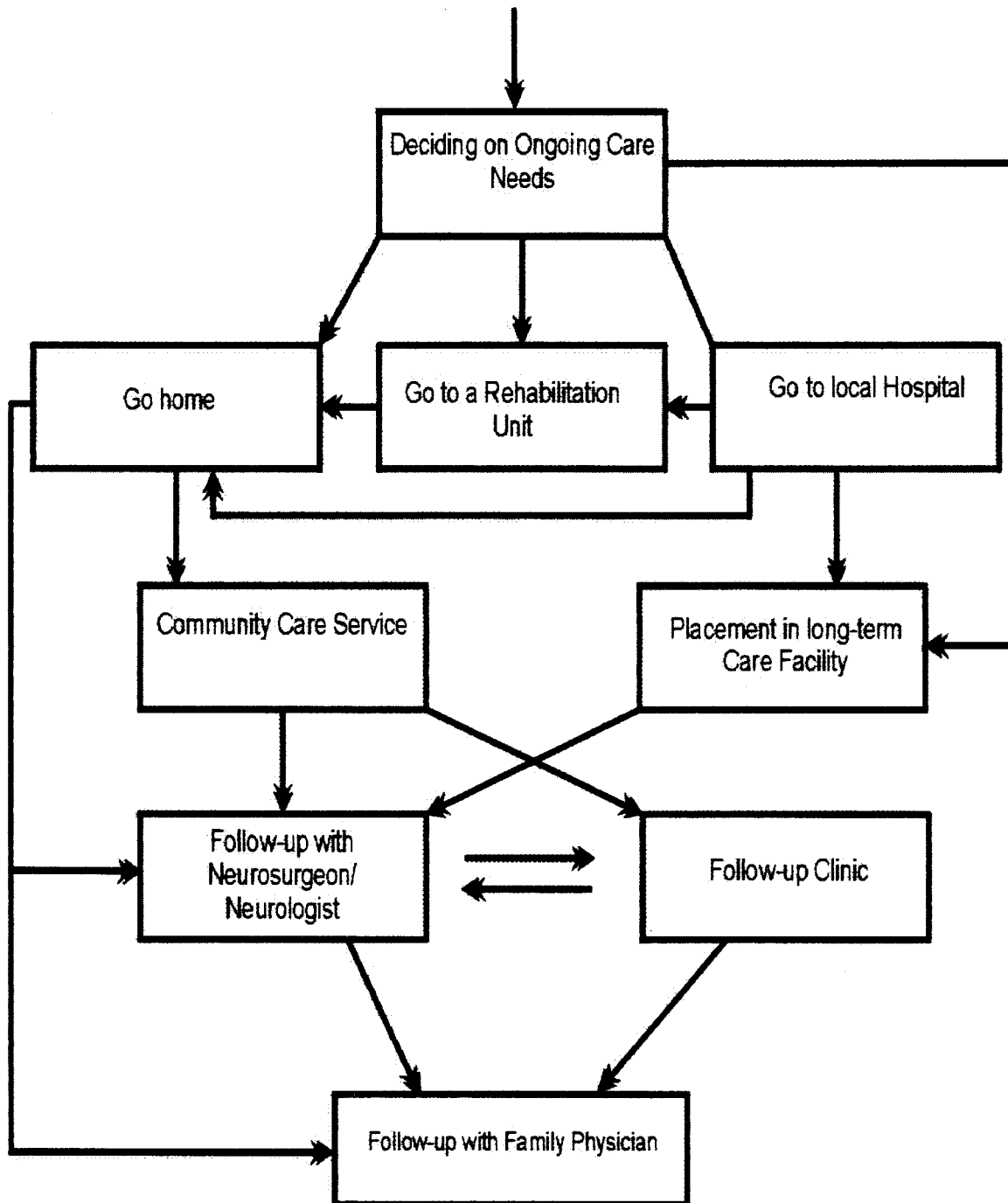


Figure 2: Patient Experience Flowchart
 (Niles, Tarbox, Schults, Swartz, Wolf, Robb, Plume, Nelson & Nugent, 1996 p.325)

NEUROSCIENCE PATIENT FLOW CHART FOR URGENT AND ELECTIVE ADMISSIONS







The *measurement phase* involves determining what data will be collected, who will be involved in the collection, and when, where, and how the data will be collected (Joint Commission on Accreditation of Healthcare Organization, 1995,p.90). Fotter, Ford & Bach (1997) also identified guidelines that may be useful when developing a process or quality plan for measuring patient satisfaction. These guidelines are as follows:

- Use multiple sources when collecting patient data.
- Review the current state of knowledge regarding patient population to be examined.
- Determine gaps in the existing database.
- Achieve “buy in” from the employees and physicians.
- The data collected should be relevant to the needs of the patient.
- The data should help management in decision-making.
- Determine the nature of the patient sample – general or specific groups.
- Pre-test the questions in a pilot project.
- Validate the responses by gathering data on a given sample over several periods.
- Avoid recall error by collecting data within 1 week of patient care service if utilizing an interview technique, and 1 month of patient care service if utilizing a questionnaire.
- Develop the approach to follow the continuum of care.
- Use both open-ended and closed-ended questions.
- Use a wide range of responses.
- Collect data from family / friend of the patient.
- When presenting the results of the patient satisfaction study, determine the timing, the format and the recipients of the results during the design phase of the framework.
- Determine an action plan for changes and assign responsibilities for implementation.
- Communicate results to staff and to patients and their families.
- Compare results with the research literature and surveys conducted by similar organizations (Fotter, et al. 1997,p.238).

The *assessment phase* involves the collection of information regarding the health care organizations and/or their clinical programs current performance, the identification of opportunities for improvement, the determination of priorities for change in patient-care processes, and the identification of causes of problems and means of bringing about improvement. The data can be examined for key quality themes and these can be plotted on the patient flowchart of the care continuum. In the *improvement phase*, the management and staff of the program utilize the data to develop and implement an action plan. The plan should include the development of additional indicators that require further input from the patients. These will be used to evaluate the effectiveness of the change.

For all methods of evaluating patient satisfaction, there are various inherent biases. The researcher / clinical needs to be aware of these biases throughout the research process. The most common are given below:

- Non-response bias – respondents evaluate care more favourably than non-respondents.
- Interviewing results in higher response rates and higher levels of satisfaction than does the use of a questionnaire.
- Timing bias – respondents surveyed before discharge or several months after discharge may express higher levels of satisfaction than those surveyed within a few weeks.
- Response format bias – open-ended questions and questions with detailed scales tend to elicit lower ratings of satisfaction than closed-ended or dichotomous questions.
- Proxy bias – family or friends completing the evaluation for the patient will rate the care more negatively than the patient would. (Fotter et al. 1997,p.230).

These are certain advantages and disadvantages and certain potential biases that are associated with each methodological approach. The advantages and disadvantages of the methodology chosen for this particular project will be discussed after the design stage has been discussed.

CHAPTER THREE

LITERATURE REVIEW- PATIENT SATISFACTION STUDIES

Research on patient and/or consumer satisfaction with hospital-based care has become popular over the past decade. Most of the research has been conducted in the United States and in various European countries. One of the primary reasons for the prevalence of American research is the method of funding hospital care. Given the predominance of private-care hospitals and insurance-based funding, hospitals are very concerned that their patients and families are satisfied so that they will continue to use the services of the hospital and to recommend the hospital to others. Strasser, Schweikhart, Welch and Burge (1995) reported that a dissatisfied consumer tells approximately nine to ten people, whereas nearly twice as many people will hear about a positive experience. In the United States, the cost of a single dissatisfied consumer is estimated to be approximately \$6 000 - \$8,000 per person. The long-term costs to the health care organization are difficult to measure, but it is clear that dissatisfied consumers are costly, both from a fiscal and from a quality of care perspective.

So why the recent surge of interest in Canada, a country with a publicly funded system? The most evident reasons for the increased level of interest in patient satisfaction has been the political trends, changes in funding and service patterns, the rise of quality assurance programs, concern over accreditation of hospital organizations, and recent research supporting patient-focused care. In the past, the providers, such as administrators, physicians and nurses largely determined the nature of the health-care system. However, patient-focused care involves a complete switch in philosophy. The consumer's input is important in determining the most "patient friendly" method of providing care.

Politics plays a major role in the Canadian health-care industry because we have a publicly funded system. The current federal and provincial governments have cut the funding allocated to the acute health-care system and some of the savings are to go to community-based

care. This has resulted in hospital closures, mergers of hospitals, and consolidation of services within each community. A large portion of the funding for acute-care hospital costs is based on Ontario hospitals' abilities to maintain the number of patient-care days per diagnostic group at around the national average. This has resulted in increased pressure to minimize the length of stay for each patient and to shift the care to outpatient community services. Both the health care providers and the consumers of acute-care services are feeling a great deal of pressure. Thus, both the politicians and the health-care providers need data from the patients, so that they can evaluate the implications of these changes for the patient and for the health-care system.

For both the health-care providers and the hospital corporations, the drive to maintain a high quality of care for their patients is central. There are legal, clinical and moral obligations to be met. The trend is towards requiring hospital quality assurance plans. These require not only the collection of the usual types of data (for example, length of stay, infection rate, number of surgeries per year), but also data on the patients' and their families' views of hospital services. The Conference Board of Canada – Quality Health Care sets the standard for the accreditation of Canadian hospitals. In the past seven years, the accreditation standards have changed and the incorporation of a patient-focused perspective is now required. If a hospital wants to receive an acceptable accreditation rating, it must have a quality plan that provides for patient-oriented services. Is this change good or bad? Research on this shift in paradigm, from a provider-based service to a patient-based service, indicates that the following patterns result.

- (a) improved communication between the provider and the patient in the diagnosis and treatment process,*
- (b) patient satisfaction with care is associated with compliance with treatment and with the intent to return for future care,*
- (c) patients' and family members' preferences with regard to care services can help in organizing and planning care,*

(d) patient satisfaction may be a direct or indirect health outcome measure (an example is how well a patient is functioning after a procedure or after treatment in the hospital).

(e) high levels of satisfaction on the part of patients and families is a valid indicator of high quality care.

(Charles, Gauld, Chambers, O'Brien, Haynes, & Labelle, 1994; Cleary & McNeil, 1988; Gerteis, Edgeman-Levitan, Daley & Delbanco, 1993, p.1814)

Since the establishment of acute-care hospital institutions in Canada, limited information has been collected from patients and their families regarding their satisfaction with care. Most hospitals had comment cards for completion on discharge. The only other sources of data were verbal comments and letters of complaint and commendation. Therefore, the research studies discussed in this chapter focus on the limited Canadian data that is available and on the much larger body of research from the United States. In chapters three and four, data specific to the Neuroscience patient population, the Neuroscience Program, and the Hamilton Health Science Corporation regarding patient satisfaction will be reviewed.

REVIEW OF THE CURRENT LITERATURE

A) Canadian Research

Charles, Gauld, Chambers, O'Brien, Haynes and Labelle (1994) conducted a large study in Canada of patients' satisfaction with hospital care. A cross-sectional telephone survey of 4599 medical and surgical patients from 57 hospitals in six Canadian provinces was conducted. The survey was conducted between June 1991 and May 1992. Patients discharged home from acute-care hospitals within the previous three months were eligible to be surveyed. "Data collected included patients' reports about the amount and type of care they received, patients' ratings of satisfaction with their care, characteristics of patients and characteristics of their experience in hospital" (Charles, et al. 1994, p.1815). The hospitals were selected according to size and teaching status. The hospitals had to have 100 or more beds, with at least 30% of the beds being

used for surgical and medical patients. Approximately equal numbers of teaching, academic and non-teaching hospitals were included. Of the 72 hospitals eligible, 57 (79%) participated in the study. Of those hospitals that chose not to participate, lack of manpower to assist was the major reason cited. Each hospital was asked to compile the names of 150 adult patients who had been discharged home (in consecutive order) over the past three months. A total of 4599 patients (69% of the eligible patients and 89% of all of the patients contacted) were included in the study.

The questionnaire used in this study was based on the United States survey of patient-centered care conducted by the Picker/Commonwealth Program for Patient-Centered Care, Boston (Cleary, et al., 1991)(to be discussed later in this chapter). The form was changed on the basis of group input on the current health-care system. It was pre-tested in a pilot project involving 37 patients. The rationale for modifying the American survey form was the necessity of allowing for the nature of Canadian health-care system and for the nature of Canadian society. "There were 39 questions intended to elicit patients' views about possible problems with their hospital care:

- a) *provider's communication with patient, including information given (8 questions)*
- b) *provider's respect for the patient's preferences (5 questions)*
- c) *provider's attentiveness to the patient's physical care needs (4 questions)*
- d) *provider's education of the patient regarding medication and tests (4 questions)*
- e) *quality of the relationship between the patient and the physician in charge (1 question)*
- f) *provider's education of and communication with the family regarding the patient's care (2 questions)*
- g) *provider's management of the patient's pain (4 questions)*
- h) *hospital discharge planning (11 questions)."*

(Charles, et al. 1994, p. 1815)

The questionnaire was evaluated for test-retest reliability with both English-speaking and French-speaking patients. All questions had a 5- point Likert scale for response choice. Demographic data, characteristics of patients and material on their experiences in the hospital were also

collected. Patient consent was obtained either in person, prior to discharge home from the hospital, or by mail, after discharge from hospital. The Institute for Social Research at York University conducted the interviews in both English and French. A computer-assisted telephone interviewing system was used. Statistical analysis was similar to that conducted by Clearly and his colleagues at the Picker Institute for Patient-Centered Care in the United States. An overall score for each patient was calculated on the basis of the participant's responses to the 39 questions. This enabled the researchers to target those areas which patients found problematic. "Relations between the mean number of problems and characteristics of the patient, the hospital stay and the hospital were analyzed" (Charles, et al. 1994, p.1816).

The mean age of the study population was 52 years. Patients' ages ranged from 19 to 91 years. Slightly more women than men were included, and most of the respondents were married. The household income was below \$20 000 for 35% of the group. Most of the patients (61%) were admitted for surgical procedures and stayed less than 2 weeks (83%). Forty percent of the patients had been admitted to the hospital at least once in the course of the previous year. Twenty-eight percent rated their current health as "fair" or "poor".

Charles and colleagues (1994) analyzed the data for statistically significant factors associated with satisfaction / dissatisfaction with care. Appendix One summarizes the results of the questionnaire survey. "The mean number of problems reported per patient was 5.5; the median number was 4. Five percent of the patients reported having no problem with hospital care, and 61% reported 5 or fewer problems" (Charles, et al. 1994, p.1818). The results revealed problems with communication, especially with discharge planning, with explaining procedures and/or medication and with interpreting tests. Adequacy of communication with family and/or significant others was also documented as being an area in need of improvement. The response of the health-care workers to patients' expressed concerns regarding their levels of pain and the adequate management of their pain symptoms were also identified as problematic. The researchers also examined the relationships between the nature of the problems experienced by the patient and

the characteristics of the patients, length of hospital stay, and type of hospital (teaching/ academic/ non-teaching). The results revealed that:

- a) *younger patients reported more problems than older patients*
- b) *women reported more problems than men;*
- c) *patients who had higher levels of formal education tended to report more problems*
- d) *single patients reported more problems than married patients;*
- e) *patients who spoke French as a first language identified fewer problems*
- f) *patients who identified themselves as having poorer health reported more problems (7.5) with their care than those patients in good or excellent health (4.6 problems)*
- g) *patients with emergency admissions reported more problems with their care than did elective patient admissions*
- h) *patients who received care in the intensive care unit reported fewer problems than those patients who had not received this care*
- i) *patients in Quebec and Nova Scotia reported the fewest problems. Ontario and Alberta patients reported the most problems.*

This Canadian study did not find any significant relationships between household income, length of stay, number of previous admissions to hospital, and the type and/or size of hospital (Charles, et al. 1994,pp.1819-1820).

This study had many new and valuable features. The first national and large-scale Canadian survey of patient satisfaction allows for hospital peer-group comparisons within Canada and also for comparisons with other health-care organizations in other countries. The study identifies areas for improvement in patient care; it outlines specific patient populations that require improvements in care; and reveals areas of patient care that require further study. As one would expect, the results are similar to those of other studies of patient satisfaction, which are reviewed later in this paper. The questionnaire explored several dimensions of patient care and was

assessed for test-retest reliability. This provides evidence of the stability of patients' views over time.

One of the major limitations of the study stemmed from the nature of the study sample. The study did not include patients who had been transferred to other health-care facilities, cases of patients who had died, and other patients beyond the medical/surgical patient population. Some of the sickest patients tended to be excluded. The study demonstrated a higher degree of dissatisfaction with care among the patients with previous illnesses. Thus, the exclusion of these kinds of patients biases the results. Of the eligible study population, about 14% of the sample could not be contacted by telephone. It is difficult to know how the loss of this group of patients from the sample may have skewed the results. Charles and colleagues did not distinguish between people who did not have a telephone number and people who did not answer the telephone. These two populations may be very different. The study sample also had a predominantly surgical patient population, and included relatively few medical patients. Surgical patient outcomes may be different from those of the medical patients and/or other patient populations that were not included in the study. These sampling biases could potentially alter the results. Further examination using a broader patient sampling technique would minimize this bias and improve the generalizability of the results.

The 1994 study by Charles and colleagues of patient satisfaction in Canadian patients discharged from acute-care hospitals was methodologically sound. It provided a valuable opportunity to evaluate satisfaction with acute-care services, to suggest opportunities for improvement in patient care, and to provide a base-line for comparison in future Canadian studies. Comparisons can also be made with other countries. This study is currently the only multi-centered Canadian study of patient satisfaction that is available.

B) United States Research

Cleary, Edgman-Levitan, McMullen, & Delbanco (1992) reported on a nationwide survey conducted in the United States on patient satisfaction. In fact, this study was used as the template for the study by Charles and colleagues discussed above. The methodologies of the two studies were very similar. Cleary and colleagues studied 6,455 adults who had been discharged from medical or surgical patient care units in 1989. The questionnaire elicited information on the following matters:

- a) *courtesy and helpfulness of nurses (five-point scale)*
- b) *courtesy and helpfulness of doctors (five-point scale)*
- c) *availability of nurses (five point-scale)*
- d) *organization of hospital staff (five-point scale)*
- e) *cleanliness and comfort of the room (five-point scale)*
- f) *patient preferences for involvement in care (yes/no response)*
- g) *patients preference for information (yes/no response)*
- h) *current perceived level of health (four-point scale) and their expectations for their health after hospitalization*
- i) *billing and financial assistance (yes/no response)*
- j) *social demographic characteristics: age, sex, race, education and income.*

The interview was offered in English and Spanish. As has been described, the questionnaire was slightly different from that used by Charles and colleagues in Canada. Cleary and colleagues had two types of questions – Likert scale and close-ended questions. Their questions reflected American culture and certain aspects of American practices, for example, the importance of financial assistance and billing processes. Charles and colleagues, on the other hand, used Likert scale responses in almost all of their questions, and paid more attention to education, to communication and to the discharge process.

The procedure for the selection of hospitals was similar to that in the Canadian study. Of the 141 American hospitals eligible to participate in the study, only 62 agreed to participate. The most common reasons given for nonparticipation were: lack of staff and/or resources to assist with the study; lack of interest in patient satisfaction; concern over hospital identity being revealed; hospital closures or relocations; unwillingness to comply with protocols; possible interference with the hospital's current internal marketing survey; and/or refusal by the hospital board. Each hospital provided lists of patients discharged home during the previous six months prior to the start of the study. A total of 8,728 patients or their relatives were eligible to be included in the telephone survey. Of these, 239 patients were not eligible because of transfer to other medical or care facilities, readmission, and/or death; 1,128 patients did not complete an interview on account of illness; and 906 patients refused to be interviewed. Thus 6,455 (76%) patients were interviewed.

Cleary and colleagues (1992) used multivariate statistical analysis in order to tease out the impact of various factors on patients' evaluations of their care. "They looked at several possible predictors variables, including (1) patient demographics, (2) patient health status, (3) patient preferences for being more or less informed and involved in their own care, and (4) patient reports on problems that relate to specific processes of care (for example, physical care, emotional care, pain management)" (Cleary, et al., 1992, p.54). The authors concluded that "health status was the strongest predictor of the number of problems reported, even after numerous potentially confounding factors were statistically controlled" (Cleary, et al, 1992, p.56). Generally, the patients were satisfied with their care but the sicker patients gave lower ratings than the healthier patients did, and the older patients were more satisfied with their care than the younger patients were. No other statistically significant findings were noted.

The strengths of this study are the high response rate, the large sample size, and the involvement of many hospitals of various types. The questions probed areas of concern in patient satisfaction that had already been identified in smaller studies conducted by Cleary and by others

in this field. However, the study did have some shortcomings. For example, the study only included medical and surgical patients, who had been discharged home, thus excluding other patient populations, potentially sicker patients who had to go to other facilities and/or those who had died. In addition, the patients had been discharged from one to six months prior to the survey requiring some people to recall events of several months earlier and there is the issue of varying levels of recovery and improvement in health over time. The patients' names were provided to the research team with no information as to whether these patients had experienced successive discharges or whether or not these survey patients had been randomly selected. There could have been biases in selecting the study sample. Fewer than half of the hospitals eligible to take part did so. This decreases the generalizability of the study results.

Gerteis, Edgman-Levitan, Daley & Delbanco (1993) examined the issue of patient satisfaction from both qualitative and quantitative perspectives. These researchers developed the conceptual framework for the study on the basis of patient input. The data from three focus groups of recently discharged medical or surgical patients and their families were utilized in the development of the conceptual framework. The findings on which the conceptual framework was based were verified through open-ended telephone interviews with fifty patients from all parts of the United States. The analysis of the focus group data, analysis of the telephone interviews, and discussions with physicians and other health professionals, gave rise to the seven concepts underlying patient-centered care. These are given below.

1. *Respect for the patients' values, preferences and expressed needs. This involves assessing the impact that the illness has on the patient's quality of life, involving the patient in decision-making, treating the patient with dignity, and understanding and meeting, as much as is possible, the needs of the patient as he/she defines them to be.*
2. *Coordination and integration of care. This refers to the coordination of the patient's clinical care among the physicians, support services and "front-line" staff.*

3. Information, education, and communication. This involves providing timely and readily understandable information to the patient and his/her family regarding the patient's current condition, prognosis and progress. Explaining to the patient the need for the test(s), indicating what to expect during the test(s), and when the results will be available. Finally, education of the patient and significant others on how to care for self and preserve autonomy and health following discharge.
4. Physical Comfort. This refers to providing a clean, comfortable, accessible environment for the patient and his/her family; providing effective and efficient pain management; and providing assistance with personal care.
5. Emotional support and alleviation of fear and anxiety. Caregivers need to be assisted when experiencing anxiety related to clinical condition, treatment and prognosis; the impact of the illness on the patient and his/her family; and the financial impact of the illness.
6. Involvement of family and friends. The need to recognize the family members and friends as part of the care process and to involve them in decision-making as the patient wishes. In addition, supporting families can result in improved patient outcomes.
7. Transition and Continuity. Discharge planning should include the patient in the decision-making. To achieve this, the patient must be informed of his/her options and the regimen of services/ treatment established, with support being provided to meet the patient's ongoing needs.

(Gerteis, et al.,1993, pp. 5-11)

This framework was utilized in additional focus groups with discharged medical and/or surgical patients. These group discussions provided additional qualitative data regarding patient satisfaction.

The conceptual framework and the qualitative data provided the basis for the development of a telephone questionnaire. The researchers wanted to obtain quantitative data to substantiate the qualitative data. A questionnaire contained sixty-two questions relating to the seven concepts of patient-centered care. It was evaluated by health professionals and pre-tested in a pilot project on 400 patients from 14 hospitals across the United States. The questionnaire was designed for both the patients and/or their families. The hospitals chosen for participation were from the 1988 American Hospital Association Survey database. The hospitals were a mixed group in terms of ownership (profit or non-profit) and teaching status (academic and non-teaching). All of the hospitals had more than 100 beds. Of the eligible hospitals, 62 agreed to participate and to supply the researchers with the names of 100 patients who had been discharged from medical or surgical wards within the previous six months. In total, 6,428 patients and 2,000 of their providers were interviewed. Of the hospitals studied, 20 demonstrated high levels of satisfaction and patient-centered care. These facilities were visited, and both staff and patients were interviewed in order to develop a rich database.

The researchers brought together the information from the focus groups, from the national telephone survey, from the hospital site visits, and from their extensive review of the research literature to explore the current levels of satisfaction with patient care. The data was also to be used to assess the current status of patient-centered care in the United States and to develop a better understanding of patient groups who are “at risk” of experiencing low levels of satisfaction. The resulting database is rich and extensive. It would be impossible to summarize all of the information provided by Gerteis and colleagues in their book -Through The Patient's Eyes- here, but some main points will be presented in the next section using the headings from their conceptual framework.

1. Respect for Patients' Values, Preferences, and Expressed Needs

Patients are usually satisfied with the technical quality of care but feel that their needs and their individuality are lost sight of in the process of care. As patients become more

knowledgeable consumers of health care, they demand more input into their care. The patient's cultural values and beliefs regarding his/her illness affect not only his/her understanding of the disease, but also the treatment, and the outcome. Clinicians need to take the time to reach a consensus concerning etiology, diagnostic labels, physiological processes, prognosis, and optimal treatment (Helman, 1990). Most patients want to participate more in their care decisions, but often clinicians do not reveal all of the options with regard to treatment for fear that the patient might choose a less suitable option than the one that the physician would recommend (Waitzkin, 1985). Often the clinician over estimates the time he/she actually spent informing the patient, and underestimates the extent to which he/she discussed the alternative medical procedures with the patient (Waitzkin, 1985). The telephone survey by Gerteis and colleagues showed that 98 percent of the patients interviewed expressed the desire to discuss in greater length the various medical options for treatment (Gerteis, et al. 1993, p.29). In addition, more collaboration and improved communication between health-care providers seems to be needed in order to decrease miscommunication with the patient and his/her family (Gerteis, et al. 1993, p.31). Patients' levels of participation may vary at different times during the course of their illnesses, and clinicians need to be aware of their patients' current levels of participation.

2. Coordination and Integration of Care

Patients expressed the importance to them of feeling that competent professionals were managing their health care. "Patients' judgement about quality and competence are influenced by such things as the training and experience of the professionals who tend them, their ability to diagnose and treat what ails them, the availability of up-to-date equipment, and other more-or-less tangible features of technical quality" (Gerteis, et al. 1993, p. 45). They also speak of "efficiency" in the system and of the need for coordination and integration within the system as a whole. Given the large number of health-care providers involved in clinical observation, decision-making and treatment, each with a different status and with a different area of expertise, it is difficult to tell who is actually in charge and when the various players communicate with one another. In teaching hospitals, 15 percent of the patients did not believe that one particular doctor was in

charge of their care. This proportion rose to 20 percent in academic hospitals and to 40 percent in non-teaching hospitals (Gerteis, et al. 1993, p.49). Clinicians frequently ask the same questions of the patient, and communicate inconsistent messages back to the patient.

Diagnostic and therapeutic procedures are often not explained to patients. No one tells them how long the wait will be, how much pain to expect, and exactly when the results will be available. "Part of the problem is that for most diagnostic tests and procedures, the primary "customer" is the doctor – not the patient (Gerteis, et al. 1993,p.59). What matters are how quickly, accurately, and completely information is conveyed to the clinician to help rule out possibilities or confirm a diagnosis. Patients (or their bodily parts) are the subjects of investigation, in this schema, whose needs and perceptions can easily be overlooked" (Gerteis, et al. 1993, p.56-57). Finally, there are so many front-line workers, each with his/her own job descriptions and his/her own responsibilities, that the patient can not tell who should answer his/her questions or provide assistance. The division of tasks on the ward and the differentiation of roles contribute to the efficiency and cost-effectiveness of patient care, but it does not meet the needs of the patients' and their families (Gerteis, et al. 1993,p.61).

3. Information, Education and Communication

Gerteis and colleagues (1993) reviewed the research literature in this field regarding patient outcomes in cases in which the health-care staff provided effective communication with appropriate and timely information and education. Research shows that patients who receive this are more satisfied with their care, have better recall of medical information, and are more likely to follow their treatment and rehabilitation regimens (p.97). The physicians also experience higher levels of satisfaction with the care they provide, if they not only provide the medical information, but also allow for time for the patients to discuss their feelings regarding the illness. Gerteis and colleagues (1993) found that 42 percent of the hospitalized patients sought more information about their conditions and care than they are provided with, particularly information about the management of pain and discomfort (pp 98-100, 121). As one would expect, hospitalized

patients' needs for information and for certain styles of communication change over the course of their hospital stays and over the course of their illnesses. Patients need time to hear and to assimilate information and some patients find it more difficult than others to deal with uncertainty (Gerteis, et al. 1993,p.100). Cultural values, health status, age, income, and socio-demographic characteristics all affect how information is perceived and how it is utilized. Patients with poor health status, patients of lower socioeconomic status and patients who do not speak English are all vulnerable to experiencing dissatisfaction with their care (Gerteis, et al. 1993, p. 81-86).

According to Evans & Stoddart (1990), health status is determined by many other factors other than the physiological condition. For example, socioeconomic status, physical environment, social environment and genetic endowment all play some part in determining the health and the functional ability of an individual (pp. 1347-63).

According to Gerteis and colleagues (1993) and the other researchers in the field they cite, patient education was found to enhance knowledge, to increase adherence to medical regimens, to improve physical outcomes, to decrease rates of re-hospitalization, and to encourage more effective utilization of health services (pp.96-98). However, patient education ranks low on the list of priorities for in-patient care because of the pressures to decrease length of stay (p.97). Hospital patients are sometimes too sick to learn effectively. The medical model of illness emphasizes pathophysiology. To patients, on the other hand, illness presents a larger problem, the problem of living. "Thirty-four" percent of the patients interviewed felt that they did not receive enough information and education to prepare them adequately for discharge home. Nor were they taught enough about maintaining their health. Often the patients looked to their physicians for their education and disregarded the role of other health professionals in preparing them for discharge home (Gerteis,et al. 1993,p.98). To be effective educators, health-care professionals have to take their cues from patients and families regarding their particular learning needs. If these needs cannot be met in the hospital setting, perhaps community-based care or outpatient clinic education may be more effective. Unfortunately, education and information can only overcome some of the barriers to achieving improved health and function. In the case of patients

experiencing financial problems, social/relationship difficulties and language/cultural barriers, extra efforts should be made to link these patients with the appropriate social and community services, recognizing that there are limited resources available.

4. Physical Comfort

Physical comfort refers to the controlling or alleviating pain, providing for the patient's basic care needs, and minimizing the stresses of the hospital atmosphere. Although technology has advanced significantly over the past two decades, our ability to control pain has not. A review of the research shows that experiencing pain is quite common (Gerteis, et al. 1993,p.121). In their study, Gerteis and colleagues found that 86 percent of the patients had experienced moderate or severe pain. Eighteen percent of these patients also felt that much of their pain could have been alleviated through prompt action by the hospital staff (Gerteis,et al. 1993,p.121). Cohen (1980) found that 75 percent of the post-operative patients he surveyed had experienced moderate or severe pain (p. 272). Donovan, Dillon and McGuire (1987) found that 58 percent of a randomly selected group of patients who had received either medical or surgical services had experienced either moderate or severe pain during the course of their hospitalization.

So why is pain control poorly managed when the technology and medications are available to relieve pain? The literature indicates that individual differences in pain thresholds and in responses to pain make objective assessments difficult and these factors also complicate pain management (Gerteis, et al. p. 122). In 1956, Beecher compared the gravity of wounds in military and civilian surgical patients with their reports of their level of pain. Though the wounds soldiers had suffered during battle were far more extensive than the wounds of a group of civilian surgical patients, only one-third of the soldiers requested analgesic, as compared with 83 percent of the civilian surgical patients. Beecher (1956) found that surgery represented a crisis for the civilian patients. However, for the soldiers, being wounded and undergoing surgery meant that they were released (at least temporarily) from the terrors of the battlefield. Beecher concluded that the

perceived severity of the pain is largely dependent on its meaning to the patient (Gerteis, 1993,p.122).

Other factors that affect the objective assessment of pain are the following -- differences in language, cultural factors, the patient's relationship with health-care providers, the patient's sense of control over their pain, and his/her level of anxiety (Gerteis, 1993,p.123). Clinicians' attitudes towards pain control can also play a significant part in pain management. The available research suggests that most clinicians fear that their patients will become addicted to the narcotics and that they tend to prescribe less than the recommended dosage. Nurses also tend to aim for pain control rather than alleviation. Several studies described by Gerteis and colleagues (1993) show that nurses will give the lowest possible prescribed dosage of narcotics when given a range of dosages to chose from by a physician (pp.122-124).

With regards to basic care needs, Gerteis and colleagues (1993) found that 28 percent of patients felt that the nurses were often too busy to attend to their personal care needs. Fifteen percent of the patients said that they had to wait 15 minutes or longer for their call bells to be answered. In addition, 25 percent of the patients felt that they had been awakened unnecessarily simply to accommodate the nurses' task schedule. Six percent of the patients surveyed noted difficulties in getting assistance in order to go to the bathroom. Seven percent of the patients surveyed had difficulty getting assistance with bathing (Gerteis, et al. 1993, pp. 130-3). These findings are consistent with other research on this topic.

5. Emotional Support

Hospitals and clinicians cannot afford to ignore patients' emotional needs. Research has shown that the patient's emotional state does influence the outcome of his/her illness. Emotional support is associated with compliance with medical regimen, decreases in the need for pain medication, earlier ambulation, earlier discharge home, and increased satisfaction with care (Gerteis, et al. 1993,p.154 – 155). However, addressing the emotional needs of patients can be

expensive in terms of manpower. With cut-backs in the nursing staff and decreased lengths of stay, the provision of time for emotional support may come to be a low priority. Dakof and Taylor (1990) studied 55 cancer patients, in all stages of disease, in order to identify what emotional support they would find most helpful and by whom it should be given. The results showed that expressions of positive affect, the bolstering of the patient's self-esteem, the expression of concern and empathy by the staff, and the showing of special interest in his/her illness were all helpful. Most important were expressions of optimism and hope from all staff members (Gerteis, et al. 1993, p.158). Physicians who provided realistic estimates and expectations, while also offering hope, were viewed as most helpful. Finally, it is important to recognize that each person copes with illness differently and that a person's ability to comprehend information may vary during the course of the illness. Health-care providers need to assess each patient individually and they need to respond to individual differences.

6. Involvement of Family and Friends

Many health-care providers are accustomed to thinking of family as next of kin or relatives. However, this concept needs to be expanded to include anyone that the patient recognizes as being significant or as being involved in his/her care. For the purposes of this paper, the term family will include all of the significant people identified by the patient. Families play many different roles during the course of patients' illnesses. Family members tend to undertake the following tasks.

- *Looking out for the patient's best interests.*
- *Being involved in care and in decision-making*
- *Taking care of the patient upon discharge, if able*
- *Influencing health behaviours which in turn alter the patient's health status, clinical outcomes, and patterns of service utilization..*

The health-care staff should support family members in these tasks. The three major complaints noted by Gerteis and colleagues (1993) and also by other researchers in this field were lack of information, lack of support, and lack of recognition of family member's roles in the patients'

care. These complaints were more prevalent among care partners who were not biologically or legally related, among those who belonged to ethnic minority groups, among patients in fair-to-poor health, and among patients under forty years of age. Research has shown that a family group, which is taught the necessary clinical skills and provided with adequate health information, can assist the patient's recovery. The patient's recovery is influenced by the family through helping to ensure compliance with medical regimen, encouraging the use of fewer health resources, and ensuring that the patient has improved coping behaviours and health outcomes (Gerteis, et al. 1993,p.182 – 185). In addition, health-care professionals and administrators need to appreciate that all family members are present and future customers and that their impressions of the care will affect their future use of the services and also the advice that they give to their acquaintances.

7. Transition – Leaving the Hospital

Traditionally, this aspect of care has been called discharge planning. This refers to the patient leaving the hospital. In a patient-centered model of care, the focus of planning is on the transition into the community. Evidence suggests that improving certain aspects of the transition from the hospital to the community can have benefits for both the hospital and for the patient. For the patients, the benefits are improved health outcomes, better coping skills, and higher rates of compliance with medical regimens. For the hospital, the results are higher levels of patient satisfaction, decreased length of stay, fewer hospital admissions, greater cost-effectiveness, and lower mortality rates (Gerteis, et al. 1993, p.204 – 206).

Is the transition to the community going well? The answer – NO! According to the research of Gerteis and colleagues (1993) and also that of other researchers in this field, planning for this transition is the most important concern of the patients and their families. Most of the concerns relate to the communication between the hospital staff and physicians and the patients and their families. Gerteis and colleagues found that 33 percent of the patients stated that they were not told of the side effects of their medication(s) (p.207). Thirty-six percent of the patients were not told about the possible unfavorable symptoms of their disease and were or how to

monitor these. They were also not told how they could speed their recoveries. Twenty percent of the patients surveyed reported having serious concerns regarding their ability to cope after leaving the hospital, and nearly half of these patients stated that no hospital personnel had addressed these issues prior to discharge. Twenty-two percent of patients stated that physicians and nurses spent less than 5 minutes discussing what to do at home (Gerteis, et al. 1993, p.207-210). Planning for the transition from the hospital to home is an area in which major improvements could be made.

The conceptual framework developed by Gerteis and his colleagues, using both the qualitative and quantitative data, provided both a foundation and a process for this project. Analyses of comments made by patients and families quoted throughout the text provided additional insights into the quantitative data. Reading the book allows one to truly appreciate the vividness and depth of the data. The large sample size coupled with the national scope of this study means that one can generalize from the results. Gerteis and his colleagues link their findings with those of earlier researchers in the field. And, as been mentioned, the findings of the various researchers in this field are consistent with one another.

Telephone surveys do have their limitations. However, these limitations are minimized because the data was supplemented by the focus group findings. The main shortcoming of the study by Gerteis and colleagues was the limited amount of information relating to the non-medical and surgical patients, relating to those patients who were not discharged home, and relating to the families of deceased patients.

Proctor, Morrow-Howell, Albas, and Weir (1992) examined patient and family member satisfaction with discharge planning among patients with complex diagnoses. The study group of patients had admission diagnoses of cerebral vascular accident (stroke), congestive heart failure, pneumonia and/or chronic obstructive lung disease, and/or a recent hip fracture. Patients with one of these diagnostic conditions have many complex needs that need to be considered when

developing a discharge plan. The rationale given for examining this patient population was based on the following considerations:

- (1) their potential for future hospitalization;
- (2) patients with complex illnesses have demonstrated in the literature to have relatively low satisfaction as compared to that of the general population with discharge planning;
- (3) level of satisfaction with care has been linked with family and patient involvement in discharge planning;
- (4) patient satisfaction with care has been linked with previous experiences and expectations;
- (5) the research literature shows, as one would expect, that the elderly and the disabled are the most vulnerable to inadequate discharge planning. This is partially due to the lack of caregiver support and insufficient community services.

(Proctor, et al. 1992,p.264).

The study population consisted of 126 patients and 130 family representatives of the 369 patients eligible for the study in the ten-month study period. The study population was interviewed 24 hours prior to discharge of the patient to his/her home. The patients and their families were asked to give ratings on a 5-point scale as to their perceptions of the adequacy of the discharge plan with regard to the patient's medical treatment and his/her psychosocial needs. Data were obtained on the following: age, race, sex, payment resources, diagnosis, length of stay, cognitive condition at discharge and extent of dependency on nursing for care (according to the Northwest Oregon Health Systems tool completed by the nursing staff). The availability of social support at the time of discharge, the timeliness of the discharge plan, and the degree of involvement of the patient and his/her family in the actual planning were measured by a social worker. The patient's post-discharge destination and the number of formal services (for example, skilled nursing care) and informal services (for example, meal preparation and housekeeping) that were planned for prior to discharge home were recorded.

This study showed that the predictors of perceptions of the adequacy of the care were different for the patients and for the family members. For the patient, the degree of his/her involvement in decision-making was an important variable. Also, patients who were married had higher levels of satisfaction with their medical and social aspects of the plan, because they knew that their spouses would be able to monitor their symptoms and keep them company. Patients who were single had more concerns about the medical aspects of the discharge plan. They were concerned about the level of monitoring of their physical condition available to them in the community. In addition, single males tended to be less satisfied with the psychosocial aspects of the plan because of their need for emotional and social support. The authors hypothesized that single women did not demonstrate this concern because they could rely on the relatively well-developed social support networks available to women in our society. Patients with low levels of physical functioning had rather high levels of concern about the viability of their discharge plans due to their inability to get out of the home without assistance. Patients with chronic illnesses, for example, lung disease or heart failure, had more concerns about the medical aspects of the plan because of the frequent health changes that they experience.

The adequacy of the discharge plan as perceived by the family was related to four main variables. One of the important variables was the patient's competency to make his/her own decisions. When the patient was unable to make decisions, the family felt that the patient's spouse should make the decisions. If the patient was single or if the spouse was unable to participate, the family expressed greater concern with regard to the adequacy of both the medical and the psychosocial aspects of the discharge plan. A second important variable was the amount of time that the social worker and staff spent reviewing the discharge options. Thirdly, the number of options that were considered was also positively correlated with a positive outcome following discharge. Finally, the number of dead-end options that were actively pursued was negatively associated with family satisfaction with the plan. These findings indicate the importance to family members of the time invested by professionals in making decisions relating to discharge. In this cost-conscious era, this level of service is difficult to maintain.

In Procter and colleagues study (1992), the social worker identified several factors that sometimes complicated the discharge planning process. These included:

- (1) lack of patient cooperation (14%);
- (2) lack of family cooperation (8%);
- (3) limited availability of family to participate in planning (13%);
- (4) Medicare guidelines (8%);
- (5) unexpected medical complication (12%)
- (6) financial problems (18%).

(Proctor, et al. 1992,p. 266).

A major strength of the study was its focus on discharge planning for a complex patient population. This patient population, albeit not identical to the Neuroscience population (except in the case of the stroke population), did legitimized the issues that the Neuroscience team addresses when planning discharges. The examination of both the medical and the psychosocial aspects of discharge planning from the perspectives of the patients and their family members provided some useful insights into the differing needs of these two populations. A major limitation to the study is the fact that the data was collected prior to discharge. It is widely known that the collection of data whilst patients are still in the care of the health providers will result in higher ratings than if the data was collected from patients when they are discharged. For example, patients and families may fear that giving a poor rating may affect their access to care in the future. Secondly, only 44 percent of the eligible cases were interviewed, thus casting doubt on our ability to generalize from these results.

Sanguinetti and Catanzaro (1987) examined the consequences of discharge education for the family preparedness to meet the needs of patients who are cognitively impaired because of a brain injury. Nine patients in the control group received the standard discharge education program. Twenty-nine families received the standard program plus additional education and an

open discussion period. These families were tested prior to discharge on their knowledge level and their ability to cope following discharge. The results showed that members of the group that received the extra education and the extra time received higher scores in their knowledge levels and had higher levels of satisfaction. Are these positive outcomes related to the extra time spent by the professionals, as is implied in Procter and colleagues (1992) in their study described above, or to the actual knowledge that is passed on to family members? Or are they both related? The sample size is very small and the study is limited because no attempt was made to actually assess the families following discharge. Unfortunately, research on the cognitively impaired is very limited.

Although the research literature discussed above does not focus on patient satisfaction among the Neuroscience population, it does provide a foundation for the further examination of this population. The research also highlights important aspects of patient care that should be studied in the Neuroscience patient population. In the next section, I will describe the Neuroscience population and the Neuroscience Program at the Hamilton Health Science Corporation.

CHAPTER FOUR

THE NEUROSCIENCE PATIENT POPULATION
&
THE NEUROSCIENCE PROGRAM

A neurological patient is a patient with an acute or chronic neurological disorder of the central nervous system, which includes the brain and the spinal cord. The Neuroscience Program at the Hamilton Health Science Corporation is a regional referral center for adults experiencing disorders of the nervous system in Central West Region (see map below).



Figure 3: Central West Region

(Neuroscience Annual Report, 1998,p.1)

The role of the Neuroscience Program is to provide “exemplary and comprehensive care for persons’ with neurological problems and their families” (Neuroscience Vision, 1997,p.12).

Neurological and Neurosurgical care has been available for over forty years. During the past two years, four of the major Hamilton hospitals have merged to form one large hospital, the Hamilton Health Science Corporation. With this merger came the shift to program management. As a result, the Neuroscience Program evolved as an interdependent program. The management structure is given in the diagram below.

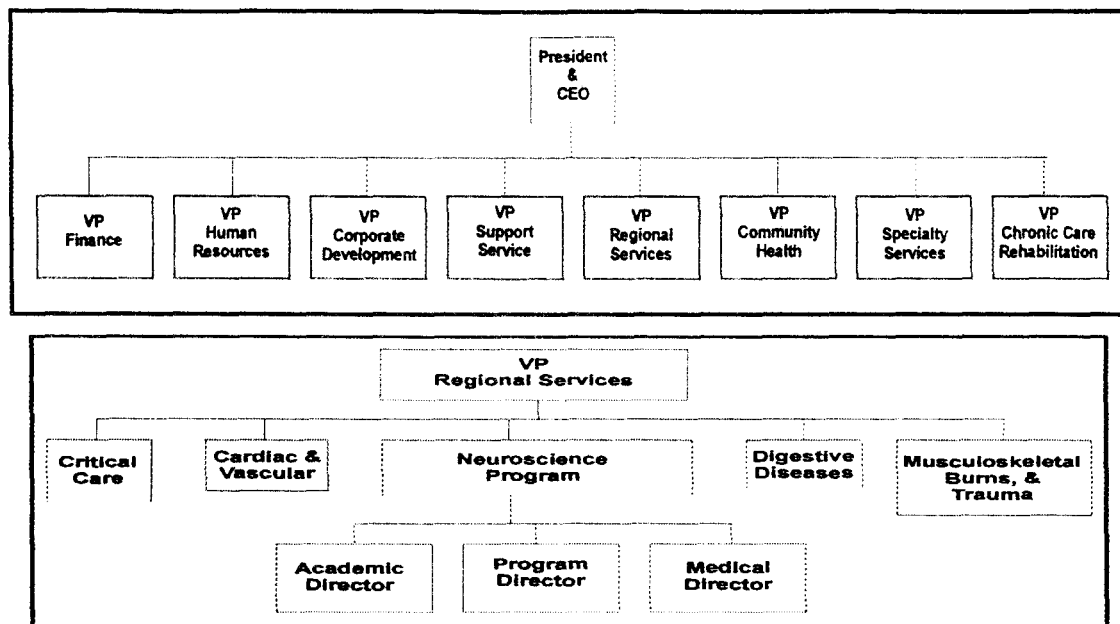


Figure 4: Hamilton Health Science Corporation, Management Structure

(Neuroscience Annual Report, 1998, p.14 & 16)

When the General and Henderson Hospitals merged in 1997, the Neuroscience Program developed a vision statement on the care of the adult neurological patient. Following the inclusion of McMaster Hospital in the corporate merger, this vision statement will have to be revisited. The

VISION of the NEUROSCIENCE PROGRAM	
OUR ROLE	The Neuroscience Program will provide exemplary and comprehensive care for persons with neurological problems and their families. We will strive for excellence in all aspects of clinical neuroscience, including health care, education, and research. We will collaborate with others in our hospitals, our community, and our region as vigorous and helpful partners, welcoming both our responsibilities and our interdependencies.
POPULATION FOCUS	The Neuroscience Program will provide a full spectrum of clinical services to all adults in this community who present with acute or recurring neurological disorders. Services will adapt to demographic changes prospectively. They will respect the many cultural and religious diversities that exist in our community. The Neuroscience Program will be active in the Central West region as a provider of tertiary level care for neurological and neurosurgical disorders. Its members will cultivate close and mutually supportive relationships with colleagues in other areas of our region and with those who work in clinical neuroscience elsewhere in our province and nation. They will maintain strong links with community organizations in order to work together to provide optimal service to both local and regional populations of persons with neurological problems.
DELIVERY OF CARE	Care delivery will be patient focused. It will be provided by an interdisciplinary team and based upon the needs and wishes of the patient and his/her family or close associates. We will endeavour continuously to advance the quality of clinical service. We will monitor costs and benefits of current treatment and will adopt new treatments, technologies, and methods of care as soon as possible after they are found to be more efficacious.
ACADEMICS: EDUCATION AND RESEARCH	We will promote educational and research activities which hold promise for bringing better care for neuro patients in the future. We will support systems of reward, accountability, and remediation relative to teaching, learning, and research activities. We will continue to promote and operate scholastic and service alliances within the domains of our program. Research methods will be adopted to monitor and evaluate outcomes of cases in order to identify strengths and weaknesses in current practice. Independently and in collaboration with others, members of the Neuroscience Program will test hypotheses in an ethical and systematic manner and will report the results of their investigations to peers and public in journals and at scientific meetings.

Table 1: Neuroscience Program Vision

(Neuroscience Program Annual Report, 1998, p, 12)

The clinical activities of the program are conducted in outpatient clinics and also in inpatient settings. The outpatient clinics are scattered throughout the Hamilton Health Science Corporation, at the General, Henderson and McMaster hospital sites. For inpatient care, the patients are admitted to the general medical wards at the Henderson and McMaster hospital sites. However, at the General Site, an inpatient ward has been designated specifically for Neuroscience patients. All of the adult Neurosurgical activity is conducted at the General site. The Neurosurgeons and the Neurologist on staff at the hospital are the only physicians with admitting privileges to the Neuroscience patient care unit. Patients can be admitted on an elective basis or urgently, usually via the emergency room or by direct referral, to the Neuroscience ward, to the Neuroscience Step Down Unit (i.e. increased observation unit), or to the Intensive Care Unit. The care is provided by the neurological team described in the chart. The composition and the responsibilities of this team are currently being redesigned. Responsibilities have been redefined and new positions and roles, with new titles, have been developed. By the year 2000, environmental aides, health care aides, and business clerks will be supporting and assisting with the patient care. These employees will replace the Registered Practical Nurses (RPN) and the ward clerks.

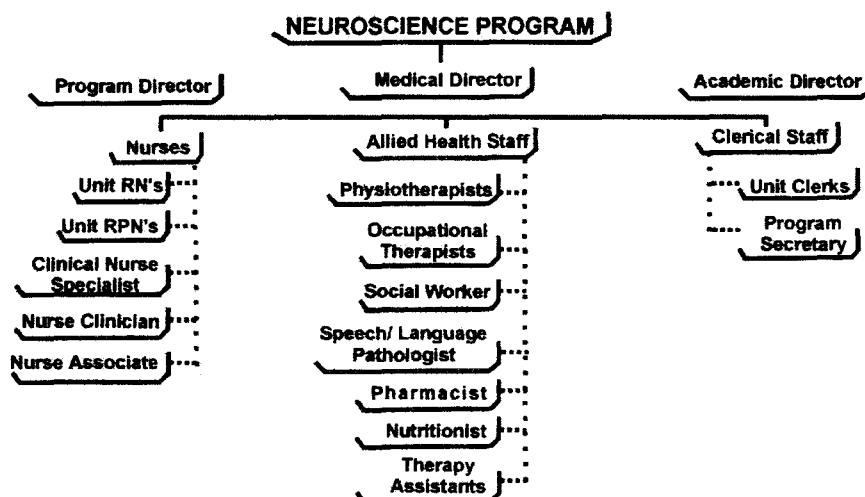


Figure 5: Neuroscience program structure
(Neuroscience program annual report, 1998, p.16)

Figure 5: Neuroscience Program Structure

(Neuroscience Program Annual Report, 1998, p. 16)

The Neuroscience Program works in collaboration with other programs and specialized services within the organization to provide care to the inpatient population, for example, critical care, trauma, vascular, endocrinology, orthopedics, thrombosis, radiology, general surgery and medicine. Most of the diagnostic tests that are required are available at the General Site. However, patients who require a magnetic resonance imaging (MRI) have to be transported to the McMaster site. The General site is to obtain a MRI in the near future. Endovascular neuroradiological procedures are primarily completed in our neighbouring Neuroscience centres in Toronto, Mississauga, and London. However, we hope to be developing this aspect of care at the General site in the near future.

For the purpose of this project, only adult patients admitted to the Neuroscience patient unit at the General site (7 South) will be reviewed and a methodology developed to examine their levels of patient satisfaction. In the future, methods for collecting and comparing data from neurological inpatients admitted on other patient care units throughout the Hospital Corporation, and from outpatients receiving care in the Neuroscience clinics, will need to be developed.

The Neuroscience Program at the General site has been developing a database on its patient population since October 1996. All patients admitted or discharged under the care of a Neurosurgeon and/or Neurologist are included. However, the database does not contain information about neuroscience inpatients at the other hospital sites within the Hamilton Health Science Corporation, outpatients from the neuroscience clinics and/or pediatric neuroscience patients. Patients are grouped in the database according to diagnoses. "It includes numeric codes from the International Classification of Disease so that comparisons can be made with similar populations elsewhere. Diagnoses are grouped into categories. These categories are as follows: *hydrocephalus, infection/inflammation, multiple sclerosis, neoplasia, operation problem, other, pain, seizure, spinal degenerative, trauma, and vascular*" (Neuroscience Annual Report, 1998, p.24). Appendix 2 outlines the diagnostic groups with the corresponding diagnoses. The data regarding the numbers of patients discharged with these diagnostic categories are also given in

Appendix 2 (Neuroscience Annual Report, 1998,p. A2-4). These statistics provide useful information regarding the patient population to be evaluated. However, to a lay person, these diagnostic groupings may be confusing. The diagnostic categories will be described briefly outlined using some *very* general definitions.

- *Hydrocephalus* refers to the accumulation of excess fluid within one or more of the chambers in the center of the brain.
- *Infection/Inflammation* refers to the inflammation and/or infection of the brain and/or spinal cord as a presenting problem or secondary to a procedure.
- *Multiple sclerosis* is a disorder characterized by progressive destruction of the myelin sheath that covers and insulates nerves of the brain and spinal cord white matter. Each patient can have different levels and types of impairments depending on the exact area and degree of the brain and/or spinal cord affected.
- *Neoplasia* refers to a collection of abnormal cells, which can be either benign or malignant or a combination of both, within the brain and/or spinal cord. These neoplasms are also commonly referred to as tumors. They can generate from the central nervous system (i.e. primary tumor) or migrate from other areas of the body to the central nervous system (i.e. metastases).
- *Operation Induced Problems* refers to complications as a result of the surgery.
- *Other* category has a variety of acute and chronic neurological conditions.
- *Pain* refers to the diagnostic reason for admission. Common sources for pain is migraine, headache, and lower back with or without nerve involvement.
- *Seizure* is the result of brain tissue irritation that may be idiopathic or may result from injury, surgery or a space-occupying lesion. The person experiences uncontrolled movement of part or all of the body.
- *Spinal degenerative* refers to a variety of spinal cord diagnoses related to the deterioration or abnormality of one or more of the components of the spine, that results in pain and/or deficits.

- *Trauma* refers to an injury of the brain and/or spinal cord. These patients may have minimal to extensive damage resulting in varying degrees of recovery or in death.
- *Vascular* refers to the blood flow within and to the brain. Patients have an elective procedure in order to improve the blood flow to the brain or to prevent the rupture of a blood vessel with an abnormality in its structure. Other patients with vascular diagnoses have sustained a bleed (hemorrhage) within various regions of the brain. This can result in varying degrees of recovery, or in death.

The total number of inpatients between October 1996 to September 1997 was 1,230. Of this number, 691 were male and 539 were female. The age and gender distribution is given below in Figure 6. Of the total patient population, 564 were from Hamilton Region and 666 were from surrounding communities primarily within the Central West Region. Figure 7 indicates the number of patients in each diagnostic group (Neuroscience Annual Report, 1998,p.24). The top four patient groups were vascular, neoplasia, trauma and spinal degenerative.

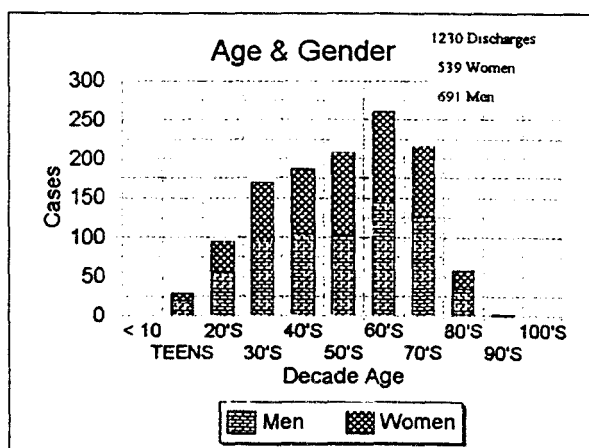


Figure 6: Age and Gender Distribution

(Neuroscience Program Annual Report, 1998, p.28).

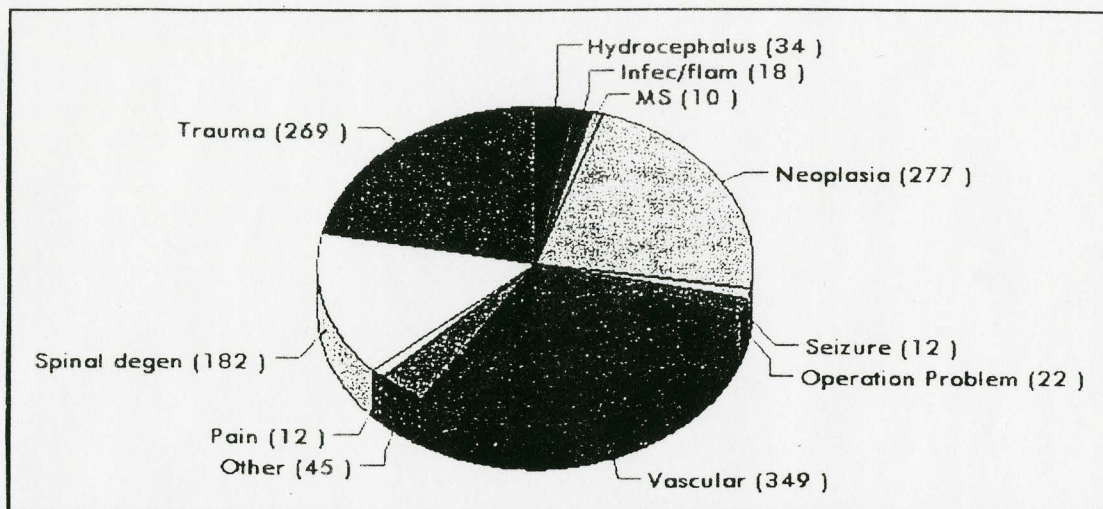


Figure 7: Types of Neurosurgical / Neurological Cases
(Neuroscience Program, Annual Report, 1998,p24)

The mean length of stay as an inpatient for all diagnostic groups was 14.6 days. Patients with a short length of stay in hospital from 1–7 days were primarily elective patients, for example those undergoing carotid endarterectomy, brain tumor biopsy, lumbar and cervical disc removal, and pituitary tumor removal. Among those with medium length of stays of 8–20 days were both elective and urgently admitted patients. Diagnoses ranged from closed head injury, bleed (hemorrhage) within different regions of the brain, and tumors. Patients with longer lengths of stay, ranging from 20 days to a year, included those with more acute and unforeseen illnesses and those with more extensive neurological disorders and disabilities, such as spinal cord injuries, aneurysm ruptures, cerebral infarction, and hydrocephalus (Neuroscience Annual Report, 1998,p.48-50).

Of the 1,230 patients, 112 patients died after admission to the hospital. Of these 112 patients, the three main diagnostic groups were vascular (60), trauma (33), and neoplasia (16). The mortality rate for the neoplasia population may be lower than the actual number of deaths recorded. This is probably related to the transfer of the patient's care to an oncologist at the Hamilton Regional Oncology Center, to begin the next stage of treatment. Eighty-three percent of the deaths involved acute admissions. The mortality rate in this group was substantial in all age groups (Neuroscience Annual Report, 1998, p.52-53).

The Neuroscience patient population experiences varying degrees of disability and handicap. Some patients make complete recoveries. Other patients continue to experience physical, cognitive, communication deficits, personality and/or behavioural changes. Currently, the Neuroscience database is not able to evaluate the health burdens in a detailed manner. However, a Karnovsky score, which is a measure of global function and burden of illness, was obtained for patients in the final 5 of the 12 months reported in the annual report. The Karnovsky score is a crude measure of the patient's overall ability to function. It does not identify the patient's actual disability(s). The Karnovsky scale is summarized below.

KARNOVSKY SCALE

- 0: Dead
- 10: Moribund
- 20: Very sick; active supportive care needed
- 30: Severely disabled; hospitalized; death not imminent
- 40: Disabled; requires special assistance
- 50: Requires considerable assistance and frequent care
- 60: Requires occasional assistance; cares for most of their own needs
- 70: Cares for self; unable to carry on normal activities
- 80: Normal activity with effort; some symptoms
- 90: Carries on normal activities but with minor symptoms
- 100: Normal with no complaints or evidence of disease

The Karnovsky scores were only collected on patients discharged in the last 5 months of the Neuroscience database. The total Karnovsky scores for patients discharged in the past 5 months is shown below in Figure 8. A detailed account of the Karnovsky scores for the 11 diagnostic groups is provided in Appendix 3.

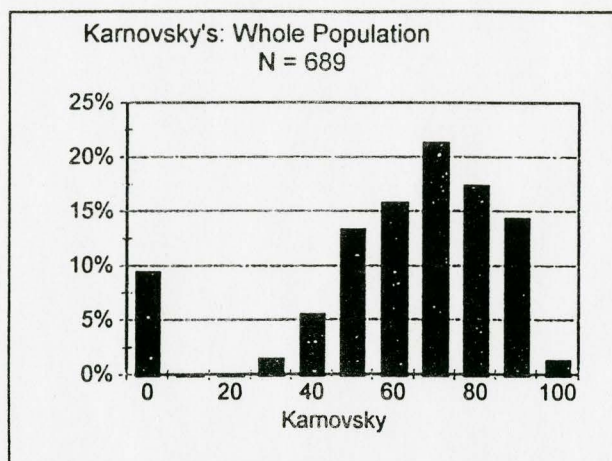


Figure 8: Karnovsky Scores – Whole Population
(Neuroscience Annual Report, 1998, p.62)

The information that has been provided can assist us in understanding the complex nature of the Neuroscience inpatient population. These patients have a wide range in severity of illness, length of stay, age, and likelihood of disability or death. As was discussed in the previous chapter, little research was available on the Neuroscience patient population and their satisfaction with the hospital care. One question remains. Are the Neuroscience patients and their families different from the general medical and surgical patient population that is discussed in the patient satisfaction literature? My view is that there are differences in the patient care needs of the Neuroscience patient population and that these differences need to be taken into account when evaluating patient satisfaction.

When one reviews the research literature, the following studies suggest that there are probably some differences. Newton and Mateo (1993) reviewed strategies for assisting patients and families with the uncertainty of cancerous brain tumours. It was noted that uncertainty is common in both the acute and chronic phases of the disease process. However, the degree of uncertainty and level of stress was notably higher among patients who had experienced cognitive, language and/or behaviour changes. The need for support and for current and relevant information

provided in a timely manner was a basic need expressed by all patients and by all families at each stage in the progression of the disease. These needs were significantly more pronounced among the caregivers of patients with cognitive, behavioural or personality changes.

Corrigan, Smith-Knapp and Granger (1998) reviewed the outcomes during the first 5 years after traumatic brain injury. They found that patients who were physically and cognitively well enough to resume most of their previous activities experienced continued improvement. However, it was noted that these patients had relatively high scores on the depression scale and relatively low test scores in societal functioning assessments, in comparison with those of the general population. Those patients with more significant cognitive and/or behavioural deficits also had problems with depression and social relationships. These led to further problems with regard to community and social integration. They were also associated with lowered productivity and caregiver stress. In addition, increased rates of substance abuse were also noted in the patient population studied.

When one examines the research on family satisfaction and family needs in the Neuroscience population, three articles seem to stand out as being especially important and worthy of discussion. Jane Stover-Leske has published numerous articles on family needs during the critical-care phase of care. In 1992, Stover-Leske conducted an empirical review and summary of the research on family needs. The most important three needs that were identified were the need for hope and assurance, the need to be near the patient and to be involved in his/her care, and the need for timely, understandable information. Are these needs different in the families of Neuroscience patients? Mathis (1984) conducted a study comparing the needs of families of patients with and without head injuries. Engli and Kirsivali-Farmer (1993) replicated this study. Both studies showed that the needs were similar, but that the degree of importance and the rankings of needs were different. In the case of the head injury families, the need to have questions answered honestly, to be offered hope, to have explanations given in understandable language, and to be informed of specific facts concerning the patient's prognosis was central.

Although these families ranked proximity as important, information and hope were ranked much higher. The authors of these two studies hypothesize that these needs are greater because of the mental status and the personality changes associated with acute brain injury. The cognitive changes are considered to give rise to higher levels of stress than do the physical disabilities.

Stenager and Stenager (1992) reviewed and critiqued the research on suicide risks among patients with neurological diseases. They examined the research on patients who were diagnosed with multiple sclerosis, epilepsy, Huntington's chorea, traumatic spinal cord lesions, cranial trauma, brain tumors and migraine. They concluded that the research on patients with multiple sclerosis and traumatic spinal lesions was reliable, and that the risk is significantly higher than in the general population. For the cranial trauma (i.e. brain injury) patient, the evidence was that the risks were significantly higher for these patients, but the research studies were not current. Only case-study reports were available for the vascular and migraine population. Epilepsy, Huntington's chorea and brain tumor studies all showed increased risk of suicide, but in order to accurately determine the extent of risk, large-scale studies are needed.

In all patient care there is varying degrees of unpredictability and uncertainty. According to the research discussed above, the acute and unforeseen illnesses, such as brain injury, brain hemorrhages, traumatic spinal cord injury and brain tumor, have a high degree of stress associated with them. This stress is most evident in families when the patient experiences cognitive, personality and/or behavioural changes. These diagnostic patient populations were identified in the Neuroscience Annual Report (1998) as having the medium to long lengths of stay as inpatients in the hospital. Part of the reason for these longer stays was the need for medical observation and management. However, a major problem is the lack of available inpatient rehabilitation, community-based services and appropriate living environments within the Central West Region (Neuroscience Regional Access Team Report, 1998, p.32; Neuroscience Annual Report, 1998, p.51).

The rehabilitation beds are limited and access to these beds is limited by the lack of community services available to meet the needs of their discharged patients. Although the current government refers to there being increased levels of care in the community, the complex neurological patient does, in fact, experience greater difficulty in living in the community because the necessary services are either extremely limited or non-existent. The situation leads to high levels of frustration for the patient and family who have to deal with the delays and with the inadequacy of services, combined with the uncertainty about the degree of recovery and risk of further medical complications. This high level of stress contributes to dissatisfaction with care.

With regard to the question that was raised earlier— is the neuroscience patient population different from the general medical and the surgical populations? The answer is both “yes” and “no”. The patients and their families still have care needs that are similar to those of the general patient population, as was described earlier in the review of the existing research. The difference is that some neurological patients have significant impairments and/or poor prognoses. This population has unique care needs and must face special challenges. These needs must be taken into account when developing an appropriate methodology for evaluating patient satisfaction. To begin, we must first reflect on what we already know about the level of patient satisfaction within the Neuroscience Program and within the Hospital Corporation as a whole. This information will enable us to narrow the scope of the evaluation and to pay particular attention to previously neglected areas that require special attention.

CHAPTER FIVE

THE CURRENT KNOWLEDGE REGARDING PATIENT SATISFACTION IN THE NEUROSCIENCE PATIENT POPULATION

The Neuroscience Program has collected a limited amount of data relating patient and family member satisfaction with care. The three main sources identified are: (1) the Neuroscience Focus Group, (2) letters of complaint and commendation, and (3) the hospital's patient satisfaction survey. These three main sources of data will be described below.

NEUROSCIENCE FOCUS GROUP

In 1996, the Neuroscience Program evolved as a separate program within the Hospital Corporation. The Program was charged with the responsibility of monitoring and improving the quality of care. The Neuroscience planning team felt that it was important to collect data from a variety of sources in order to evaluate existing practices and plan for future care. One of the most important sources of information is the patients and families that we serve. Initially, the goal was to identify priorities for change and to identify those aspects of care that were/were not meeting the patients' and families' needs. The plan was to collect qualitative data from patients and families in the context of a focus group. The goal was to examine themes in patient comments regarding their current level of satisfaction with care and to identify opportunities for improvement. This information would be compared with the general body of research on patient satisfaction. The long-term plan involved the development of quantitative and qualitative methods to monitor and evaluate patient and family satisfaction. The Neuroscience Program saw this as part of its ongoing quality improvement plan (i.e. this is the current focus of this project outlined in this paper). The methodology utilized, and the results and various

limitations of the study will be discussed below. Because I served as a co-chair of this project, I can comment on the process and on patients' and family members' responses.

The patient sample was obtained by selecting twenty-five patients each from five frequently encountered diagnostic groups. These diagnostic groups were recognized as characteristic of a large proportion of the Neuroscience patient population. These five major groups were (1) neuro-oncology/ neoplasia; (2) trauma; (3) spinal degenerative; (4) vascular – unforeseen hemorrhages/bleeds and (5) neurological degenerative diseases (e.g. multiple sclerosis, Parkinson's disease). The names of patients were obtained through medical records, and names were selected according to diagnosis, discharge date (those who died in hospital were excluded), and hospitalization within the previous six months on the Neuroscience ward at the General site of the Hamilton Health Science Corporation.

The patients were mailed a letter of invitation outlining the purpose of the study, the types of sessions planned, and the confidentiality procedures and protocols. A self-addressed stamped envelope was included for the response card. Of the 100 patients contacted, 20 patients wrote that they would attend with a family member; 21 patients wrote that they did not wish to attend; 4 patients had died since discharge (these were neuro-oncology patients); 3 envelopes were returned unopened with no forwarding address given; and 52 patients did not respond. Of the 21 patient who did not wish to attend, 18 belonged to the spinal degenerative group and some of these people were unable to attend on account of work or personal commitments. Three of these 21 patients were from the trauma and vascular group and they stated in their replies that visiting the hospital would be "too painful" and that the patient would "relive the experience of being sick".

On the day of the session only 11 of the 20 patients who had agreed to participate actually attended. Prior to the commencement of the session, consent was obtained using the standard written consent form used by the hospital. The consent form indicated that the information obtained was to be used for research purposes. No personal information would ever be shared with other health professionals. In addition, before the focus group started, the participants were asked to fill out a questionnaire (Appendix 4). The questionnaire was anonymous. Respondents were asked whether patient, a family member, or friend had completed the form. Data on age, reason for hospital stay, length of stay, details relating to positive and negative aspects of care, any communication and/or language difficulties, any unmet needs relating to cultural or religious background were elicited. The questionnaire also requested comments about the various stages of the hospital stay. Finally, the participant was asked to rank on a 5-point Likert scale his/her assessment of the health-care team. The team was rated on its ability to be open and receptive, to be honest, to demonstrate care and compassion, to be respectful, and to provide patient care. The emphasis was on obtaining data relating to the variables affecting patient satisfaction and information that was directly pertinent to defining patient needs.

The focus group was led by a trained facilitator employed by the corporation. The session was to have been tape-recorded. A recorder, who was not a participant in the group session, was responsible for recording non-verbal information. Unfortunately, the group did not wish to be tape-recorded due to the fear that their physicians and/or members of their health-care teams might recognize their voices, and that their future care might be affected. An alternate solution was reached by consensus. The recorder was asked to note down the main points on a flipchart so that all participants could view them. After each comment, the recorder would verify that the written statement was correct. The session lasted 2 hours, including the refreshment break.

The data collected during the session were given to three individuals with expertise in qualitative research and/or neuroscience patient care. These three people reviewed the material seeking themes and relationships. The data from the questionnaires were tabulated. The responses to the open-ended question were reviewed for themes. The three evaluators compared their findings in order to draw conclusions and validate their interpretations.

Questionnaire Survey:

Eleven people completed questionnaires. Below is a summary of their responses.

- 1) Age: 73% (8) participants were aged 50 years or more
27% (3) participants were aged 16-24 years
- 2) Length of Stay: 64% (7) participants stayed 15-30 days
9% (1) participant stayed longer than 30 days
27% (3) participants stayed 8 – 14 days
- 3) Diagnostic Categories: Vascular – 5 participants
Trauma – 3 participants
Neurological diseases – 3 participants
- 4) Positive and Negative Comments: 2 respondents. Both respondents expressed concerns about communicating negative comments regarding their care because of the fear of future repercussions with their physicians and the nursing staff.
- 5) Language / Communication: 3 respondents. These people felt that positive efforts were being made to assist with differences in language and with the use of communication boards in the case of patients with communication impairments.
- 6) Cultural Needs: 3 respondents. These people felt that positive efforts were being made to meet their needs.
- 7) Process of Care: 11 respondents. These people expressed concern regarding the lack of continuity in care from one area in the hospital to another or from one member of the team to another. In addition, these participants identified poor communication as a

problem in discharge planning. For example, they complained of the lack of notice regarding upcoming discharge, the limited discussion of discharge options, and lack of opportunities to discuss caregivers' and patients' concerns regarding their ability to cope at home.

8) Evaluation of Health Care Team:

Open and Receptive	- 2 respondents – scored 1 (poor) - 9 respondents – scored 3 (average)
Honest	- 7 respondents scored 3 (average) - 4 respondents scored 4 (above average)
Caring and Compassionate	- 8 respondents scored 3 (average) - 3 respondents scored 4 (above average)
Respectful	- 2 respondents – scored 2 (below average) - 6 respondents – scored 3 (average) - 3 respondents – scored 4 (above average)
Direct Patient Care	- 1 respondent – scored 2 (below average) - 2 respondent – scored 3 (average) - 4 respondents – scored 4 (above average) - 4 respondents – scored 5 (excellent)

The patients indicated that they completed the questionnaires themselves, but the recorder noticed that all family members assisted them with reading, interpreting and/or writing some of the responses. Therefore, both patients and family members were, together, providing opinions and information.

Focus Group Themes: (given in order of frequency)

(a) The respondents commented on the need for current medical information from the physicians regarding the patient's condition.

- (b) The respondents commented on the limited period of time that they had with the physician(s) for the discussion of the patient's condition and prognosis.
- (c) The respondents commented on the inconsistencies in the information provided to them by the physicians, nurses and therapists during the course of the patient's hospitalization.
- (d) The respondents were reluctant to make negative comments regarding care for fear that this would affect the patient's future care.
- (e) The respondents commented on their lack of preparation to provide for all of the patient's needs.
- (f) The respondents commented on the need for more information regarding the community services available and their limitations.
- (g) The respondents spoke of their need for additional education to assist them with managing the cognitive impairments of the patients following discharge.
- (h) The respondents outlined the need for additional education regarding skills such as transferring, mobilizing and bathing patients following discharge.
- (i) The respondents expressed concerns about not being able to readily access acute-hospital services following discharge. This was a concern when families were uncertain as to how they would manage the patient's care at home.
- (j) The patients and families commented on the lack of expression of hope when discussing prognoses.
- (k) The respondents commented on the lack of privacy when patients and medical staff were discussing prognoses.

The data from both the questionnaire and the focus groups appear to be consistent. As has been discussed, these kinds of concerns have already been identified in the existing research on patient satisfaction.

The study does suggest areas that need further exploration within the neuroscience population. However, the study has some limitations that must be noted.

The sample size is very small. Many qualitative studies have small samples. However, when compared with the 1,230 patients outlined in the Neuroscience Annual Report for 1997, eleven patients and their family members is a very small group in the total patient population. Patton (1990), in his book titled Qualitative Evaluation and Research Methods, notes that intensive research on a homogenous group of eight to ten people can be a useful means of obtaining rich and useful information (p.173). But do these eleven focus groups participants represent a homogeneous sample of the neuroscience patient population? Or are we dealing with an extreme group?

A homogeneous sample can represent a subgroup in a population. Neuroscience patients are a subgroup of the general patient population. They receive specialized services for patients with neurological diseases. Within the neuroscience patient population, there are further homogenous subgroups, as evidenced by the division in the sample population into diagnostic groups. There were no participants from the neuro-oncology or spinal degenerative diagnostic patient population. However, the sample population did represent the normal range in terms of length of stay. There was some diversity in age, and there were participants from three of the five major diagnostic groups (i.e. trauma, vascular and neurological degenerative diseases). In the future, conducting individual focus groups representing each diagnostic subgroup would allow for more intensive research and for the development of comparisons between subgroups.

Our participation rate of 11 percent is poor. Apparently, holding the focus group meeting in the hospital discouraged patient participation. It was also quite clear that the patients feared discussing their concerns in case in the future their care from the physician and nursing staff would be jeopardized. The scheduling of the focus group during regular business hours was inconvenient for spinal degenerative population, as was indicated in some of the returned invitations. For the neuro-oncology patient population, holding the meeting six months after discharge may be too long a time

interval, because of the likelihood of substantial declines in health or the deaths of these patients. The participants were from the local area and did not represent the greater Central West region that the Neuroscience Program cares for. The collection of information was severely limited by the fact that we could not tape-record the conversations. The displaying of the comments on the flipcharts and the verification of the information once it was written down did ensure accuracy, however the nuances of the conversations are often lost when one can only evaluate written comments.

The questionnaire completed at the beginning of the session also had its limitations. By having the participants complete a questionnaire prior to discussion, the researcher is biasing the conversation towards the material covered in the questionnaire. The open-ended questions regarding cultural background and language were added to the questionnaire in order to meet a hospital committee's request for information on cultural sensitivity. It was not included for the purposes of our study. This matter should be studied in greater depth. The open-ended questions on patients' positive and negative experiences during their stays were too lengthy, and had too many descriptors. They could therefore be confusing. In fact, only two of the eleven participants completed this section. The section on hospital process did provide useful data but further elaboration would have been more useful and provided more depth. Sometimes focusing on a single issue in depth is more effective than gathering small amounts of data on numerous issues.

The focus group did provide a useful "spring board" to exploring the issues as relating to the experiences of the neuroscience patient population at the Hamilton Health Science Corporation. The themes in the responses were consistent with the research findings on patient satisfaction. Future studies, both quantitative and qualitative, are necessary.

LETTERS OF COMPLAINT AND COMMENDATION

The Neuroscience Program receives written comments from patients and families on patient care and on the services provided. In the past, every patient throughout the hospital was given a comment card to complete upon discharge. The card asked, "How Did We Do?" (Appendix 5). It requested information regarding the "things they liked about their stay" and "the things you think need improving". The patient could answer anonymously but also had the option of leaving his/her name and telephone number so that he/she could be contacted. The completion rate was low, below 30 percent. Patient comments from 42 of the comment cards collected within a five-month period, January to May 1997, were analyzed for recurrent themes. The corporation stopped using the comment cards in May 1997 and unfortunately all of the cards that had been received prior to January 1997 were destroyed.

The second main source of data was written letters by patients and/or family members. The program received 56 letters between September 1996 and June 1998. These letters were examined for positive comments and criticisms. As one would expect, positive comments were commonplace in the hospital's comment cards. Although there were some positive comments in the written letters, the letters were not so congratulatory. This is probably because people who have complaints often write letters in order to raise their concerns with administrators.

Many positive comments were made regarding the personal care provided by the nursing staff. "The nurses showed me how to provide care for my son and I felt that I could be helpful." "The nurses always had my husband shaved and bathed every morning before I came to feed him lunch." The professionalism of the whole health-care team was noted frequently. The patients and their families valued the fact that the health-care team was interested in the patients' outcomes and really cared about patients and

family members. The physicians and nurses instilled confidence in the patient and family. The therapists were viewed as dedicated and knowledgeable people who were very helpful with discharge planning. The physical environment was described as clean and well maintained by most respondents.

Personal care, safety and communication were the three areas most frequently noted as being in need of improvement. The nurses were viewed as having difficulty in meeting all of the patient's personal care needs. Here are some of the examples given: delays in changing the incontinent; insufficient mobilization of the patient; infrequent turning of patients in bed; leaving a patient up in the chair too long; skin breakdown; inconsistency in toileting patients; and family member(s) feeling forced to assist with care because staff appeared to be too overworked and/or not available because of staff shortages.

Safety was identified primarily as a nursing concern. Some of the safety concerns noted were delays in the response time of the nurses in meeting patients' needs, the lack of staff to monitor wandering and cognitively impaired patients, concerns regarding the use of too few or too many personal restraints, and loss of personal belongings during transfers between patient-care areas. One of the major complaints regarding safety and personal care was the delay in responding to the call bells. Sometimes, the person who answered the call could not provide the care. "She needed to find the nurse". Sometimes, the person responding to the call did not know whether or not the patient was capable of communicating. Some family members felt that they "could not leave the patient's bed side for the nurse may not answer the call bell, and the patient may choke or try and crawl out of the bed and hurt themselves". Patients isolated in single rooms because of the need to take precautions against infection, felt that lack of frequent monitoring, limited opportunities to engage in therapy, and the use of isolation apparel resulted in conditions that were "unsafe and inhumane".

Communication was felt to be as important area of concern for the whole health-care team. The physicians were experienced, at times, as being rude. Sometimes they did not take the time to answer patients' questions. Family members and patients alike complained that they were not being kept up to date as to changes in patients' condition, changes in severity of illnesses and/or prognoses. Some physicians were regarded as "cold" and "unable to provide any hope", "just grim statistics." Lack of communication between the physicians, and the nursing and therapy staff was frequently noted, especially with regard to discharge planning. Nurses were described as not being able to tell the family "how the patient was doing and what tests or treatments were arranged for the patient." A few families felt that they were not involved enough in treatment decisions.

The determination of patients' capability (formally competence) to make decision with regard to treatment, financial matters and personal care decisions was often a matter that families found confusing. The legal requirements for determining capability with regard to making decisions about treatment, financial and personal care decisions, and the family's perception of a particular patient's capability can be very different. In addition, the patient's condition may fluctuate, requiring frequent reassessments by the physician. Of course, this further confuses the family. One family member stated, "First I had to make all of the decisions when my mother was very ill. Later, when I still felt I should be making the decisions, they were asking my mother when I felt she was not thinking clearly. The doctor said she was competent, but I do not know why he thought this."

Physical environment was sometimes seen as being in need of improvement. Limited supplies and lack of equipment, for example, lack of proper restraints and limited numbers of wheelchairs, were noted. There were also complaints about the limited

availability of private and semi-private accommodations and about the lack of personal space in the four-bed wardroom. The four-bed wardrooms were said to be noisy and not conducive to rest. The physical layout of the ward and the lack of a secure environment made it difficult to monitor wandering patients. The families saw the distances between the patients' rooms and the nursing station and the limited visual monitoring of isolated patients as problematic. The food was said, at times, to be tasteless. Some patients complained that their menu requests were not fulfilled. The unavailability of food after scheduled meal times was a concern, especially in the case of post-operative patients and patients admitted late in the day.

Our review of the written comments provides useful insights into the particular needs of the neuroscience patients and families. Are these isolated complaints or are these concerns widespread? Research shows that many patients have concerns regarding personal care, safety, communication and aspects of the physical environment. These are frequently seen as areas that are in need of improvement. Patients with high levels of personal care needs, with potential or actual cognitive impairment, with physical impairments, isolated patients and/or patients with limited or poor prognoses all tend to express relatively high levels of dissatisfaction. This particular patient population was identified in the Neuroscience Annual Report (1997) as having medium to lengthy stays and complex care needs.

HOSPITAL PATIENT SATISFACTION SURVEY – “MEASURING UP”

In 1995, the Hamilton General Hospital and the Henderson Hospital, called the Hamilton Civic Hospital at that time, undertook a hospital-wide evaluation of patient satisfaction. The questionnaire that was used had been developed and utilized by many hospitals in the United States. The Conference Board of Canada's Quality Health Care

Network agreed to modify the questionnaire and to use it in 10 health-care facilities. The results of this survey were to be used as a benchmark when evaluating and making plans for improvement of the quality of patient care. The two hospitals in Hamilton were chosen to participate in this initiative. The questionnaire was designed to be a self-administered, to be completed after discharge home and to be returned by mail in a pre-addressed stamped envelope. The questions dealt with the care process from the pre-admission stage to post-discharge stage.

A sample of 1,600 recently discharged patients from the two hospitals was selected. A stratified, selective random sampling strategy was used. Patients discharged within the previous 3-6 months were included in the sample. Excluded from the sample were duplicate admissions, patients not discharged home and newborn babies. The questionnaire was sent out initially with a covering letter from the Chief Executive Officer of the hospitals outlining the purpose of the study and requesting participation. The questionnaire was to be completed anonymously. If a completed form was not received, the patient received a post card reminder in two weeks. If a completed form had not yet been received, a second questionnaire was sent out in two more weeks.

The response rate was 58.2 percent. In all, 931 patient questionnaires were returned. Fifty-five percent of those who responded were female, 45 percent were male. The average age was 55 years. The average length of hospital stay was 11.5 days. This patient population was slightly older than those of the other ten participating Canadian Hospitals, and our Hamilton patients also stayed approximately 3 days longer in hospital. Half of the patients were planned admissions, and 38 percent were urgent admissions through the emergency room. The remaining patients were direct urgent hospital transfers. The neuroscience patients were not treated as a single patient group when the statistics were compiled and the data were analyzed. The majority of the neuroscience patients were included in the surgical patient population data and in the Intensive Care

patient population data. Therefore, only the relevant data under these two categories will be reviewed.

Generally, the Intensive Care population gave higher ratings on all aspects of care than did the surgical patient population. These higher ratings were attributed to the greater number of physicians and nursing staff available to provide the care and information that the patient perceived as satisfactory. Communication between the physicians, nurses and patients appeared to be an important area in need of improvement on all fronts, especially on the wards. The nurses in particular were criticized and seen as needing to respond more quickly to patient's call bells. Also, nurses needed to improve their monitoring of patients' conditions, and to provide up-to-date information to patients and their families. Discharge planning and communication with patients and families, and the community care providers were seen as being in need of improvement. Physicians were seen as needing to improve their communication with patients, especially regarding treatment plans, upcoming tests, test results and prognoses.

The younger adult population (18-35 years) and the oldest patient population (80 +years) appeared to be the most dissatisfied with the care. The men were slightly more satisfied with their care than the women. Most patients found that the hospital environment was not conducive to rest. Also noted was the limited availability of rooms in which the patient and/or family member could rest and/or engage in private discussions.

The results of this Hamilton study are consistent with the data presented previously and also with the research on this topic. The Hamilton data were also consistent with the other ten hospitals surveyed. However, there are several limitations to this patient satisfaction survey. For example, the patient population was limited to those patients who had been discharged home, and who could read, comprehend and complete

the questionnaire. The use of this methodology may eliminate a significant proportion of our complex neuroscience patient population. Because the neuroscience patients were not treated separately from the general patient population, we do not even know how many questionnaires the neuroscience population completed. Also, the questions explored general care issues and the answers did not provide the kind of in-depth information that is necessary when one is planning changes in patterns of patient care.

Having reviewed the data available with regard to the Neuroscience Program and the Hospital Corporation, it is clear that certain care needs do require further study. Care issues regarding communication, information, physical care needs, the responsiveness of the staff to the patients' and family members' needs, safety concerns, the need to improve discharge planning and to provide hope were noted as important areas in need of improvement. It is clear that future studies need to take into account the very real fears that the patients and families have regarding anonymity. It will be important to collect data away from the acute-care setting. However, having these data is not enough to enable us to successfully evaluate patient satisfaction. If the stakeholders do not "buy into" the project our ability to use research findings to improve care will be limited. Therefore, I will also explore the stakeholders' views and their requirements with regard to the evaluation of patient satisfaction

CHAPTER SIX

STAKEHOLDERS PERSPECTIVE ON EVALUATING PATIENT SATISFACTION

Stakeholders are people with vested interests in particular events, objects, organizations, and so on. In a health-care organization, there can be many stakeholders. However, the main groups interested in patient satisfaction are the administrators, the health-care providers, the researchers, and the patients and their families. These four primary groups need to be involved in the process of evaluating patient satisfaction so that they utilize the results in improving patient care and so that they can feel responsible for the success of the research project and for the improvements in patient care. Each group of stakeholders has different goals, objectives and needs, and each will have views on the appropriateness of the methodology, research scope, and the ways in which the results are utilized. At times these varying opinions may be in conflict with each other and negotiation will be required (Dull, Lansky & Davis, 1994). Dull and his colleagues (1994) suggests that each group of stakeholders should provide input regarding their own particular individual goals, objectives and needs at the beginning of the research process.

CONSUMERS				
	Hospital Administrators	Researchers	Health Care Providers	Patients
Goals	<ul style="list-style-type: none"> -Marketing -Public relations -Risk management -Employee morale -General patient satisfaction 	<ul style="list-style-type: none"> -Rigorous methods -Increased knowledge -Validation of other studies -Measure change 	<ul style="list-style-type: none"> -Salary increases -Promotions -Increased pride -Satisfied patients -Creative problem solving 	<ul style="list-style-type: none"> -Improved future care -Improved community resource -Community pride
Requirements	<ul style="list-style-type: none"> -Inexpensive -Informative -Effective uses -Timely 	<ul style="list-style-type: none"> -Sensitive -Unbiased -Valid -Reliable 	<ul style="list-style-type: none"> -Timely -Relevant -Informative -Effective 	<ul style="list-style-type: none"> -Easy to complete -Comprehensible -Valuable use of time
Products	<ul style="list-style-type: none"> -Survey comments -Highlighted results 	<ul style="list-style-type: none"> -Research methods -Statistical results 	<ul style="list-style-type: none"> -Positive/negative comments -Satisfaction with health service 	<ul style="list-style-type: none"> -Completed questionnaire -Changes in care due to responses
Interventions	<ul style="list-style-type: none"> -Design institutional changes -Respond to individual negative comments 	<ul style="list-style-type: none"> -Evaluate services -Incorporate measures 	<ul style="list-style-type: none"> -Design solutions -Implement 	<ul style="list-style-type: none"> -Provide opinion

Table 2: Patient Satisfaction Consumers: Their Goals, Needs, Products, and Interventions

(Dull, Lansky & Davis 1994, p. 446).

ADMINISTRATORS

Administrators are people such as chief executive officers, vice presidents, directors, chief medical officers, and so on, who are involved with the administrative, legal and financial functioning of the hospital organization (Figure 9). In the case of the Neuroscience Program, the diagram below, showing the administrative structure, indicates the key individuals who have to be considered in this process (Figure 10).

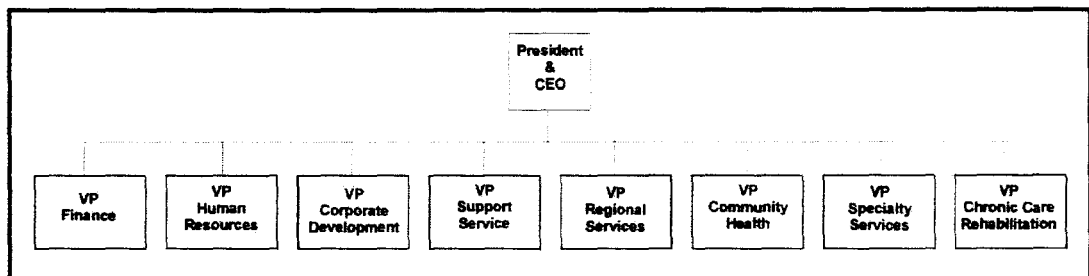


Figure 9. Senior Management at the Hamilton Health Science Corporation

(Neuroscience Annual Report, 1998, p.14).

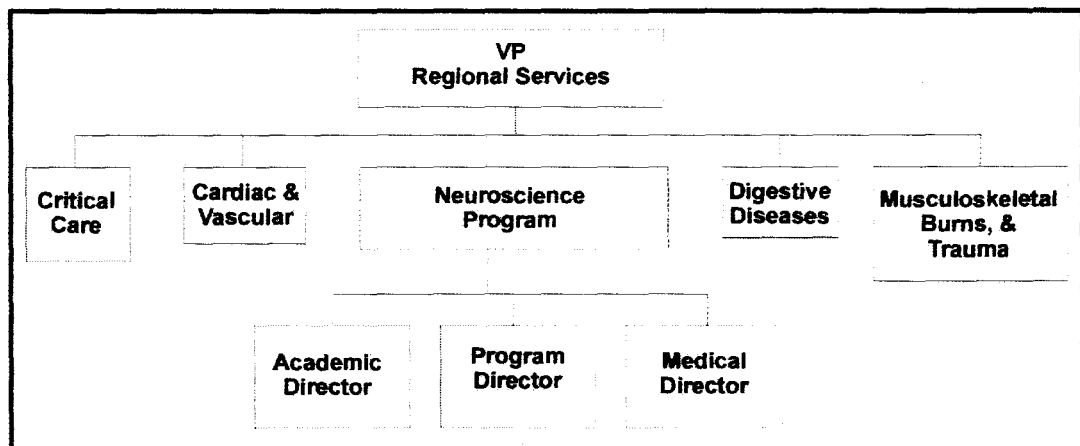


Figure 10. Regional Programs in the Hamilton Health Science Corporation

(Neuroscience Annual Report, 1998, p.14)

The corporation's mission, vision and value statement (Table 3) outlines those aspects of patient care that it might be especially useful to evaluate. This corporate statement is the fundamental "spring board" that the organization uses to evaluate its performance, to proclaim its accountability to the public and to the government, and to develop plans for change. The Neuroscience Vision Statement (Table 4) incorporates the corporation's mission, vision, and value statement, as well as defines the role that the Neuroscience Program plays in striving for excellence in patient care for the neurologically impaired and their families, as is perceived by the program staff.

<p>MISSION The Hamilton Health Sciences Corporation is the major regional provider of comprehensive health services for Central-West Ontario, a partner with McMaster University and others in the education of future health professionals and the creation of new knowledge through research, and is committed to participating in the improvement of the health of the residents of Hamilton-Wentworth Region.</p>	<p>HHSC VALUES The Hamilton Health Sciences Corporation embraces the following values as fundamental success in the achieving our mission and vision: CARING: Caring for patients, their families, and communities is the basic mission of all health care organizations. HHSC will strive to meet needs sensitively, personally, and competently within the limit of available resources. Our care will recognize the whole person and their physical, emotional, and spiritual needs. EXCELLENCE: Our clinical and support programs, teaching and research will be driven by a desire to achieve excellence and a high and measurable standard of quality. We will create an organizational climate which relentlessly pursues improvement in structure, process, and outcome. INNOVATION: HHSC encourages new approaches to care, service, and management. We acknowledge our responsibility to contribute to the advancement of the understanding of human biology and the healing disciplines. We will create a culture that facilitates and promotes innovation. RESPECT: We will value and respect the worth of all people associated with HHSC including patient, staff, volunteers, and communities. HHSC celebrates diversity. As an employer, HHSC will establish a workplace characterized by fairness, honesty, and freedom from harassment in all its forms. PARTNERSHIP: Partnerships, both internal and external, are the way of doing business at HHSC. Teamwork is highly regarded so that the skills and knowledge of diverse staff can be brought to bear to fulfill our service, academic, and excellence objectives. HHSC will be an ethical and responsible partner with external collaborators and suppliers. VALUE: HHSC embraces our responsibility to bring value to health care in our use of public funds, private donations, and other resources. We will continuously seek to increase the quality and quantity of service we provide with each dollar received to maximize community benefit. ACCOUNTABILITY: HHSC takes seriously our obligation to be accountable for the use of funds and the quality of service. We will strive to achieve the highest standards ethical, open, honest, and competent governance, management and service.</p>
<p>HHSC VISION Our vision for the Hamilton Health Sciences Corporation is of a contemporary, sustainable, academic health sciences organization that:</p> <ul style="list-style-type: none"> • provides high quality health care services which meet the expectations of our patients and their families. • works collaboratively to integrate health and social services into a network, through partnerships and alliances, to meet the comprehensive health care needs of individuals and communities. • uses resources responsibly, balancing quality, access, and cost to maximize value. • continuously teaches and learns from students, staff, patients and their families, and communities. • creates and applies new knowledge from basic, clinical, health services, and population health research. • is data driven, evidence based, and outcomes oriented. • contributes to regional economic development through commercialization of research and appropriate services. • responds to assessed community need to foster health for all. • is a fair employer, providing an environment which encourages personal and professional growth. • acts at all times in the public interest. 	

Table 3: Hamilton Health Science Corporation's Mission, Vision and Value Statements

(Neuroscience Annual Report, 1998, p.11)

VISION of the NEUROSCIENCE PROGRAM

OUR ROLE

The Neuroscience Program will provide exemplary and comprehensive care for persons with neurological problems and their families. We will strive for excellence in all aspects of clinical neuroscience, including health care, education, and research. We will collaborate with others in our hospitals, our community, and our region as vigorous and helpful partners, welcoming both our responsibilities and our interdependencies.

POPULATION FOCUS

The Neuroscience Program will provide a full spectrum of clinical services to all adults in this community who present with acute or recurring neurological disorders. Services will adapt to demographic changes prospectively. They will respect the many cultural and religious diversities that exist in our community.

The Neuroscience Program will be active in the Central West region as a provider of tertiary level care for neurological and neurosurgical disorders. Its members will cultivate close and mutually supportive relationships with colleagues in other areas of our region and with those who work in clinical neuroscience elsewhere in our province and nation. They will maintain strong links with community organizations in order to work together to provide optimal service to both local and regional populations of persons with neurological problems.

DELIVERY OF CARE

Care delivery will be patient focused. It will be provided by an interdisciplinary team and based upon the needs and wishes of the patient and his/her family or close associates. We will endeavour continuously to advance the quality of clinical service. We will monitor costs and benefits of current treatment and will adopt new treatments, technologies, and methods of care as soon as possible after they are found to be more efficacious.

ACADEMICS: EDUCATION AND RESEARCH

We will promote educational and research activities which hold promise for bringing better care for neuro patients in the future. We will support systems of reward, accountability, and remediation relative to teaching, learning, and research activities. We will continue to promote and operate scholastic and service alliances within the domains of our program. Research methods will be adapted to monitor and evaluate outcomes of cases in order to identify strengths and weaknesses in current practice. Independently and in collaboration with others, members of the Neuroscience Program will test hypotheses in an ethical and systematic manner and will report the results of their investigations to peers and public in journals and at scientific meetings.

Table 4. Neuroscience Vision Statement (Neuroscience Annual Report, 1998, p.12).

The examination of patient satisfaction is one of the goals of the corporate quality plan and also one aspect of the Neuroscience Program's quality report. The Neuroscience Program is also seeking patient feedback with regard to the inpatient care that they provide. This feedback is seen as being an important component of the evaluation plan for the redesign of patient care. Therefore, the goals, requirements, products (tasks) and proposed interventions of the administrators are drawn from their vision statement, quality plans and redesign plan, and also from discussions with individual administrators.

Goals:

- Maintaining and/or improving the quality of care
- Assessing the current levels of patient satisfaction
- Providing a baseline measurement for future comparisons
- Maintaining, promoting and enhancing patient-centered care
- Evaluating the program's ability to uphold the mission, vision and values of the corporation
- Effective marketing
- Public relations

- Appropriate risk management

Requirements:

- Cost effectiveness
- Effective resource utilization
- The collection of useable data
- Efficiency
- Ability to evaluate the broad range of our clients and their families

Products:

- Survey results - analyzed
- Identification of potential areas that need improvement and certain sub-populations with especially high levels of dissatisfaction with care

Interventions

- Design (or redesign) of patient care services
- Provision of feedback to health-care providers
- Enhancement of ability to respond to individual negative comments

HEALTH- CARE PROVIDERS

Health-care providers are the “front-line” providers of patient care. Health-care workers employed in the Neuroscience Program are described below in Chart 3. The neurosurgeons, neurologists, medical internists, respiratory therapists, and support services, for example, palliative care team, housekeeping, community access coordinators, and so on, are in fact direct care providers. However they are funded outside of the program, and are therefore not included in the Neuroscience Program structure (Chart 3). Also, this chart was prepared prior to the recent changes in the work roles of health-care providers. New roles, and positions, for examples, environmental aide, health-care aide, and business clerk, are in the process of being introduced. This inevitably results in changes in the roles of the

ward clerk, housekeeping staff, porters and nursing staff. Some staff members are being laid off, some have been given new responsibilities. These and other changes within the organization are aimed at redesigning patient care. The primary goal is that of saving money while continuing to maintain the quality of patient care.

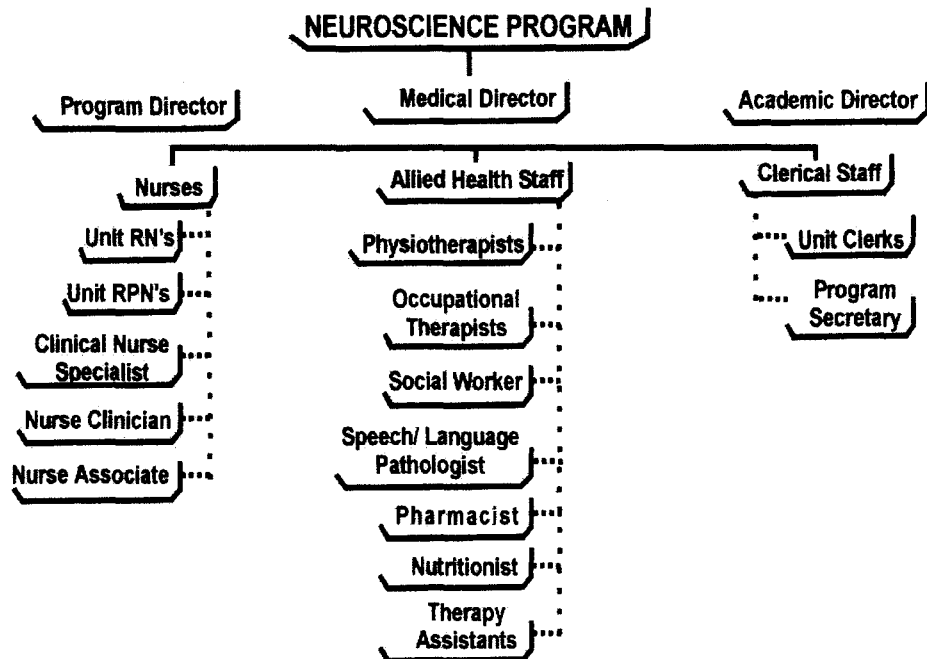


Figure 5: Neuroscience program structure
(Neuroscience program annual report, 1998, p.16)

Figure 11: Neuroscience Program Structure (Neuroscience Annual Report, 1998,p.16)

To determine health-care providers' goals, requirements, products and interventions, I interviewed a random sample of health-care providers from a range of professions. The new health-care roles had not yet been introduced. The data were obtained from the current front-line staff. A total of 18 people were interviewed. Of these people, there was one Neurosurgeon, eight were Registered Nurses, three were Registered Practical Nurses, three were Therapists, one was a Pharmacist, one was a Ward Clerk, and one was a Community-Care Access Coordinator. This group of people is representative of the group of staff who provide care in the Neuroscience patient care unit on any particular day. They

were interviewed individually and their responses were tape-recorded (with their permission). The purpose of the interview and the way in which the data were to be utilized was outlined prior to the interviews. Participation was voluntary. Complete confidentiality was promised. The following are the three questions asked:

- (1) When a patient states that he/she is satisfied with his/her care on our ward, what **components of care** is he/she referring too?
- (2) Based on the range of **neurological patients** (from the simple to the complex cases) that we serve, what do you feel needs to be considered when examining patient satisfaction?
- (3) Given the **changes in health care and in our current patient care model**, what do You believe needs to be monitored, with regard to patient satisfaction?

The answers to these three questions were analyzed and themes categorized.

1) **Patient satisfaction – Components of Care**

- Information needs are met. Information regarding diagnosis, prognosis, and expected outcome from physician.
- Discharge plans were completed with the patient and family in a timely and sequential manner and these plans were communicated to everyone. Staff were concerned that, because of the shortening of hospital stays, the discharge process lacks coordination and plans are not being adequately communicated to all members of the team and to patients families in a timely manner.
- Family kept informed regarding the patient's condition. Families need to be notified of changes in the patient's medical conditions in a timely fashion.
- Patient, family and staff informed and given rationale for upcoming tests, assessments and procedures.
- Patients' and family members' concerns addressed by a knowledgeable health-care provider.

- Information consistent from all health-care providers.
- Physical-care needs must be met in a timely manner.
- Physician visits and examines the patient daily.
- Psychological and emotional needs of patients and families are met.
- Patient obtains therapy to assist with recovery.
- Patient is kept comfortable and pain-free. Pain medication is given in a timely manner.
- Call bells answered in a timely manner and by appropriate providers who can deal with the needs of patients.
- Nurses monitor the patient's medical condition frequently.
- Meal trays delivered and patients are assisted to eat, in a timely and safe manner.

2) Neuroscience Population – What needs to be considered when examining patient satisfaction in the Neuroscience patient population.

- Cognitive impairments -affects judgement, reasoning and decision-making. Often family members become substitute decision-makers.
- Communication impairment- impairments resulting in inability to express and/or receive information (such as speech, written words, and so on). Family members often become substitute decision-makers.
- Uncertainty of outcome. This is evident in two primary patient populations: the patients who have experienced catastrophic injuries or patients who have uncertain prognoses.
- Patients may not return to previous functional levels or may have experienced permanent changes in personality, behaviour and/or memory.
- Significant physical impairments and/or handicaps that limit independence in the daily activities of living.
- Family members' involvement in the patient's care is imperative due to the patient's impairments and his/hers long-term care needs beyond the acute-care stage.

- Patients and family members required considerable emotional support when dealing with catastrophic illnesses, poor prognoses, and/or major changes to their lives.
- 3) Health-Care Changes- Which components of patient satisfaction should be monitored with regard to the change in the skill levels of the staff delivering care and the method of delivery.**
- Consistency in patient-care is maintained
 - Staff are skilled and able to frequently monitor the patients physical condition.
 - Patients and family members' questions should be answered in a timely manner by knowledgeable staff.
 - Information provided to the patient and family by the various care providers should be consistent.
 - Family and patient should be aware of the various health-care roles and of the responsibilities and limitations of these roles.
 - Patients and families should feel prepared for discharge home. They should have had the appropriate education and should be aware of their responsibilities.
 - Physical-care needs should be met.
 - Patient should be ambulated regularly.
 - Patient should be fed meals in a timely and safe manner.

After reviewing the health-care workers' comments, the material will be analyzed in order to determine their particular perspectives with regards to goals, requirements, products and interventions.

Goals:

- Evaluation of the current level of patient satisfaction
- Evaluation of families' level of satisfaction with care
- Monitoring and evaluating patient satisfaction before and after the redesign of patient-care delivery

- Identifying areas for improvement in patient and family care.
- Identifying effect of earlier discharge home from the hospital

Requirements:

- Information collected should relate to patient care
- Information collected should be readily utilizable in planning for improvement
- There should be opportunities for family input
- Implemented action should take place in a timely manner with the input of the staff.

Products:

- Positive and constructive feedback
- Higher levels of satisfaction with the care provided
- Opportunities for improvement

Interventions:

- Designing a plan for improvement
- Implementing the plan
- Evaluating the patients level of satisfaction with changes

RESEARCHERS

There is a range of research expertise among the various professionals within the Neuroscience Program. A few people with experience in both quantitative and qualitative research were selected to provide advice. Additional input was requested from a representative from the quality council for the hospital organization. The accreditation documents prepared by the Conference Board of Canada's Quality Health Care, outlines

aspects of care to be examined from a patient-centered perspective. This document was used for input on evaluation of patient satisfaction.

Goals:

- To increase the current knowledge base regarding patient satisfaction within the Neuroscience Program
- To improve patient care
- To evaluate levels of patient satisfaction before and after the change in the design of patient care. This data will provide one component of the evaluation process.
- To provide a base-line data set that can be utilized in future evaluations of levels of patient satisfaction.
- To identify subgroups of patients with the highest levels of dissatisfaction
- To contribute to the current research on this topic
- To publish results in research journals

Requirements:

- The methodology must be sensitive enough to detect change
- The methodology must be stringent enough to minimize biases
- The research supports other research in the same field
- The instrument for collecting information must be reliable
- The information collected must be relevant to the assessment of patient satisfaction

Products:

- Sound research methods
- Statistical analyses of the results of the quantitative studies
- Careful content analyses of qualitative studies

Interventions:

- Evaluation of patient-care services
- Incorporation of measures that will allow continuous monitoring and comparison
- Identification of areas for further research
- Implementation and evaluation of changes in patient care

PATIENTS AND THEIR FAMILIES

Information about patients and their families regarding their goals, requirements, and intervention was obtained from the analyses of the comment cards, the focus groups, the letters of complaint and commendation, the corporate surveys and the existing research. This information has already been reviewed in previous chapters.

Goals:

- Improvement of patient care
- Improvement of family care
- Research that supports the need for additional resources for the care of the neuroscience patients

Requirements:

- Anonymity, confidentiality of interviews
- Data should not be collected in the hospital setting
- Methodologies need to take into account the potential disabilities of patients and to allow for a variety of approaches
- Data should be utilizable in planning for the improvement of care
- Opportunities for family input should be provided
- Reports should be easily comprehended

Products:

- Input into patient care
- Changes in care resulting from participation in study
- Data should be utilizable in presenting arguments for further additional resources for care in the community

Interventions:

- Respondents had an opportunity to express their opinions
- Received patient input into the delivery of care

As was discussed, the various stakeholders in patient care have both shared and individual goals when evaluating patient and family satisfaction. The Neuroscience Program needs to develop a variety of methods of collecting data from patients and their families. These methods should allow for both continuous monitoring and also for the exploration, as needed, of identified areas of concern. No one individual method will be suitable for evaluating all goals and all aspects of care. The Hamilton Health Science Corporation is implementing a corporation-wide patient satisfaction survey, to be utilized by each patient-care program. This survey will be discussed in the next chapter in order to identify which aspects of care will be evaluated.

CHAPTER SEVEN

HAMILTON HEALTH SCIENCE CORPORATION'S PATIENT SATISFACTION SURVEY

The Hamilton Health Science Corporation has implemented a patient satisfaction survey that all patient care programs are to utilize. Initially, each program was told to develop its own patient satisfaction questionnaire, specific to its own patient population. However, the Transitional Quality Task Force introduced a common patient satisfaction questionnaire that examined quality of care in all patient care programs. The rationale for this change was the need to develop quality markers for the corporation, the need for a valid and reliable tool that could be used by all, and the need to assist individual programs with their evaluations. The usefulness of this patient satisfaction survey for measuring patient satisfaction in the Neuroscience patient population will be considered.

The Transitional Quality Task Force (TQTF) was formed in April 1997 during the amalgamation of the four Hamilton hospitals into one corporate hospital. "Its purpose was to facilitate the design and implementation of systems so that the Hamilton Health Science Corporation (HHSC) could meet the changing needs and expectations of the community and other stakeholders" (Transitional Quality Task Force Report, 1997,p.1). One of its first tasks was to develop a framework for the corporation and for each of its programs in order to plan, measure, evaluate and improve care throughout the Hospital Corporation. The TQTF (1997) defined planning as "a detailed process that defines action to achieve desired results" (p.6). Measurement was defined as "a process that allows comparison of an experience or event over time, through use of specific tools" (p.6). Evaluation was defined as " a process of assessing the value of an experience or event based on data obtained from the measurement process" (p.6). Finally, improvement was defined as " a measurable change for the better" (p.6). This framework provided the basis for evaluating corporate services and initiatives, and also for evaluating patient cares within each patient-care program.

“**Quality** was defined as meeting the needs and expectations of patients, families and other customers within available resources. Needs and expectations are determined by consensus involving the care or service provider(s) and the patient, family or other customer” (Transitional Quality Task Force Report, 1997,p.5). To determine the quality of care using this particular framework, the TQTF recommended the use of a Measures’ and Indicators’ Matrix (see Appendix 6). The matrix gives various dimensions and their attributes that the corporation values as indicators of high quality care. The quality dimensions are **communication, responsiveness, system competency and quality of work life**. Three of the dimensions are directly related to the evaluation of patient satisfaction – communication, responsiveness and system competency. These three dimensions and their associated attributes will be described below. They form the foundation for the evaluation of patient satisfaction and for the development of patient satisfaction surveys.

Communication was defined as “interacting with the clients in a manner that enables them to be participants in care and service delivery” (TQTF Supplemental, 1997, p.3). The associated quality attributes of communication are **courtesy and respect, consistency and confidentiality**. **Courtesy and respect** are defined as “the degree to which politeness and consideration is incorporated in all interactions with clients” (p.3). **Consistency** is defined as “the degree to which the message is consistently conveyed” (p.3). Finally, **confidentiality** is defined as “ the degree to which all information, entrusted to be kept private, is safeguarded” (p.3).

Competency was defined as “ the system, program or service is consistently provided in the best possible way, given the current state of knowledge, in order to achieve for the client, the desired benefit, with minimal degree of harm” (TQTF Supplemental, 1997,p.2). The attributes associated with the examination of competency are **appropriateness, health outcomes, adverse occurrences, legitimacy and caring**. Of course, patients and their families are not asked to evaluate all of these attributes. But of the attributes, for example, appropriateness, legitimacy and caring, can be evaluated to some extent by the patients and their families. Other aspects are

governed by legislation and/or by each professional's regulating body. Patients and their families are extremely important sources for evaluating the **caring** attribute. **Caring** is defined as "the degree to which the service involves the client and demonstrates sensitivity to and respect for the client's needs and expectations" (p.2). **Appropriateness** is defined as "the use of relevant, needs based, correctly done, processes and technologies, including credentialling, which have been demonstrated to produce benefits or information" (p.2). Patients and families may not be able to evaluate all of the components of the appropriateness attribute, as it has been defined, but they can determine the appropriateness of the care that they received based on their interactions with the health-care team. Finally, **legitimacy** is defined as "the degree to which the delivery of care and services conform with the ethical principles, values, conventions, laws and regulations" (p.2). Regulatory and governing associations and laws are established and maintained in order to monitor this aspect of care. However, feedback from patients and families regarding their perceptions of this aspect of care serve as one means of monitoring and of ensuring the health professionals continued practice.

Responsiveness was defined as "responding to the wishes, desires and expectations of (potential) clients within the context of expediting the care and service necessary to meet the corporation/program mandate and stated mission" (TQTF Supplemental, 1997,p.1). The attributes that are considered when examining responsiveness are **availability, accessibility, timeliness, and continuity**. **Availability** refers to the "existence of an agreed upon program, program focus or essential element of a service to meet the client's needs" (p.1). **Accessibility** is defined as "the ease with which our clients obtain required and available care or service" (p.1). **Timeliness** refers to "the provision of the required care or service to meet the client's needs at the most beneficial or necessary time" (p.1). Finally, **continuity** is defined as "the care and service is provided and coordinated among providers within HHSC/programs and between organizations" (p.1).

The questionnaire was developed using these dimensions of quality and associated attributes, as well as the available research on patient satisfaction (see Patient Satisfaction Survey

in Appendix 7). The questionnaire follows the process of care through the hospital stay and focuses on aspects of care that have been recognized to be problematic both in the research literature and also in the earlier patient satisfaction survey. Each program was afforded the opportunity to make changes and/or add items to the questionnaire (with the approval of the quality council) to better meet the needs of their own particular patient populations and programs. Since the Neuroscience Program had recently set up a pre-operative clinic, the program committee decided to add several questions that pertained to this clinic. Some questions that were specific to roles, responsiveness, communication and competency were added as a result of the redesigning of the patient-care model. The redesign committee wished to utilize the patient satisfaction survey before and after the redesign of the patient-care model. Questions about student learners were also added to the survey, as part of an evaluation of the interaction between students, learners and patients. Finally, certain demographic data, such as postal codes, other personal data relating to individuals who completed the survey (including their states of health) were included.

The Quality Task Force, the Neuroscience Redesign Committee and the Neuroscience Patient Satisfaction committee linked the questions on the patient satisfaction survey with their corresponding quality dimensions and their attributes (see Appendix 8). This allowed the Neuroscience Program to measure and evaluate each of the quality dimensions from a patient perspective and to identify opportunities for improvement. This process is in keeping with the framework outlined by the TQTF. The questionnaire was pre-tested in a pilot study of Neuroscience patients and their families in order to assess readability, ease of use, and validity of the survey questions. The questionnaire was first distributed early in April 1999, prior to the implementation of the new patient-care model in May 1999.

The purpose of the study and the methods that are used to ensure confidentiality and anonymity are described in the introductory section of the survey. The patients will be mailed the survey with a pre-addressed stamped envelope. If the questionnaire is not returned within three weeks, the patient is sent a postcard reminder. After eight weeks, if the questionnaire has not been

returned, the patient is sent another questionnaire and another return envelope. Initially, all of the patients discharged home from the Neuroscience Program will be mailed a survey. Their names and addresses will be obtained from medical records. The surveys will be mailed within the first three months after discharge. A database will be developed. Analyses will be conducted by the corporate statisticians and used for program and corporate purposes.

A questionnaire survey has many benefits. For example, it will be possible to contact with all patients discharged home from the Neuroscience Program. This ensures a large number of responses for analyses regardless of exact return rate. The questionnaire is sent to the patient's home. This allows the patient to complete the form without being influenced by the acute-care environment and/or by health-care professionals. The survey is anonymous, allowing patients to provide feedback free of fear of exposure to the health-care providers. This issue was clearly identified as a deterrent in the Neuroscience focus group session. The survey method also allows for comparisons following changes, for example the redesign of roles. It also enables one to make comparisons with other programs. In addition, comparisons can be with the existing research findings in the field.

The questionnaire addressed issues identified in the research literature, issues raised by Neuroscience patient and family population and issues raised by health-care professionals. The survey allows us to quantify patient and family responses regarding communication, continuity of care, discharge process, provision of care, and the responsiveness of the health-care providers to patients' needs, emotional support, education and physical environment needs. Patients and families, stakeholders, and researchers have all identified these aspects of care as areas that are frequently seen as being in need of improvement. The survey allows for the monitoring of trends in these aspects of care with the goal of improving patient care.

Satisfaction surveys do, of course, have its drawbacks. Low response rates present problems. Even with all of the reminders, the average response rate to a mailed patient

satisfaction survey is 25 to 40 percent (Barkley & Furse, 1996,p.427). “The hospitals set goals of 30% to 35% for patient response to the questionnaire” (Smith, Scammon & Beck, 1995,p.29). Virtually every study of the patterns of return of self-administered questionnaire shows that early returns are biased (Smith, et al., 1995). Results from the first 20 to 30 percent to respond among the total population surveyed do not represent the actual patterns in the total population. Barkley and Furse (1996) have examined the implications of low response rates for surveys. Satisfaction data from 19,556 patients discharged from 76 hospitals were studied. Responses from the first 30 percent of the respondents were compared with those of the respondents overall. The responses of the first 30 percent were different from those of all the respondents taken together. The authors concluded “the capriciousness of within-hospital differences based on the first 30% versus all respondents brings into question the utility of patient satisfaction data based on low response rates even with a reliable instrument and with controlled, consistent data collection methods. Target response rates should be set at 50 percent or higher” (Barkley & Furse, 1996,p.428).

Certain factors contribute to the success or failure of a mailed survey. Inaccurate and incomplete mailing lists, moves to new addresses, or simply patients’ lack of interest in filling out or returning the questionnaire affect the results. In the case of the Neuroscience population, simply reading and completing the form may be difficult because of sight impairments, limitations in movement and/or ability to comprehend the questions. However, family members’ evaluations of the patient care cannot be used in lieu of patients’ own evaluations. Family members are known to be less satisfied than patients with the hospital care (Gerteis, et al., 1993,p.185). Family members view their satisfaction with care differently because of their different roles. This result is that patients and family members give rather different responses. Therefore, patients’ and family members’ differing expectations, experiences and needs, and their different attitudes towards the health-care system and health-care personnel need to be recognized as variables that influence levels of patient satisfaction. Patient and family information should also be documented and analyzed separately.

The cost of conducting a self-administered mailed survey can be quite high. One must budget for the development of the questionnaire, for printing, for postage and for the cost of software and personnel to generate the patient lists. In addition, inputting the data can be quite expensive. High cost must be considered as a major factor when choosing this method. In the case of the Neuroscience population, the group surveyed was drawn from all patients who had been discharged. Large surveys can be very costly, especially if continued over long periods. Once the initial data have been analyzed, the approach to sample selection will need to be further examined.

The time frame is also a factor in evaluating the effectiveness of the survey. The questionnaire is sent out three months after the patient's discharge from hospital. Fottler and colleagues (1997) recommend that questionnaires be completed within the first month following discharge in order to avoid recall bias. In the case of patients with a limited prognosis, for example, malignant brain tumor population, timing is a critical issue, as these patients may soon face further deterioration and/or death. A three-month waiting period may be too long. Given that there are numerous patients, who have experienced catastrophic events and who require ongoing care beyond the acute-care stage, a significant proportion of the Neuroscience patient population may or may not be excluded from the survey. Appropriateness of the timing of the survey will need to be examined according to response rates of each diagnostic category.

The survey questions do touch on many of the concerns that have been raised in the research and in our current research on Neuroscience patients. However, the survey does not enable us to probe deeply. Nor does it provide suggestion for improvement. Williams (1998) noted that patients and their families distinguish between "caring about the patient" and "caring for the patient". "Caring for the patient" involves the tasks that are necessary to ensure the health and survival of the patient. These "caring for" components are the major aspects of patient care that are examined in the satisfaction survey. On the other hand, the "caring about the patient" refers to concern for the patient and the interpersonal aspects of patient care. The survey approach

makes this information difficult to obtain. Qualitative methods are better suited for exploring these aspects of care.

In conclusion, the corporate patient satisfaction survey that the Neuroscience Program will be utilizing provides a fairly effective means of obtaining quantitative data on satisfaction with care. However, the limitations of this approach must be acknowledged, especially if the response rate is low. Low response rates decrease the usefulness and representativeness of the information that is obtained. When the pilot testing results are available, the response rate and the types of respondents (patient/family, diagnostic category) will need to be evaluated. However, there still are recognizable gaps in the data for assessing the “caring about” components of care. Also, areas of concern with care, which have been identified by the patients, their families, the stakeholders and the research literature (discussed in previous chapters) may be noted on the survey form, but why these issues are a concern, and how to improve is not addressed with this methodology. In the next chapter, I will suggest an alternative method for collecting qualitative data from the Neuroscience patient population.

CHAPTER EIGHT

CRITICAL INCIDENT TECHNIQUE

John Flanagan (1954) first described, in the research literature, a qualitative methodology called critical incident technique. He defined critical incident technique as a “ set of procedures for collecting direct observations of human behaviour in such a way as to facilitate their potential usefulness in solving practical problems and developing broad psychological principles. The critical incident technique outlines procedures for collecting observed incidents having special significance and meeting systematically defined criteria. An incident is an observable human activity that is sufficiently complete in itself to permit inferences and predictions to be made about the person performing the act. To be critical, an incident must occur in a situation where the purpose or intent of the act seems fairly clear to the observer and where its consequences are sufficiently definite to leave little doubt concerning its effects” (Flanagan 1954, p.327).

Flanagan (1954) outlines five stages that are necessary when utilizing the critical incident technique. These *five stages* are:

- (1) Stage One: Formulating the General Aim of the Study.
- (2) Stage Two: Plans and Specifications
- (3) Stage Three: Collecting the Data
- (4) Stage Four: Analyzing the Data
- (5) Stage Five: Interpreting and Reporting the Data

(Flanagan, 1954,p. 336)

Stage One: Formulating the General Aim of the Study

The general aim is a brief written statement obtained from the authorities in the field, which expresses in simple terms those objectives which most people agree form the basis for the study. This serves as the framework for the development of the interview questions or guide, and for interpreting and reporting the results. The difficulty in developing this document is that there

can be more than one general aim. It is important to seek consensus among the stakeholders prior to initiating the research. This will ensure the acceptance of the study by the stakeholders and increase the likelihood that the results of the research will actually be utilized (Flanagan, 1954, pp. 336-338).

Stage Two: Plans and Specifications

“The second stage in the critical incident technique procedure involves deciding who should be the observers (interviewers), which situations should be observed and which activities should be noted” (Norman, Redfern, Tomalin & Oliver, 1992, p.593). Flanagan (1954) recommends that the observers be familiar with the activity to be observed. To ensure objectivity in the data collection, Flanagan (1954) suggests that a clear set of specifications be established (p.339).

The *first specification* is that the situation to be observed must be clearly outlined. Information regarding the place, the persons, the conditions, and the activities must be stated. *Secondly*, the specific incident observed must relate to the general aim of the study (Flanagan, 1954, p.339). Flanagan (1954) notes that the degree of objectivity that is necessary when assessing the relevance of the data to the general aim will depend on the level of experience of the observers with the aim of the study (p.340). Observers with considerable experience with the study subject will need minimal assistance, whereas observers with limited experience will need considerable detail as to the activities that can be expected to have an effect on the general aim.

Thirdly, the observer must decide how important an effect the observed incident has had on the general aim. Flanagan (1954) defines the incident as significant if it contributes, either positively or negatively, to the general aim of the study (p. 338). Significance is defined according to the nature of the study. Finally, the *fourth specification* is related to the selection of the observers. “Whenever possible, the observers should be selected on the basis of their familiarity with the study” (Flanagan, 1954, p.339). The training of the observers should include a

review of the general aim, the research plan and the specifications outlined for the respondents. When the situation is complex or when the observer is not familiar with the activity, supervised sessions allowing observers/interviewers to practice applying the exact research methods are necessary. Flanagan provides a format for the development of the specifications for the observers. This is given below.

SPECIFICATIONS REGARDING OBSERVATIONS	
1.	Persons to make the observations.
	a. Knowledge concerning the activity.
	b. Relation to those observed.
	c. Training requirements.
2.	Groups to be observed.
	a. General description.
	b. Location.
	c. Persons.
	d. Times.
	e. Conditions.
3.	Behaviours to be observed.
	a. General type of activity.
	b. Specific behaviours.
	c. Criteria of relevance to general aim.
	d. Criteria of importance to general aim (critical points).

Table 5: Form for Developing Specifications for the Observers
(Flanagan, 1954, p.339).

Stage Three: Data Collection

Data can be collected using individual interviews, group interviews, mailed questionnaires, or record forms. For the purpose of this project, only the individual interview approach will be discussed. The rationale for this format will be explained in the following chapter. As part of the interview process, the observer must indicate: (1) the sponsor of the study; (2) the purpose of the study; (3) the value and the use of the results; (4) the group of respondents selected for participation; (5) the confidentiality of the data; (6) and the format of the interview (Flanagan 1954, pp.340-342). The interview process is guided by a set of open-ended questions.

This approach ensures that the interview remains focused on the general aim of the study, but still yields a wealth of information.

“The essence of the interview technique is that only simple types of judgements are required of the observer, reports from only qualified observers are included, and all observations are evaluated by the observer in terms of an agreed upon statement of the purpose of the activity. Of course, simplicity of judgement is a relative matter. The extent to which a reported observation can be accepted as a fact depends primarily on the objectivity of the observation” (Flanagan, 1954,p.335). To be objective, a number of independent observers must report the same observations. “Judgements that two things have the same effect or that one has more or less effect than the other with respect to some defined purpose or goal represent the simplest types of judgements that can be made. The accuracy and therefore the objectivity of the judgements depend on the precision with which the characteristic has been defined and the competence of the observer in interpreting its definition with relation to the incident observed” (Flanagan, 1954, p.335). Flanagan outlined five criteria to be applied as the incident(s) are collected.

The criteria are:

- (1) Is the actual behaviour reported?*
- (2) Did the reporter observe it?*
- (3) Were all the relevant factors in the situation given?*
- (4) Has the reporter made a definite judgement regarding the criticalness of the behaviour?*
- (5) Has the reporter made it clear just why she or he believes the behaviour was critical?*

(Norman, Redfern, Tomalin & Oliver, 1992,p.591)

Stage Four: Analyzing the Data

Once the data have been collected, a classification system for the data is established based on the intent or “aim” of the research and through the inductive examination of the critical incidents. “The induction of categories from the basic data in the form of incidents is a task requiring insight, experience, and judgement” (Flanagan, 1954,p.344). To obtain objectivity, it is necessary to submit the tentative categories to others for review. Each category is defined so as to verify the meaning and to assist with sorting the critical incidents. The observed behaviours are then categorized by applying the classification system (Flanagan, 1954,p.344).

Stage Five: Interpreting and Reporting

Flanagan (1954) suggests that “the greatest error in applying the critical incident technique is not in the collection and categorization of the data, but with the interpretation of the results” (p.345). The researcher must define the limitations of the study as well as the value of the results. The results can be utilized to promote change, to support or to dispute research results, or to develop theories for further testing.

Application of the Critical Incident Technique

The critical incident technique has been utilized in a variety of settings. Initially, Flanagan (1954) reported the use of this methodology when studying Air Force Pilots during World War II. He studied the reasons why pilot candidates did not learn how to fly, why air pilots failed during bombing missions, and the characteristics of good combat leader (p.328). Critical incident technique has been utilized in medical and nursing research over the past twenty years. Most of this research dealt with professional practice standards, clinical errors and professional behaviour. Benner (1984), for example, utilized the critical incident technique to investigate how various nurses described a clinical incident. From these descriptions, Benner was able to identify the major competencies of nurses at different levels of skill acquisition. Only in recent years has the critical incident technique been used with patients and family members who are evaluating health professionals’ behaviour and the quality of care. For this project, the literature review will

focus on the use of critical incident techniques in examining patient and family responses to satisfaction with their health care. Four studies were identified in the nursing and medical literature. These studies will be evaluated with regard to the application of the critical incident technique methodology and the advantages and disadvantages of using this approach.

LITERATURE REVIEW

Grant & Hryack (1985) and Grant & Reimer (1987) reported on the perceptions of the residents of long-term care facilities with regard to the quality of nursing care. The researchers focused on 18 categories of care/service. Aspects of care such as the admission process, privacy, respect for personal belongings, and nursing care were examined. The residents were asked to give examples to describe an instance in which a nursing service was/was not provided. One sample question was -- "Can you give me an example for when the personal care that you received could have been done better?" (Grant & Hryack, 1987,p.44). A major advantage was that this study followed the process of care from admission through the stages of adaptation to the long-term care facility. This process of care is similar to the hospital process outlined in quantitative questionnaire for the Neuroscience Program (see Chapter 7). When utilizing the critical incident technique, it would be beneficial to ensure that there are parallels between the quantitative data obtained using the questionnaire and the qualitative questions obtained using the critical incident technique.

The major limitation of this study was that it focused on the tasks of nursing rather than on perceptions of quality or lack of quality. The general aim of the study was to determine the quality of nursing care, but the questions did not reflect this goal. The results did, however, provide useful information on the care of residents for the purposes of quality assurance (although that was not the original aim of the study).

Norman, Redfern, Tomalin & Oliver (1992) have examined indicators of high and low quality nursing care. They described the development and the implementation stages of their research, critiqued the critical incident technique methodology, and discussed the benefits and disadvantages applying this methodology. The results of their study have not yet been published. The general aim of the study was to examine the provision of high-quality nursing care for patients on medical, surgical and elderly care wards. "Provision of care was defined as a collaborative partnership between the nurse and patient unless the patient is unable to or chooses not to participate actively in his or her care" (Norman, et al. 1992,p.593). The researchers decided not to be more specific regarding the nursing activities, because they did not wish nursing to be defined according to the tasks of the job. The respondents (patients) were to identify those aspects of the nurses' behaviour that was meaningful to them with respect to high quality nursing (Norman, et al. 1992, p.593).

The respondents were chosen based on their ability to observe and experience nursing care directly. Since both the patients and the nurses were involved in the critical incidents, only minimal training of the observers (nurses) was needed. The nurses were instructed with regard to the general aim of the study, the purpose of the study, and the protocols that were necessary to ensure confidentiality. The study sample was drawn from two health authority regions. "The patients were men and women, of varying ages and varying levels of dependency. The nurses were at different stages of their careers and were drawn from each grade, from first-year student to ward sister" (Norman, et al. 1992,p.593).

Flanagan (1954) recommends that the sample size be determined by the number of incidents and not by the number of people. "In general, the more complex the general aim of the activity the more incidents are required to describe that aim comprehensively; the number of incidents needed cannot be predefined. Ideally, the researcher would collect the minimum number required to answer the research question. This can be achieved by continuing to collect and

analyze incidents until the last 100 incidents fail to provide any new information. This approach is dependent upon the researcher being able to analyze and classify the incidents as they are collected” (Norman, et al. 1992,p.594). Norman and colleagues (1992) felt that in applying this principle, the numbers of patients and incidents needed to satisfy the general aim of this project would be so large that it would make the study impossible. Instead, the authors chose to collect the maximum number of incidents from each respondent in a single interview.

The data were collected using retrospective accounts of the incidents. The respondents were interviewed by the nurse (observer) using a questionnaire with pre-determined open-ended questions (Questionnaire in Appendix 9)(Norman, et al. 1992,p.600). The interviews were tape-recorded with the patient’s permission. An incident was defined as a complete and clearly demarcated scene that met Flanagan’s five criteria (noted above). The analyses of the data followed a *four -step approach*.

The *first step* in analyzing the data was to transcribe the all of the data on the left-hand side of a sheet. *The second step* was to identify and record opposite the data, the various meanings and happenings in the data. A “meaning” is defined as an event that is observed which is meaningful to the respondent. “Happening” is an observed event, such as aspects of care provided by a nurse. *The third step* in the analysis entails linking the “meanings” and “happenings”. A single “happening” can have more than one “meaning” for a respondent. Finally, *the fourth step* involves the development of statements of “critical happenings”. A critical happening is made up of a “happening” and a related “meaning” (Norman et al, 1992,pp.597-598).

Through the development of the research and the testing of the questions in a pilot study, Norman and colleagues (1992) challenged three presuppositions inherent in Flanagan’s theoretical model. The first presupposition that they challenged was the definition of “critical incident”. According to Flanagan, a “critical incident is a clearly demarcated scene with a clear beginning and end, which an observer is able to make a definite judgement that the incident observed makes

a significant contribution, either positively or negatively, to the general aim of the study” (Norman, et al. 1992,p.595). The second presupposition that was challenged was the idea that a critical incident could only be valid if the respondent can produce a detailed account of the event. Norman and colleagues suggest that the respondents do, in fact, summarize their overall experiences while in hospital in their descriptions of single incidents. The respondent’s description of one incident is often an amalgam of similar incident rather than a single clearly recalled event. Within his/her description, the respondent is able to define critical happenings. The authors conclude that it is reasonable to “accept critical happenings identified by the patient as valid by virtue of the fact that they are clearly important to the patient” (Norman, et al. 1992, p.596).

The third presupposition challenged by Norman and colleagues was Flanagan’s assumption that each critical incident was the basic unit of analysis. They suggest that the “more appropriate units of analysis are *the critical happenings* revealed by the incident” (Norman, et al. 1992,p.596). An incident is revelatory (instead of critical) if it contains *critical happenings* that are critical by virtue of being significant to the general aim of the research. They pointed out that the critical incident technique was initially utilized in studies of a man and a machine (airplane). “The technique as it is originally described relied upon a number of presuppositions which may be misleading when applied to the social context of nursing. Human beings are complex creatures with varied histories and memories who create and recreate meaning within the social situations they experience” (Norman et al. 1992, p.599). Thus, the *critical happening* can not be removed from previous learning and experienced happenings. It is the *meaning* of these *happenings* that is of crucial importance.

The description given by Norman and colleagues (1992) of the development and implementation stages of their study provides readers with a complex understanding of the theoretical framework and its application to the study of nurse-patient interactions. The author’s criticisms of Flanagan’s methodology must lead us to question the adequacy and the applicability

of this methodology to the study of human interactions. However, the limitations of their research included a lack of information on the sampling technique. The fact that they had conducted only a limited pilot study makes it difficult to offer a fully informed critique.

Cox, Bergen & Norman (1993) explored consumers' views on the care provided by the MacMillan nurse using the critical incident technique. This study focused on descriptive accounts of a MacMillan nurse's work with terminal cancer patients. The general aim of the study was to examine the extent to which a MacMillan nurse was able to provide high-quality care to his/her clients (Cox, et al. 1993,p.410). Since this London Health Authority employed only one MacMillan nurse, this simplified the selection process. The respondents for the study were consumers of the nurse's services. Consumers were broadly defined to include the patients, their carers, district nurses and general practitioners. By expanding the definition of consumer, the authors were provided with multiple sources of evidence. Eight patients were randomly selected from the nurse's caseload. Consumers associated with these eight patients were also contacted. A total of five carers, five district health nurses and two general practitioners participated in the study. There was no mention on how these people were actually selected, or whether any eligible consumers declined to participate.

Cox and his colleagues chose the critical incident technique as their preferred method because this approach enabled them to obtain rich narrative data, whilst at the same time imposing a format that ensured that all respondents focused on the same issues. This approach was considered well suited to the study of terminal cancer patients. "The advantage of focusing on specific incidents is that, in addition to facilitating recall, respondents can identify and clarify feelings and meanings which they may attach to these, but otherwise be unable to articulate" (Cox, et al. 1993,pp.409-410). Requesting an exhaustive review of critical incidents from each patient was not feasible due to the vulnerability of this patient population. Also, the small sample size served to limit the range of types of incidents. "However, Flanagan (1954) pointed out that the critical incident technique should be thought of as a flexible set of principles which must be

adapted to meet the specific issues under investigation” (Cox, et al. 1993,p.411). In view of this, several adaptations were introduced in order to facilitate the study. First, only those incidents or “critical happenings” about which patients were forthcoming were elicited in order to protect the terminally ill patients. Secondly, the study used retrospective accounts rather than direct observations. Thirdly, in keeping with the study by Norman and colleagues, described above, emphasis is placed on “critical happenings” as the respondent determined them. “Critical happenings” are often an amalgam of incidents of similar type that are brought together under one descriptor that is deemed valid because of the significance of these happenings for the respondent. Finally, both positive and negative aspects were elicited from the respondents.

Informed consent was obtained prior to the interviews. The interviewer was trained in interviewing style, including techniques of checking, probing and clarifying, in order to fully understand the meanings. The interviews were tape-recorded and then transcribed. The interviews lasted between 20 and 45 minutes (Cox et al. 1993,pp. 411-412). The data were analyzed using the four-step process, as described in Norman and colleagues. Steps one, two and three were identical in nature. Step four differed slightly because of the general aim of the study. Statements of “critical happenings” were developed with the aim of defining high and low elements of the care provided by the MacMillan nurse. In addition, two further steps in the analysis process were utilized. *Step five* consisted of grouping the “critical happenings” into themes for each group of respondents (nurses, patients, carers, and general practitioners). Finally, *step (six)* involved developing group profiles on the basis of further classification. The result of steps five and six are described in Appendix 10 (Cox, Bergen & Norman, 1993,p.413).

Cox and colleagues identified that recall of an incident can be a very subjective process. However, in utilizing the critical incident technique, the focus is not just on the recall of the incident or “happening”, but also on the “meaning” of the incident. “Meaning” is defined by the respondent and not by the researcher, thus increasing the validity of the results. In addition, data relating to both positive and negative aspects of care decreased the bias of positive response

reporting. However, one can query that the researcher makes when connecting the “meanings” and the “happenings” when analyzing the data. Where possible, it is desirable to have an independent researcher review the transcripts and analyze the data. Finally, the examination of the work of one MacMillan nurse limits the generalizability of the results.

Kent, Wills, Faulkner, Parry, Whipp and Coleman (1996) conducted the fourth study reviewed here. They examined patient reactions to met and unmet psychological needs using the critical incident technique. They studied cancer patients attending a Cancer Centre for treatments. Cancer patients were chosen as the study sample, because these patients “must deal with a variety of psychological and social difficulties through the course of their illness” (Kent, et al. 1996, p.188). Since the role of the nurse in the Cancer Centre is to provide emotional support to the patients and their families, this particular aspect of care certainly needed to be evaluated.

The general aim of the study was to examine the extent to which the nursing staff were able to meet the emotional needs of the cancer patients. “Patients attending a cancer unit were asked to describe situations in which their emotional needs were and were not met by staff, to outline their feelings at the time, and to describe staff behaviour “(Kent et al. 1996,p.188). The researchers used a mailed questionnaire with open-ended questions to collect information relating to critical incidents (Appendix 11). No rationale was given for the selection of a mailed questionnaire over other methods of data collection.

“One hundred and eighty-five patients receiving treatment for a variety of (cancer-related) conditions were surveyed. Forty-three general outpatients, 38 chemotherapy and radiotherapy patients, 39 patients from outreach clinics and 65 in-patients” (Kent, et al. 1992, p.188). Ninety-two (50%) of the patients returned their questionnaires, although the rate varied from 32 percent for the in-patients to 61 percent for the outpatients. There were 68 females, 18 males and 6 respondents with no gender specified, with an average age of 58.2 years” (Kent, et al.

1992, p.188). The patients provided 61 incidents where their emotional needs were met by the nursing staff.

The positive incidents were categorized under treatment, diagnosis, physical and/or practical issues. The patients identified 21 incidents relating to the information and support that they received during the radiation and/or chemotherapy treatments, side effects of treatments, and their feelings of uncertainty about the future after treatment. The patients identified 14 incidents relating to the support that they had received from the nurses with regards to their diagnoses and prognoses. The patients identified nine positive incidents when the nursing staff assisted with physical care needs after surgery and made suggestions as to how best to manage the activities of daily living. "General positive comments (n=17) were often made about the overall level of care received, rather than outlining specific incidents" (Kent, et al. 1996,p.189).

Twenty-one respondents identified an incident when their emotional needs were not met. Seven of the patients identified incidents when the nurses did not support them at the beginning of treatment or during a "mid-term crisis" of their treatment. Five of the patients noted incidents specific to their diseases or treatments that were not addressed. Five respondents noted inadequate communication between patients and staff members or amongst staff. Finally, 4 patients commented the nurse's inability to support their emotional needs (Kent, et al. 1996, p.189). Suggestions for improvement focused on the need for the provision of more information, the need for more individualized attention and the need for improved teamwork between staff.

This study demonstrated the use of critical incident technique utilizing a questionnaire approach to data collection. The response rate, as with many questionnaires, was only 50 percent. This makes it difficult to generalize to the total patient population. In addition, this low response rate from the inpatient population underlines the importance of patients' concerns about anonymity and the affect that the severity of illness has on the patient's actual or perceived ability to respond to a questionnaire survey. This study did focus on emotional support, which has been

identified both in the research literature and in the existing data from the Neuroscience Program as an important patient need. Also, the suggestions for improvement were helpful, albeit very general. Perhaps the suggestions for improving care would have been more detailed and more useful if the information had been collected in person.

The four studies reviewed above have provided useful insights into the advantages, drawbacks, and flexibility associated with using the critical incident technique with patients and families. In developing this research project, I will need to consider the strengths and shortcomings of these four studies. In the next chapter, I will use the critical incident technique to examine components of the care provided to the Neuroscience patient population.

CHAPTER NINE

APPLYING THE CRITICAL INCIDENT TECHNIQUE TO EVALUATE PATIENT AND FAMILY SATISFACTION IN THE NEUROSCIENCE PROGRAM

The ultimate goal of this research project is to improve patient and family satisfaction in the Neuroscience Program at the Hamilton Health Science Corporation. To reach this goal, the program must collect relevant and comprehensive information from former patients and their families regarding their satisfaction with care and possible opportunities for improvement. This chapter will focus on the design, measurement, assessment, and improvement stages of this research project. The previous chapters contain most of the information necessary to complete the outline for each of these four stages. Flanagan's critical incident technique will be utilized in order to collect qualitative data on patient satisfaction.

The critical incident technique was chosen as the preferred methodology for this project because it can provide us with a comprehensive analysis of a predetermined aspect of patient care. This is an essential element of this project since an open format interview would require a large sample. This can be costly and timely. With the critical incident technique, the focus of the project can be narrowed, thus limiting the size of the sample that is required. The result is a manageable budget and the production of timely research results. Also, some neurological patients do not have the tolerance, the cognitive competence, and/or the physical stamina necessary for long interviews. In this instance, a focused approach is clearly a more appropriate choice.

To this point, data have been presented regarding the Neuroscience Program and their patient population profile, the results of the Neuroscience focus group, the Hospital Corporation's patient satisfaction survey results, and written comments/letters from patients and their families. The existing research on patient satisfaction from the general patient population was also discussed. Following this, the stakeholders in the Neuroscience Program gave their views on

patient satisfaction. Some of their feedback will have to be taken into account when planning this project. Next, the patient satisfaction questionnaire that is being implemented currently in the Neuroscience Program was described. This questionnaire should be considered to be integral to the development of this project, because some of the interview questions should be worded so that there are parallels between qualitative data and the quantitative data. This will allow for comparisons, and will strengthen the conclusions drawn from the qualitative research. Finally, the knowledge obtained from our review of Flanagan's critical incident technique and the examples of use of this methodology with patients and their families will be helpful in the development of this project.

In reviewing the above information, certain aspects of patient care are identified as areas needing improvement. In deciding which aspects of care to study, it must be acknowledged that some of the concerns expressed by patients and families are the result of larger social, economic, cultural, and genetic determinants of health (Evans & Stoddart, 1990, pp.1347-63). Also, the Neuroscience Program does not directly control all aspects of care. (see the patient flow chart, given in Chapter 2). The Neuroscience Program is responsible for patient care from the initial referral to discharge and also for follow-up care by physicians and/or follow-up clinics (with some exceptions). Within the inpatient care stream, the Neuroscience Program does not directly manage the care delivery in the Intensive Care Unit and Recovery Room care, since they are not part of the Neuroscience Program, but administrators, physicians and clinicians do have input into patient care. The inpatient rehabilitation care units and clinics, long-term care facilities, chronic care hospitals, and outpatient community care are all linked with the Neuroscience Program, but are not directly accountable to it. Within these limitations, the following aspects of care were identified as requiring further investigation.

The following patient problems are sometimes experienced:

- (1) Limited information regarding the diagnosis, treatment plan, diagnostic test results and prognosis.
- (2) Insufficient medical updates regarding the patient's current condition.

- (3) Inconsistent communication and continuity of information between patient care areas and amongst the health-care professionals.
- (4) Inadequate involvement of the patient and his/her family in decision-making.
- (5) Inadequate involvement in planning for discharge from the patient care unit.
- (6) Caregivers not informed and educated regarding the complex needs of the patient following discharge.
- (7) Personal care delayed or incomplete.
- (8) Delayed responsiveness of the staff to the call bells.
- (9) Concerns expressed by the family for patient's personal safety if confused and/or in an isolation room.
- (10) Uncertainties with regards to the process for evaluating the patient's capacity to determine treatment, personal care, and financial decisions.
- (11) Lack of expressions of hope by staff members when discussing prognoses.
- (12) Inadequate emotional support.

These concerns were more commonly noted in patients who had increased acuity of illness, poor prospects for recovery and/or limited prognoses, cognitive/behavioural impairments, and/or requiring considerable amounts of personal care.

In reviewing these patient concerns, common themes are noted – timely adequate information, sufficient education, consistent communication, continuity in care, the need for the provision of a safe environment, acceptable standards for personal care, emotional support and the need for hope. Since it is not feasible to properly evaluate all of these aspects of care thoroughly in one interview, it is important to determine which themes should be selected for study, and which would be most useful when planning for improvements. Since the provision of information, communication and education are the predominant themes noted both in the research literature and in the Neuroscience database, these would seem to be the most important to study.

Also, these three themes are interrelated and they are also related to all other aspects of patient care.

Other areas of dissatisfaction may be touched upon during the course of the interview, but these issues will also be addressed primarily in the large-scale patient satisfaction survey. Nonetheless, continuity in care may be affected by the inadequacies in the information communication to patients and families and between patient care areas. However, inability of the health-care systems' resources to meet the continuing needs of patients both in the hospital and in the community cannot be addressed in this project. Safety and personal care will not be dealt with directly. With the redesigning of the model of patient care, adequate time is needed for adaptation prior to subsequent evaluation. Emotional support issues may be identified by the patients and families in the interview, since being kept informed and receiving consistent communications can be viewed as necessary for emotion well-being. Finally, the degree of hope that is offered and the effect that hope (or lack of hope) has on the Neuroscience patients and their family members is an important aspect of care. A separate study should focus on this issue.

DESIGN STAGE

The design stage requires an assessment of the patient population served, acknowledgement of relevant clinical and organizational functions, identification of factors affecting patients, and the determination of the best method for collecting patient input. This information has been brought together and presented in the previous chapters. Next, according to Flanagan (1954), the general aim of the study needs to be formulated and plans and specifications need to be drawn up. Also, the priorities of the Neuroscience Program, the available resources, the priority population(s) and the observers to conduct the interview, need to be identified.

Flanagan's Stage One: General Aims of the Study

- 1) To explore, drawing on the experiences of previous patients and families, their satisfaction with the timeliness, consistency and quality of information, communication and education provided to them.
- 2) To identify, drawing on the experiences of previous patients and families, opportunities for improving the information, communication and education that are being provided.
- 3) To test the application of the Critical Incident Technique with neurologically impaired patients.

Definitions

Information is defined as the knowledge obtained from investigation, study or instruction (Merriam-Webster Dictionary, 1974).

Communication is defined as the transmission of information, thoughts, and feelings so that they are satisfactorily received or understood (Gerteis, Edgman-Levitan, Daley & Delbanco, 1993,p.73). **Communication** can also be defined as “interacting with the clients in a manner that enables them to be participants in care and service delivery” (TQTF Supplemental, 1997, p.3).

Education of patients and families is defined as an interactive process towards promoting an understanding of illness, treatment, and health (Gerteis, Edgman-Levitan, Daley & Delbanco, 1993,p.97).

The Priority Patient Population and The Priorities of the Neuroscience Program

It is especially important to study patients with a high degree of unpredictability and uncertainty, with long lengths of stay, increased acuity of illness, significant neurological impairments and/or poor prognoses. These patients were most commonly identified as being

dissatisfied with their care. Diagnostically, these patients are primarily admitted to the hospital with traumatic brain injuries (moderate to severe), brain hemorrhages (vascular), traumatic spinal cord injuries (with neurological impairments), hydrocephalus (with or without shunt malfunction), and brain tumours (neoplasia) (as was described in Chapter 4). The uncertainty and unpredictability of these illnesses result in high levels of stress for the patients and families (Engli & Kirsivali-Farmer, 1993; Stover Leske, 1992). The need for consistent, timely information and education is imperative in order to assist with adaptation and reduce levels of stress. Information, communication and education have all been shown to decrease miscommunication, enhance knowledge, improve adherence to medical regimens, improve physical outcomes, decrease re-hospitalization rates, and lead to the more effective use of health services (Gerteis, Edgeman_Levitan, Daley,& Delbanco, 1993, pp. 72-118). These patterns are closely tied to the Neuroscience Program's vision, to the Hospital Corporation's mission, vision and values, and also to the Ontario Provincial Government's goals for improving health-care utilization (as was described in Chapter 7). To this end, improvement in education, information and communication between the health-care providers, the patients and family members is a priority for the Neuroscience Program.

Flanagan's Stage Two: Plans and Specifications

“The second stage in the critical incident technique procedure involves deciding who should be the observer (interviewers), which situations should be observed and which activities should be noted” (Norman, Redfern, Tomalin & Oliver, 1992,p.593). Flanagan (1954) suggests that a clear set of specifications be established (noted in Chapter 8) (Flanagan, 1954,pp.337-339).

Specifications:

1) Situation must be clearly outlined.

(a)The patient and/or family member must have been an inpatient in the Neuroscience ward at the Hamilton Health Science Corporation and discharge in the past four to six weeks.

(b) The patient should have been admitted with one of the diagnostic categories: brain hemorrhage (vascular), traumatic brain injury (moderate to severe), brain tumour (neoplasia), traumatic spinal cord injury (with neurological impairment), and hydrocephalus (with or without shunt malfunction).

(c) The patient had a medium to long length of stay (8 to 20 days or more than 20 days).

(d) Patient was discharged from the Neuroscience ward. Patient may have gone to alternate locations, such as rehabilitation units, local community hospitals, and so on, prior to discharge to their permanent living environment.

(e) The patients and/or their families are willing and able to participate.

2) The specific incident observed must relate to the general aims of the study.

(a) The patient and/or family member (i.e. reporter) must directly observe the incident.

(b) The observed incidents can be an amalgamation of incidents of similar types– “critical happenings” (see Chapter 8).

(c) The incident or “critical happening” must relate to positive / negative issues regarding communication, information and education.

(d) The reporter (patient / family member) defines the criticalness of the incident or “critical happening”.

(e) All of the factors associated with the incident are clearly described by the reporter.

(f) The incident had to occur in the Neuroscience Patient Care Unit or be related to the communication / information / education between alternate care areas and the Neuroscience Patient Care Unit during the transfer of care. These alternate care areas can be within the Hospital Corporation (for example, the Intensive Care Unit, Emergency Room) or they can be outside health-care facilities (for example, Rehabilitation Units, Community Hospitals) that the program interfaces with in order to provide ongoing care for patients.

- 3) **The observer/ interviewer must determine the relevance of the observed incident or critical happening to the general aim of the study.** The incidents must positively or negatively be related to issues regarding communication, information and education. If the observer is familiar with the care process in the Neuroscience Program, determining the relevance of the incident will be easier.

- 4) **The fourth specification relates to the choice of observers.** If possible, the observers should be familiar with the patient care practices within the Neuroscience Program. The interviews should occur in the patients' or family members' living environments (i.e. homes, long-term care facilities, lodges, and so on). Interviewees would not have to experience the stress associated with returning to the hospital. The observer/interviewer should not be a health-care professional who provided care in the acute care setting. Perhaps, the best choice would be either a nurse researcher in private practice and/or a community-based nursing case manager, given that the majority of these patients are receiving community services. The observer/interviewer could also be a student in training for a health profession. The choice would be determined by the budget considerations and by the availability of personnel. The observer(s) should be informed about the care process in the Neuroscience Program, about the general aim of the study and about the research protocols.

Resource Requirements

Costs are dependent on sample size, the types of observers utilized, the costs of transcription, and the method utilized in interpreting and reporting the results. A project coordinator must be hired to monitor the study. There are also the costs of supplies, for example paper supplies, tape recorder(s), tapes and so on, and there are also costs of traveling to conduct the interviews within the Central West Region.

Flanagan (1954) suggests that the sample size be determined by the number of incidents and not by the number of people (p.343). "For most purposes, it can be considered that

adequate coverage has been achieved when the addition of 100 critical incidents to the sample adds only two or three critical behaviours” (Flanagan, 1954,p.343). In the research project conducted by Norman, Redfern, Tomalin & Oliver (1992) (discussed in Chapter 8), the use of a large sample was not feasible. Instead, the researchers collected the maximum number of incidents in the course of a single interview (p.594).

In reviewing the statistics presented in the 1998 Annual Report of the Neuroscience Program, 494 patients would meet the diagnostic criteria for the sample. However, this number does not reflect deaths. There were 112 deaths, the majority were the same diagnostic categories. Therefore, the maximum number of patients within the study sample would be approximately 380 to 400 patients. It would not be feasible to interview all of these patients. Therefore the sample size should be set at some fraction of this patient population.

In determining a sample size, the purpose, cost and feasibility must all be considered. In quantitative studies the sample sizes are often large. “The logic and power of probability sampling depends on selecting a truly random and statistically representative sample that will permit confident generalization from the sample to a larger population. The purpose is generalization” (Patton, 1990, p.169). Qualitative inquiry focuses on small samples and provides rich information. “Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research, thus the term purposeful sampling” (Patton, 1990,p.169). Patton (1990) identifies several methods for purposeful sampling, but the one most relevant to this project is purposeful random sampling. This requires the random selection of a small number of cases. The fact that the sample is selected randomly is important. “The purpose of a small random sample is credibility, not representativeness. A small, purposeful random sample aims to reduce suspicion about why certain cases were selected for study, but such a sample still does not permit statistical generalizations” (Patton, 1990,p.180).

Several approaches can be utilized when selecting a random sample. The most obvious method would be for the medical records department to select every 10th, 15th or 20th patient discharged with one of the five diagnostic categories, with a hospital stay greater than 8 days, and who had not died in hospital. The selection would be based on discharge dates, not on admission dates. By having the medical records department select the patients for study, any input on the part of the Neuroscience Program in sample selection is avoided.

The actual numbers selected will depend on the budget. If we were to interview every tenth patient, the sample size would be approximately 38 to 40 patients yearly, according to the 1998 Neuroscience Annual Report. If we were, for example, choosing every twentieth patient, the sample size would be approximately 19 to 20 patients yearly. This does not take into account those patients and/or families who are unwilling to participate or who drop out during the study.

MEASUREMENT STAGE

Flanagan's Third Stage: Data Collection

The measurement stage involves determining which data will be collected, who will be involved in the collection, and when, where, and how the data will be collected (Joint Commission on Accreditation of Healthcare Organizations, 1995, p.90). This stage has parallels with Flanagan's third stage outlined in the previous chapter. The interviews should be conducted in the patient's permanent discharge environment. Family members can be interviewed, not as proxies for the patients, but to provide other perspectives. As was described by Gerteis and colleagues, family members play different roles and tend to be less satisfied with the quality of care, and have high information needs (p.185). Therefore, their input will be invaluable. When interpreting the data, patient's responses and family member's responses need to be treated separately.

The patient and/or family member should be contacted four to six weeks after discharge from the Neuroscience Program. Fottler and colleagues (1997) recommend that interviews be conducted one week after discharge. This allows for the best recall, since the information is current. However, many Neuroscience patients will be receiving care in a rehabilitation unit, undergoing oncology treatments, or recuperating from their illnesses. Interviewing patients 4 to 6 weeks makes sense. If the patient has not yet reached their permanent discharge environment, or unable to participate on account of illness, the interview could be postponed to a later date.

Patients and family members will be contacted by telephone and asked to participate in the study. If they agree, a Corporate Patient Satisfaction Survey will be mailed for them to complete prior to the interview. The survey can be given to the interviewer, after the interview is completed, to assess for correlation in results. The observer/interviewer must obtain a written consent (Appendix 12) prior to initiating the interview. The goals of the study will be outlined. The patients and/or family members need to know that the results will be utilized to improve patient care, and will, therefore, raise levels of patient satisfaction. Also, they should be informed about the process for selecting the study recipients. The observer/interviewer will point out that the Neuroscience Program is the sponsoring the project. Then, she will describe the format for ensuring confidentiality.

Protocols governing confidentiality require that the patient and family members not be directly identified by their names, the dates of admission and/or discharge from the hospital. None of the direct care providers will be allowed to hear the taped interviews. Only the observer/interviewer, project coordinator and possibly one other researcher can have access to this kind of confidential information in order to assess for reliability of the results. Patients and family members will be assigned numbers and diagnostic categories. The patients and the families should be informed that participation is voluntary, and that they may withdraw from the study at any time.

The Interview Guide

Questions to be asked:

- 1) Thinking about your (or your family member's) stay as an inpatient on 7 South (Neuroscience Ward), what comes to mind about the amount of the information and education you (or your family member) received during the hospital stay? Does anything else come to mind? (Repeat as often as responses forthcoming)
- 2) Was the information and education that you (or your family member) received helpful? If so, why was it helpful? (Repeat as often as responses forthcoming).
- 3) Was any of the information and education that you (or your family member) received not helpful or confusing? If so, why was it not helpful or confusing? How could we improve? (Repeat as often as responses forthcoming).
- 4) Thinking about the way in which the health-care team, for example, the physicians, nurses, therapists, aides, and so on, communicated with you (or your family member) were there any times when it was not as you wished it would be? Tell me about these specific times? How could we improve? (Repeat as often as responses forthcoming).
- 5) Thinking about communication between the health-care team and you (or your family members) can you identify times when it met you needs? If so, how did it meet your (or your family members') needs? (Repeat as often as responses forthcoming).

Post-Interview Questions for the Interviewer

After the interview is completed, the interviewer should provide a post-interview commentary on how the interview went. The following are prompt questions for the interviewer:

- 1) Did the patient or family member appear to be giving their true opinions?
- 2) Was the interview too tiring or distressing to the patient or family member?

- 3) Did the patient have significant cognitive impairment impeding their understanding of the questions?
- 4) Were there any additional areas that the patient or family member would have wished to discuss?
If so what areas and why?
- 5) Were there any additional areas that the interviewer would have found appropriate to address during the interview? If so what areas and why?
- 6) Was the questions confusing and difficult for the patient or family member to understand? How would you change the wording?

Collecting the Data

In determining the best method for collecting the data during the interview, two issues must be considered. The interviews should be tape-recorded, with the permission of the patient and/or family member. The advantage of tape-recording is the comprehensiveness of the data. The disadvantage is the amount of time that is required to transcribe the interviews and the cost of transcription. Every hour of taped interview requires four to five hours for transcription. A possible solution to the cost of transcription is to have it done in a cheaper place, as has been done in third-world countries. Once the information has been transcribed, the researcher needs to determine the best approach to interpreting the large amounts of information.

Alternatively, the observer/interviewer can summarize, directly after the interview, the important points using a voice-activated system on the computer. The interviews would still need to be tape-recorded and transcribed for the database. The advantage of this method is the summarization of the results directly into the computer, which condenses what the interviewer considers to be the most relevant information in a timely manner. It also decreases the amount of time spent analyzing the transcriptions. The disadvantage to this method is the potential for loss of data and observer/interviewer bias.

The method selected for data collection will depend on sample size and confidence of the researcher in the observer's ability to accurately summarize. Possibly, if choosing the second option, the researcher will need to review three to five of the tape-recorded interviews randomly to assess for the accuracy of the observer's findings. By taping all of the interviews, the researcher can refer back to the tapes at any time to clarify the data.

ASSESSMENT STAGE

The assessment stage involves the collection of information regarding the current performance of the program, the identification of opportunities for improvement, the determination of priorities, the identification of the causes of any problems (if applicable), and also the mechanisms for bringing about improvement. To this point, most of these tasks have been completed. To identify causes of problems with communication, provision of information and education, and to plan for improvement, further patient input is needed. The next step is to analyze the data collected in the interviews. This stage is similar to Flanagan's fourth stage.

Flanagan's Fourth Stage: Analyzing the Data

Flanagan (1954) recommends that the data be interpreted using a step system as was described in the previous chapter. Norman and colleagues (1992) and Cox and colleagues (1993) also discussed the implementation of this *four – six step* approach. The benefits of this approach are that the methodology has been tried and has proven to be effective. Also, the researcher can review the data for “happenings” and “meanings” and can produce descriptions of “critical happenings”. Suggestions from the patients and family members regarding improvements in care can be categorized according to the critical happenings. If the data collection method chosen has been the interviewer's summarization of the interviews (with back-up tape-recorded data transcribed), this step process will be less time-consuming.

An alternative method would be to use a computerized system to organize the data. One such computer program is “IN VIVO” (formerly called NUDIST). Once the material has been transcribed, the researcher goes through the transcriptions placing asterisks in the text so that the sections identified parallel to the research questions. The computer is programmed to collect and group the data according to the research questions and the prompts inserted by the researcher. One advantage of this system is the speed of processing the transcribed data. In addition, this method lessens the biases associated with categorizing patients’ comments by themes. The obvious disadvantage is that the researcher who sets up the computer program can bias the way in which the data are interpreted. However, one solution is to have several researchers work on the problem independently. If they all come to similar conclusions, as to how to categorize, then it is likely that the results will not be biased.

IMPROVEMENT

Flanagan’s Fifth Stage: Interpreting and Reporting the Results.

Once the raw data have been turned into useful information about performance, this information needs to be translated into plans for improvements. To ensure that patient input is part of this effort, one must consider how the information about patients’ needs, wants, perceptions, and so on, can be incorporated into the design (or redesign) of patient care. The administrators and stakeholders in the Neuroscience Program need to follow four steps when utilizing the information.

(1) Organize Patient Requirements

The analyzed data need to be organized into various sections that highlight specific concerns. These groupings will have evolved in the course of identifying the various themes in the qualitative data. This information should be plotted on the patient flowchart (in Chapter 2) to identify which aspect of the care process is the most problematic.

(2) Rank Requirements According To Importance

The Neuroscience team needs to prioritize the themes according to importance and feasibility. Reviewing the stakeholders input (Chapter 6) would assist with prioritization. Since patients and families are major stakeholders, their input would be imperative.

(3) Translate Patient Input Into Improvement Plans

It will be necessary to translate the information obtained into plans for the new process (or redesigned process). Patients' needs, expectations and other input should be built into the actual steps used to carry out a process. A flowchart may be helpful in illustrating the various steps and relationships.

(4) Develop Indicators or Measures of the Process

Measures of performance must be developed or be identified, if available, in order to determine the adequacy of the new processes. Patient needs and expectations should be used to create these measures. This may involve repeating interviews using the critical incident technique in order to identify specific quality care components. Also, re-examining the results from the patient satisfaction questionnaire may be valuable. The exact indicators will need to be defined depending on the improvement process being implemented.

NEXT STEP

The procedure for conducting interviews using the critical incident technique to examine communication, information and education amongst a specific Neuroscience population has been presented. The Neuroscience team will need to determine the appropriate budget, the sample size and the observers/interviewers. The team will also need to determine the methods of data collection and analysis most applicable to their needs. Initially, the research project should have a slow start in order to allow for adjustments to the questions and for changes in the format as needed. Once a sample size has been identified, the team will need to correlate

the results of the interviews with the questionnaire results. Possible improvements should be identified. The evaluation of patient satisfaction and improvement in care is a cyclical process. Continuous re-evaluation and improvement is necessary if the Neuroscience Program is going to have satisfied patients and if we are to continue to develop our knowledge and understanding of the consumers' needs.

CHAPTER TEN

CONCLUSION AND RECOMMENDATIONS

What patients' experience and what they think about that experience should matter to health-care administrators, health-care professionals, and politicians. That experience, as much as the technical quality of care, will determine how people use the health-care system and how they benefit from it. Do patients get what they need from the facilities and services provided in the hospital? They expect that they will get technically sophisticated and up-to-date care. However, the choices that patients make about their health and health-care utilization are not based solely on this factor, but are largely dependent on the subjective experiences of being a patient. If patients are dissatisfied with his/her care, their health outcomes, patterns of health-care service utilization, and rates of compliance with treatment regimens will be lowered.

Throughout this paper, the similarities and differences between the Neuroscience patient population to the general patient population have been identified. The patients with the longest stays, with the most catastrophic injuries or illnesses, with the poorest prognoses, and with the fewest social supports are patients who are the least satisfied. This is true for all patients. However, the Neuroscience patient population has a significant number of these patients, because of the nature of their illnesses. Other unique features of the Neuroscience population are the cognitive, speech, and behavioural impairments, and the altered states of consciousness. These impairments cause significant stress, both to the patient and their family. Health-care interventions are aimed at saving lives and/or improving the potential for a better or for a longer life. Unfortunately, disabilities, impairments and deaths are inevitable. It is the emotional support, communication of pertinent information in a timely manner, and education which helps people begin to adapt to these tragedies.

Communication, information and education are major areas of concern and these areas probably provide for the greatest potential for improvement. The critical incident technique was

chosen as the most appropriate, feasible and cost-effective approach. It provides in-depth information on specific aspects of patient care. It has already been utilized with patients and it has provided useful information. The critical incident technique enables the physically-impaired or ill patients to participate. Interviewees are not required to read or write and the interview can be shortened, if necessary. By conducting the interviews away from the acute-care setting and by using interviewers who are not involved in providing acute-care services, the emotional trauma of returning to the hospital and the patient's identity are protected.

The stakeholders identified information, communication and education as areas of concern with patient care. So why has it not improved? It may be the result of feeling powerless to change, feeling overwhelmed by the system, or even feeling apathetic. Often, people do not realize that even a small change, for example, taking the time to listen to a patient's concerns, can make a difference. Health professionals tend to focus on the technical and scientific aspects of care, they experience pressures for early discharge, and worry about restructuring and about funding cuts. As Gerteis and colleagues (1993) state in their book, *Through the Patient's Eyes*, it is often not individual people who fail patients, but the systems as a whole that lets patients down.

To greater understand how the Neuroscience health care team can effect change, thus improve patient satisfaction, further information is needed from the patients and families. The research plan has been outline in the final chapter. The study population should focus on the patient population identified as the least satisfied with care. This patient population was identified as the patients admitted with five of the following diagnostic categories – brain tumour (neoplasia), brain hemorrhage (vascular), spinal cord injury with neurological deficits, hydrocephalus and traumatic head injury (moderate to severe). The patients hospital stay should be greater than eight days. The sample population should be randomly selected from a portion of this patient population.

The Neuroscience planning team and administrators will need to determine the budget for study. The interviews should be taped and the information transcribed into a database. The study should be repeated on a yearly basis, to be able to assess for change over time. Questions, specific to an implemented change, may be added. However, the core group of questions should remain, to be able to properly evaluate for improvements. The most imperative step in Flanagan's theory is the improvement stage. The Neuroscience team will need to determine priorities and the feasibility of each improvement effort identified. Once a plan is in place, continued monitoring using the critical incident technique will be important to monitor for positive changes in patient satisfaction.

The information provided by the patient and/or their family member will be helpful in understanding ways in which we can improve upon our current system of providing information and education, as well as the way we communicate with them. Not all issues can, or will be resolved, but I am sure that there will be many opportunities for improvement in these aspects of care. Often, recognition is the first step to change. The health-care professionals may identify these as opportunities for change, but they need the patient and families input on how to make it possible. For too long, the patients and families have been left out of the design (and redesign) of care. In the patient-centered model, patients need to be leaders in changing health-care systems to better meet their needs.

APPENDIX 1:

RESULTS OF PATIENT SATISFACTION SURVEY

By

Charles, Gauld, Chambers, O'Brien, Haynes & LaBelle

1994, p. 1819

Table 2: Proportion of patients who reported any of the 39 problems with hospital care surveyed

Problem	% of all patients (and % at risk)*	Problem	% of all patients (and % at risk)*
Communication		Education about medications and tests	
Not told what daily routine would be in hospital	41	Purpose of new medicine given to patient in hospital not explained in an understandable way	7 (9)
Not told before or shortly after admission things she or he should have been told	11	Important side effects of medications received in hospital not explained in an understandable way	16 (20)
No doctor in charge of care or doctors not available when needed	4	No one explained in an understandable way why important tests were being done	8 (11)
Did not get understandable answers from doctors in response to questions asked	8	Doctor or nurse did not explain test results in an understandable way	15 (21)
Did not get understandable answers from nurses in response to questions asked	5	Pain management	
Not satisfied with the way information about condition was given	8	Had pain that could have been eliminated by prompt attention by hospital staff	16 (23)
Privacy was not respected during hospital stay	4	Experienced more pain in hospital than told to expect	8 (11)
Doctor or nurse did not explain before a test how much pain or discomfort to expect	26 (36)	Waited 15 or more minutes on average for pain medication	6 (10)
Relationship with physician in charge		Received too little pain medication	4 (5)
In terms of confidence or trust, had a poor or fair relationship with doctor in charge of treatment	6	Family communication and education	
Patient preferences		Family given too little information about hospital care	10
Upset because examined or treated by someone who did not explain what she or he was going to do	4 (76)	Family or care partner not given all the information needed to help patient recover at home	26
Not involved in decisions about care as much as she or he wanted	10	Discharge planning	
Doctors often or sometimes talked in front of patient as if she or he was not there	12	No hospital staff tried to help with concerns about returning home	10 (37)
Nurses often or sometimes talked in front of patient as if she or he was not there	8	Purposes of medications to take at home not explained in an understandable way	3 (4)
Hospital staff did not go out of their way to meet patient needs	17	Not told when and how to take medications at home	3 (4)
Physical care		Not told about important side effects of medications to watch for	18 (26)
Not given enough help bathing	3 (9)	Not told what foods to eat or not to eat at home	57†
Not given enough help going to the bathroom in time	3 (7)	Not told what activities to do or not to do at home	29
Waited 15 minutes or more on average for help after pushing call button	3 (4)	Not told when she or he could resume normal activities	32
There were times when the nurses were overworked and too busy to take care of patient	29	Not told when she or he could return to work	18 (29)
		Not told what danger signals about illness to watch for at home	39
		Not told what to do to help recovery	24
		Received no assistance from hospital before discharge in finding help needed after discharge	9 (47)

*"Refuse to answer" and "Do not know" responses are excluded in calculating percentages. Patients at risk include only those exposed to the event: 3361 patients had tests, 227 were examined by someone who did not explain what they were going to do, 1785 needed help bathing, 1793 needed help going to the bathroom, 3380 used the call button, 3800 received new medicine in hospital, 3296 had pain, 2827 requested pain medication, 3457 received pain medication, 1258 had concerns about returning home, 3297 were given medicine to take at home, 2801 were returning to work, and 891 needed help after discharge.

†This may be an overestimate, because no question was asked to determine the relevant population at risk for this item; for example, patients could have been asked whether they felt they should have been told what foods to eat or not eat at home.

APPENDIX 2:

PATIENT DIAGNOSTIC GROUPS, DIAGNOSIS AND LENGTH OF STAY

Neuroscience Annual Report

1998,p 49-50, A2-4.

Table 23: "Numerous short LOS" discharge group analysis

Diagnosis	Discharges	Mean LOS	Bed days	Mode	cases with LOS = mode + 1 day	cases with LOS = mode + 2 days	cases with LOS > 2 x mode	bed days saved if short delays eliminated	% bed days saved if short delays eliminated
Carotid stenosis	90	3.5	315	2	22	6	9	34	10.8%
Lumbar disc prolusion	44	2.6	114	3	5	0	1	5	4.4%
Lumbar stenosis	34	4.4	151	4	4	4	1	12	7.9%
Subarachnoid hemorrhage	25	6.9	173	n/a	n/a	n/a	n/a	n/a	0.0%
Lumbar disc with radiculopathy	20	3.3	66	2	6	2	1	10	15.2%
Astrocytoma	19	4.3	82	n/a	n/a	n/a	n/a	n/a	0.0%
Cervical disc	16	2.4	39	2	3	1	1	5	12.8%
Wound infection	13	6.6	86	n/a	n/a	n/a	n/a	n/a	0.0%
Seizure, generalized	13	6.7	87	n/a	n/a	n/a	n/a	n/a	0.0%

Table 24: "Numerous, short LOS" operations group analysis

Operation	Discharges	Mean LOS	Bed days	Mode	cases with LOS = mode + 1 day	cases with LOS = mode + 2 days	cases with LOS > 2 x mode	bed days saved if short delays eliminated	% bed days saved if short delays eliminated
Carotid endarterectomy	82	3.3	273	2	22	6	8	34	12.5%
Stereotactic Biopsy	48	6.7	322	1	5	3	20	11	3.4%
Lumbar disc removal	48	2.8	135	3	6	0	2	6	4.4%
Anterior Cervical Discectomy & Graft	32	3.3	105	2	4	3	6	10	9.5%
Pituitary tumour removal, transphenoidal approach	12	6.0	72	5	3	2	1	7	9.7%

Table 25: Groups considered "numerous, with medium LOS" - Diagnoses

Diagnosis	Discharges	Mean LOS	Bed days	mode	cases with LOS = mode + 1 day	cases with LOS = mode + 2 days	cases with LOS > 2 x mode	bed days saved if short delays eliminated	% bed days saved if short delays eliminated
Cervical ddd + myelopathy	27	7.9	213.3	5	3	0	3	3	1.4%
Intracerebral hematoma	53	16.9	895	n/a	n/a	n/a	n/a	n/a	0.0%
Glioblastoma	45	11.2	504	6	3	4	15	11	2.2%
Closed head injury	137	15.5	2123	n/a	n/a	n/a	n/a	n/a	0.0%
Subdural hematoma	88	16.3	1437	5	7	5	34	17	1.2%
Metastasis, cerebral	25	10.4	259	3	2	1	10	4	1.5%
Meningioma	40	11.2	446	4	3	2	19	7	1.6%
Metastasis, spinal	23	14.5	334	n/a	n/a	n/a	n/a	n/a	0.0%
Aneurysm, unruptured	20	19.1	381	6	1	3	8	7	1.8%
Lymphoma, malignant	13	11.8	154	n/a	n/a	n/a	n/a	n/a	0.0%
Pituitary Tumour	19	8.5	161	6	3	1	2	5	3.1%

Table 26: Groups considered "numerous, with medium LOS" - Operations

Operation	Cases	Mean LOS	Bed days	mode	cases with LOS = mode + 1 day	cases with LOS = mode + 2 days	cases with LOS > 2 x mode	bed days saved if short delays eliminated	% bed days saved if short delays eliminated
Laminectomy for decompression	68	7.2	489	3	10	6	12	22	4.5%
Burr hole drainage of subdural hematoma	59	14.3	843	5	4	1	14	6	0.7%
Aneurysm clipping, supratentorial	35	42.6	2596	12	1	1	18	3	0.1%
Shunt insertion	24	11.5	275	3	1	2	11	5	1.8%
Meningioma removal, supratentorial	24	9.5	229	6	2	0	6	2	0.9%
Glioblastoma removal	23	10.9	251	6	3	2	8	7	2.8%
Subdural hematoma removal	21	19.9	418	5	0	0	17	0	0.0%
Anterior decompression with instrumentation	21	14.7	309	6	2	0	9	2	0.6%

Table 27: Procedures with long mean LOS

Operation	Discharges	Mean LOS	Bed days
Intracerebral hematoma removal, supratentorial	13	40.2	522
PEG insertion	9	44.9	404
tracheostomy	7	69.4	486
Epidural hematoma removal	6	28.2	169
Open reduction & internal fixation, posterior approach	5	57.4	287
Melanosis removal, intratentorial	5	21.6	108
Craniotomy for brain trauma	3	115.7	347
AVM removal, supratentorial	3	83.7	251
Ommaya Reservoir Insertion	3	23.3	70
Pituitary tumour removal	3	21.3	64
Open reduction & internal fixation, anterior approach	2	44.0	88
Decompressive Craniectomy	2	37.5	75
Posterior thoracic laminectomy	2	33.5	67
subdural hematoma drainage	2	27.0	54
Hickman insertion and trach clipping of aneurysm	1	364.0	364
PEG and Trach	1	152.0	152
trach and peg	1	135.0	135
Transoral removal odontoid peg tube insertion	1	96.0	96
peg tube insertion	1	87.0	87
Aneurysm clipping, supratentorial, clot removed	1	84.0	84
Cystoscopy and changing suprapubic catheter	1	75.0	75
Third ventriculostomy with biopsy	1	74.0	74
Intracerebral hematoma removal, negative exploration for Ant Com aneurysm	1	74.0	74
Basilar aneurysm clipping	1	71.0	71
removal bladder calculus	1	68.0	68
resection of tumor and pinning of humerus	1	54.0	54
Cystoscopy	1	49.0	49
Third ventriculostomy for tumour removal	1	39.0	39
Brain abscess drainage	1	34.0	34
brain abscess drainage via burr holes	1	32.0	32
Meningioma removal, intratentorial	1	32.0	32
Ependymoma removal, supratentorial	1	32.0	32
stabilization of bilateral tibia fractures	1	31.0	31
Repair of tibia fracture	1	30.0	30
TURP & removal bladder calculi	1	29.0	29
Cerebellar cyst removal	1	27.0	27
liver biopsy	1	25.0	25
ORIF radial shaft and application of casts for ankle instability	1	21.0	21
ORIF left hand	1	21.0	21

Table 28: Diagnostic groups with long LOS

Diagnosis	Discharges	Mean LOS	Bed days
Aneurysm, ruptured	74	42.3	3130
Cerebral infarction	33	23.1	761
Shunt malfunction	16	28.9	463
Vertebral column fracture with spinal cord injury	15	35.0	525
Hydrocephalus, communicating	12	56.8	681
Hydrocephalus, obstructive	6	41.7	250
Penetrating head injury	4	102.5	410
Hemorrhagic infarction	4	52.8	211
Traumatic cervical spondylotic myelopathy	3	75.7	227
Parkinson's Disease	3	56.0	168
Myelitis	3	26.7	80
Myelopathy due to rheumatoid arthritis	2	51.5	103
Subdural hygroma	2	50.5	101
Myeloma, spinal	2	21.5	43
Primary malignant tumour, spine	1	79.0	79
Conversion disorder	1	45.0	45
Encephalitis, post infectious	1	41.0	41
Ependymoma	1	32.0	32
Neurosyphilis	1	27.0	27

Table 29: Long LOS analysis

Diagnosis	Discharges	Mean LOS	Bed days	Cases > mean LOS	Excess Bed days
Aneurysm, ruptured	74	42.3	3130	16	1712.2
Cerebral infarction	33	23.1	761	11	327.3
Shunt malfunction	16	28.9	463	1	335.1
Vertebral column fracture with spinal cord injury	15	35.0	525	5	214.0
Hydrocephalus, communicating	12	56.8	681	1	478.3

Diagnostic Groups by Type

Type	Diagnoses	Discharges	
Hydrocephalus	Shunt malfunction	16	
	Hydrocephalus, communicating	12	
	Hydrocephalus, obstructive	6	
Inflammatory/infectious	Brain abscess	4	
	Discitis	2	
	Meningitis, no organism	2	
	Myelitis	2	
	Toxoplasmosis	2	
	Arteritis, cerebral	1	
	Cholesteatoma	1	
	Encephalitis, post-infectious	1	
	Neurosyphilis	1	
	Osteomyelitis	1	
	Parasitic cyst	1	
	MS	Multiple sclerosis	10
	Neoplasia	Glioblastoma	45
		Meningioma	40
Metastasis, cerebral		25	
Metastasis, spinal		23	
Astrocytoma		19	
Pituitary tumour		19	
Lymphoma, malignant		13	
Metastasis, cerebellar		11	
Acoustic neuroma		9	
Glioma		8	
Myelopathy due to extradural metastasis		6	
Meningioma, spinal		5	
Oligodendroglioma		5	
Schwannoma		5	
Colloid cyst		3	
Craniopharyngioma		3	
Hemangiopericytoma		3	
Meningioma, atypical		3	
Oligoastrocytoma		3	
Ependymoma of spinal cord		2	
Ependymoma of filum terminale		2	
Hemangioblastoma		2	
Meningioma, malignant		2	
Myeloma, spinal		2	
Osteoma		2	
Primitive neuroectodermal tumour		2	
Dermoid tumour		1	
Dysgerminoma		1	
Ependymoma		1	
Epidermoid		1	
Ganglioglioma		1	
Metastasis, skull		1	
Myelitis, paraneoplastic		1	
Myeloma, sacral		1	
Neurocytoma		1	
Oligodendroglioma, anaplastic		1	
Paraganglioma, nasopharyngeal		1	
Peripheral nerve tumour		1	
Primary malignant tumour, spine		1	
Seizure, generalized		1	
Trigeminal neuralgia		1	
Operation Induced Problem		Wound infection	13
		CSF leak	6
		Cranial defect	1
		Epidural fibrosis	1
		Pseudoaneurysm	1
		Other	Cerebral cyst
	Dementia NYD		5
Guillain-Barre syndrome	3		
Parkinson's disease	3		
Toxic reaction to drug	3		
Cerebellar cyst	2		
Confusion NYD	2		
Cranial defect	2		
Myasthenia gravis	2		
Amyotrophic lateral sclerosis	1		
Benign intracranial hypertension	1		
Conversion disorder	1		
Double crush median neuropathy	1		
Dystonia	1		
Facial nerve palsy	1		
Huntington's disease	1		
Oculomotor palsy	1		
Peripheral neuropathy	1		
Peripheral neuropathy, drug induced	1		
Poisoning, methanol	1		
Sellar lesion NYD	1		
Syncope	1		
Syringomyelia	1		
Thoracic outlet syndrome, cervical rib	1		
Pain	Headache NYD		4
	Migraine		3
	Trigeminal neuralgia		3
	Low back pain, chronic		1
	Neuralgia		1

Seizure	Seizure, generalized	10	
	Seizure, epileptic	2	
Spinal	Lumbar disc protrusion	48	
	Lumbar stenosis	34	
	Lumbar disc with radiculopathy	20	
	Cervical stenosis with myelopathy	18	
	Cervical disc with radiculopathy	16	
	Cervical disc with myelopathy	14	
	Lumbar stenosis with radiculopathy	10	
	Cervical disc degeneration	8	
	Myelopathy due to thoracic disc	5	
	Myelopathy due to rheumatoid arthritis	2	
	Failed fusion	1	
	Low back pain	1	
	Myelopathy due to heterotopic ossification	1	
	Post lumbar laminectomy syndrome	2	
	Spinal instability	1	
	Trauma	Closed head injury	137
		Subdural hematoma	88
Vertebral column fracture with spinal cord injury		15	
Epidural hematoma		6	
Penetrating head injury		4	
Myelopathy due to trauma, without vertebral fracture		3	
Traumatic cervical spondylotic myelopathy		3	
Vertebral column fracture without spinal cord injury		3	
Anoxic brain injury		2	
Cervical sprain		2	
Intracerebral hematoma		2	
Seizure, generalized		2	
Subdural hygroma		2	
Vascular	Osteomyelitis	1	
	Carotid stenosis	90	
	Aneurysm, ruptured	74	
	Intracerebral hematoma	51	
	Cerebral infarction	33	
	Subarachnoid hemorrhage	25	
	Aneurysm, unruptured	20	
	AVM, ruptured	10	
	Cerebellar hemorrhage	10	
	TIA	5	
	Cerebellar infarction	4	
	Hemorrhagic infarction	4	
	Intraventricular hemorrhage	4	

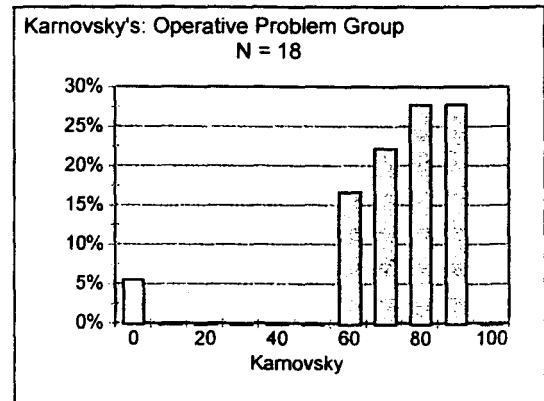
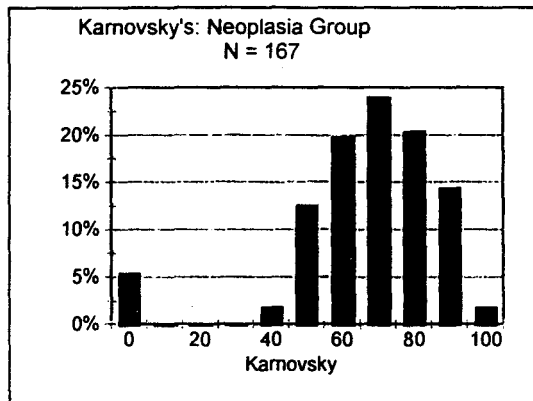
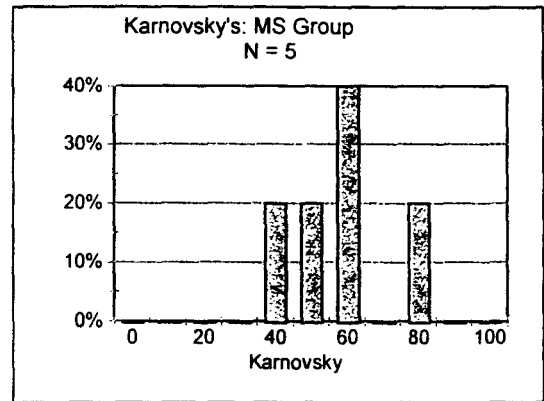
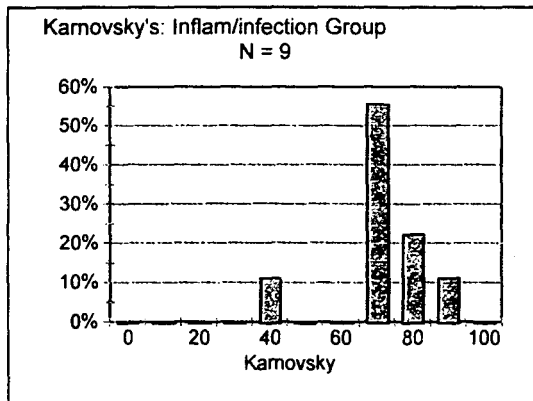
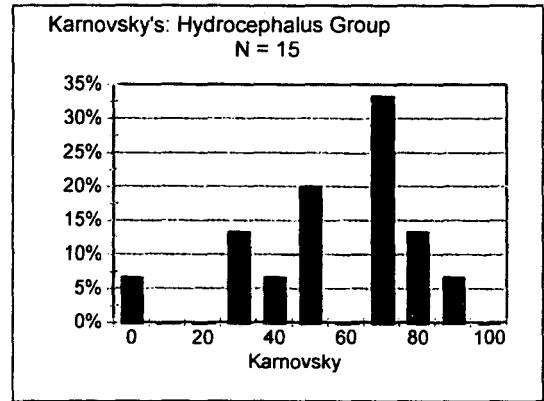
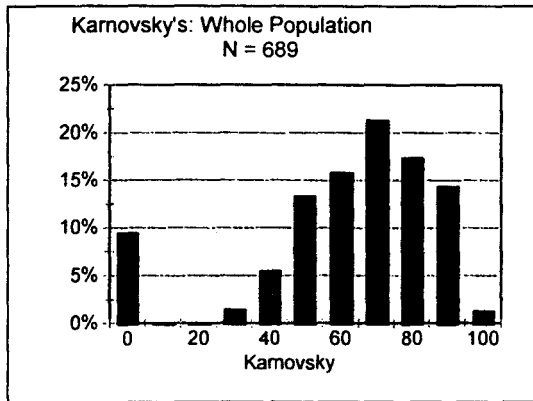
APPENDIX 3:

KARNOVSKY SCORES
FOR ALL
DIAGNOSTIC PATIENT GROUPS

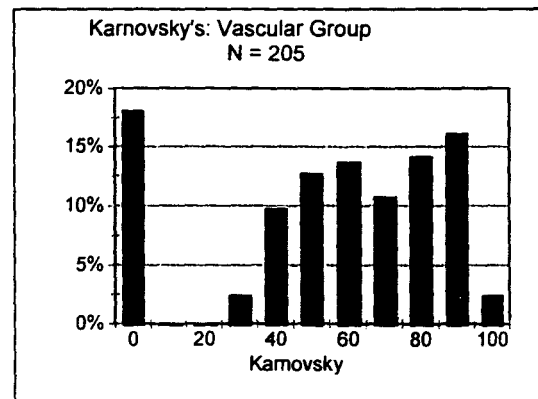
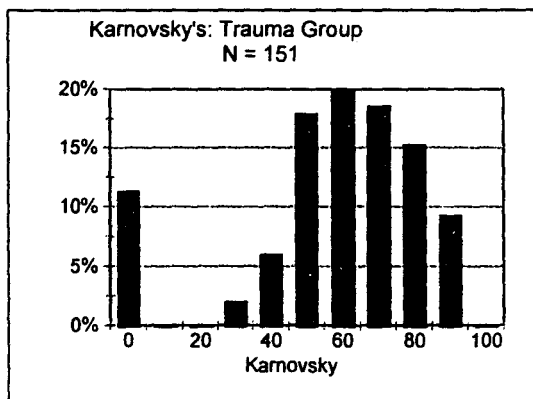
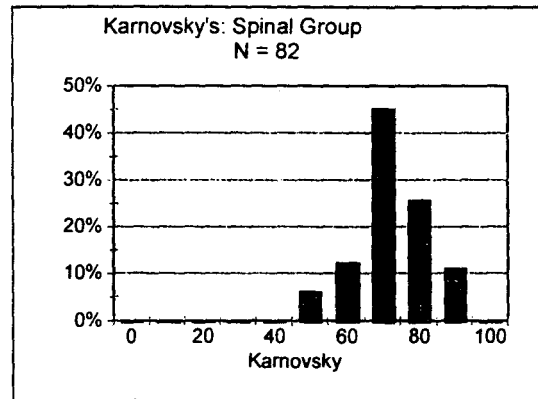
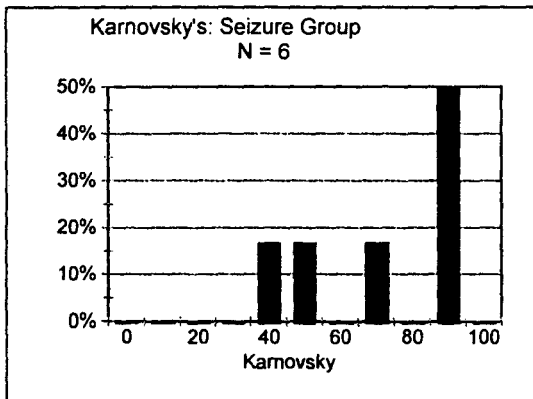
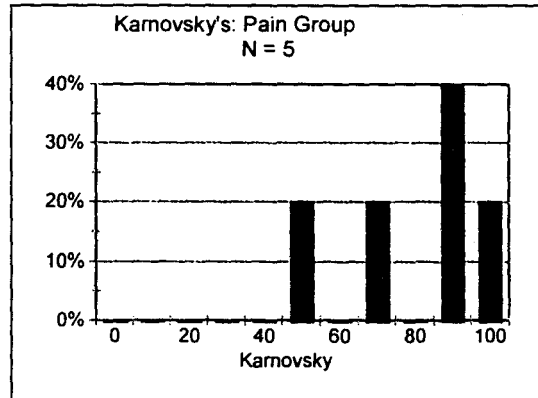
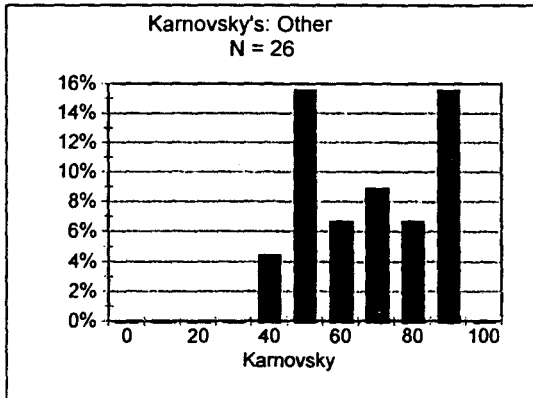
Neuroscience Annual Report

1998,p.62-3.

PERFORMANCE



PERFORMANCE



APPENDIX 4:

NEUROSCIENCE PATIENT
FOCUS GROUP QUESTIONNAIRE

Neuroscience Strategic Planning Committee

1996

Please do not put your name on this form.

1. Who is completing this form:

Previous patient ___
Family member ___
Friend ___

2. How old was the patient during his/her hospitalization?

16 - 24 years ___
25 - 40 years ___
41 - 65 years ___
65 - or greater ___

3. What was the reason for being in the hospital as a patient?

4. Length of hospital stay

a) less than 7 days ___
b) 8 - 14 days ___
c) 15-30 days ___
d) greater than 30 days ___

5. What surprised, pleased and /or disappointed you during your stay?

6. What was your biggest fear, frustration, need, difficulty and / or uncertainty during your stay?

7. Did the staff understand what you (or the patient) wanted to let them know?

yes ___ no ___

If no, why?

8. Were we able to meet your (or the patient's) cultural needs?

yes ___ no ___

If no why?

9. Do you want to comment on any one of these aspects of your stay.

Please circle:

Admission:

Tests:

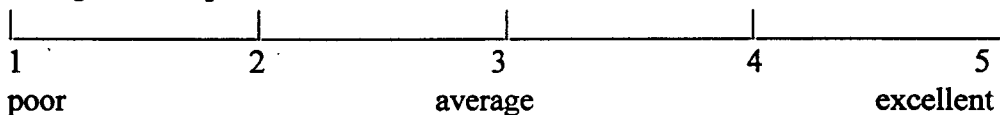
Surgery (if applicable)

Staff

Transfer from Intensive Care Unit to the Ward (if applicable)

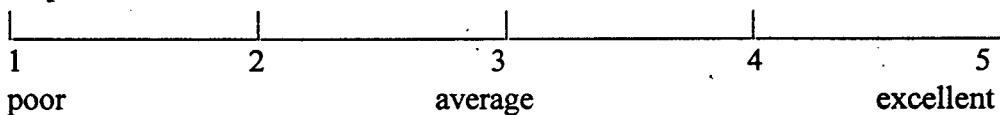
Comment:

c) Caring and compassionate



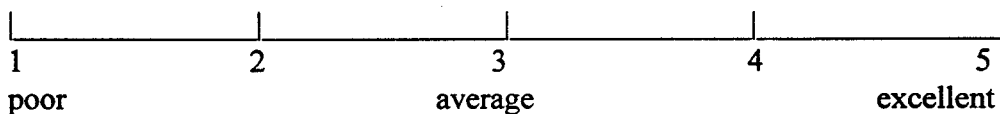
Comment:

d. Respectful



Comment:

e. Providing best possible care



Comment:

Your injury

The results

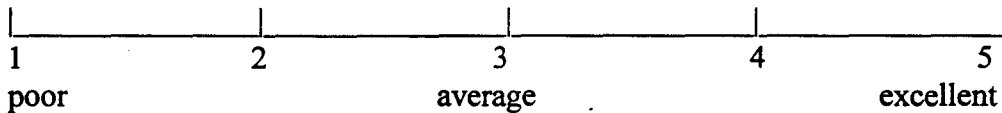
Transfer to another hospital

Discharge home

After affects

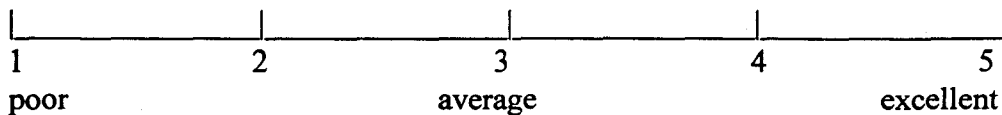
10. Was the health care team:

a) Open and receptive



Comment:

b) Honest



APPENDIX 5:

“HOW DID WE DO?”

Hamilton Civic Hospital

Discharge Questionnaire

Name (optional): _____

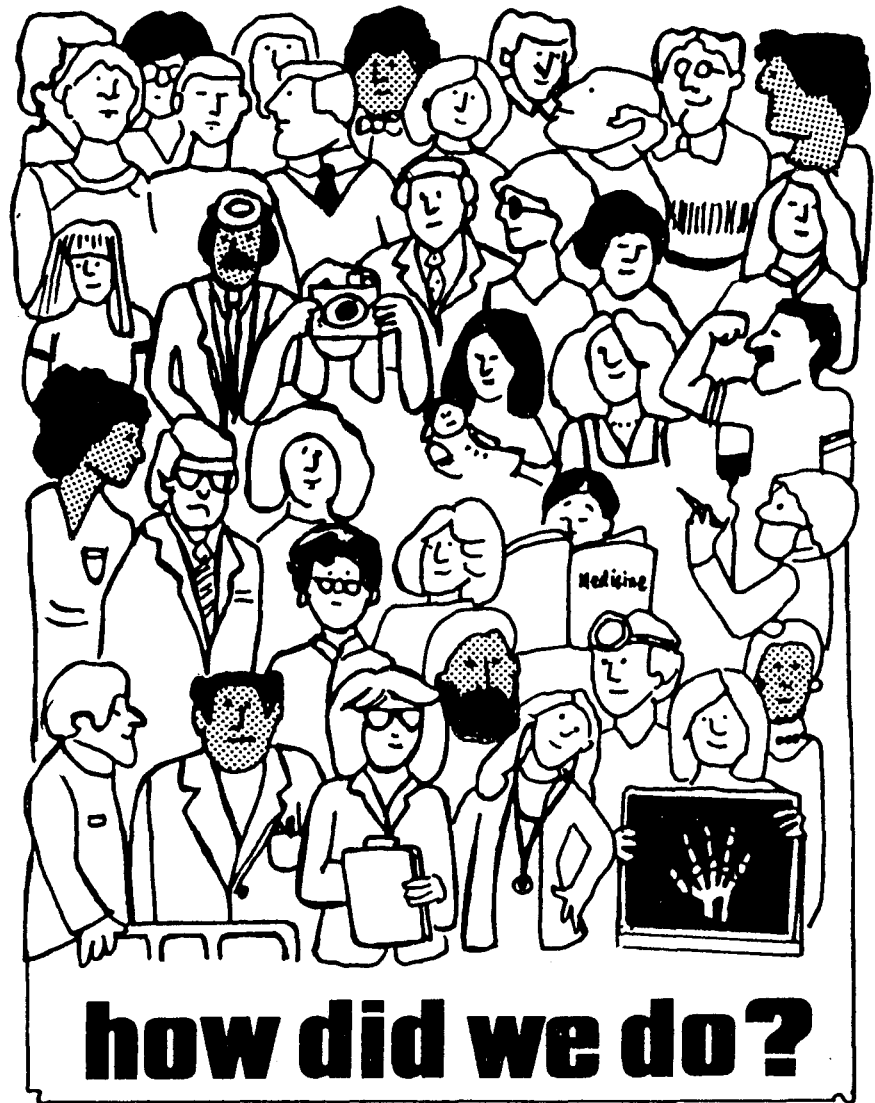
Ward / Department: _____

Would you like one of our staff members to call you directly to discuss your comments?

Yes No Home Telephone #: _____

Once you have completed this questionnaire, please hand it to one of our staff members. Your comments are very much appreciated.

Board of Directors
Hamilton Civic Hospitals



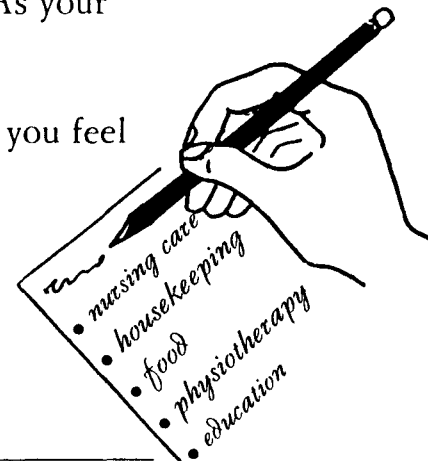
*Together in
caring, teaching
and discovery*

Hamilton Civic Hospitals

The Hamilton Civic Hospitals has been serving your community for more than 100 years. As your health care team we work hard to give you the best possible care.

We would like to know if you were pleased with the treatment and services you received. If you feel that there are things we should be improving, please let us know.

How did we do?



What are the things you liked about your stay?

What are the things you think need improving?

APPENDIX 6:

TRANSITIONAL QUALITY TASK FORCE

MEASURES' AND INDICATORS' MATRIX

Transitional Quality Task Force, HHSC

1998

Measures' and Indicators' Matrix

Dimensions and Their Attributes	Categories and Their Focus				
	Community Benefit	Patients, Families and Other Customers	Internal Business	Financial	Innovation & Learning
<p>Communication</p> <p>Courtesy & respect Consistency Confidentiality Integrity</p> <p>Responsiveness</p> <p>Availability Accessibility Timeliness Continuity Equity</p> <p>System Competency</p> <p>Appropriateness Effectiveness Caring Legitimacy Adverse occurrences</p> <p>Quality of Work Life</p> <p>Decision latitude Role clarity Learning Environment Co-worker/supervisor support Health and safety</p>	<p>To work collaboratively and integrate health and social services into a network, through partnerships and alliances, to meet the comprehensive health care needs of individuals and communities.</p> <p>To contribute to Regional economic development through commercialization of research and appropriate services.</p> <p>To act at all times in the public interest.</p> <p>Focus</p> <ul style="list-style-type: none"> ➤ Public ... residents of catchment area ➤ Community physicians ➤ Community agencies ➤ Community hospitals ➤ Universities and colleges ➤ Local industry ➤ Media ➤ MOH ➤ Others 	<p>To provide high quality health care services which meet the needs and expectations of patients, families, other customers and the community.</p> <p>To respond to assessed community needs to foster health for all.</p> <p>Focus</p> <ul style="list-style-type: none"> ➤ Patients and families ➤ Long term care residents ➤ Co-workers ➤ External suppliers of services ➤ External customers 	<p>To excel with each of the key business processes.</p> <p>To act as a fair employer, providing an environment that encourages personal and professional growth.</p> <p>Focus</p> <ul style="list-style-type: none"> ➤ Strategic planning ➤ Care management ➤ "Human resource" management ➤ Support services ➤ Information management ➤ Utilization management 	<p>To use resources responsibly, balancing quality and cost to maximize value.</p> <p>Focus</p> <ul style="list-style-type: none"> ➤ Budgets ➤ Financial audit self-assessment ➤ Opportunity costs 	<p>To create and apply new knowledge from basic, health services and population health research.</p> <p>To continuously learn with and from patients, families, students, staff and communities.</p> <p>Focus</p> <ul style="list-style-type: none"> ➤ All staff, employees and volunteers

APPENDIX 7:

NEUROSCIENCE PATIENT SATISFACTION SURVEY

Neuroscience Program

Hamilton Health Science Corporation

1998



Inpatient Survey:

Quality of Care

**in the Neuroscience
Program**

(1998)

The Neuroscience Program is currently making changes in the way we provide patient and family care. The goal of the Neuroscience Program is to provide the best care possible to patients and families.

We are sending you a survey to complete. The answers you give us will help us to make changes that improve the care and service we provide to patients and families.

Please return the survey in the stamped, self addressed envelope provided. Your answers are confidential, and will not be made known to the people who have or will provide care for you.

***Thank you for helping us provide the best care possible!
The Neuroscience Team, General Campus
Hamilton Health Sciences Corporation***

Please tell us about your hospital stay. If you are completing this form for your partner, relative or friend, please rate that person's care while in hospital. Most questions can be answered by circling the number that best describes your answer or by filling in the blank. Your answers are confidential; they will not be known to the people who provided care to you this visit or who may provide care in future visits. The results will only be reported when grouped with other people's answers.

The feedback we receive is used to help improve the care and services we provide. Please use the return addressed envelope to mail your completed questionnaire. Thank you for your help.

We would be happy to answer any questions that you may have about the survey. Please write or call us at (905) 527-4322, Ext. (), Ms. _____ will be available to answer your questions or to help with filling out the survey. To write to us the address is:

Name: ()

Neuroscience Program
Hamilton health Sciences Corporation
General Campus
237 Barton Street East
Hamilton, Ontario
L8L 2X2

A. NEUROSCIENCE PREOPERATIVE CLINIC

1. Did you use the Neuroscience Preoperative Clinic? *(Please circle the number that describes your answer.)*

- 1 Yes
2 No → *Go to Section B.*

Please rate each item by circling the number that best describes your opinion. If you do not have an opinion, circle 8 (Does Not Apply).

	Poor	Fair	Good	Very Good	Excellent	Does Not Apply
2. The nurse's ability to answer questions in a way you could understand	1	2	3	4	5	8
3. How much information you got from the clinic nurse about your upcoming surgery and tests	1	2	3	4	5	8
4. The help with the upcoming surgery provided by other staff from the Neuroscience Program	1	2	3	4	5	8
5. The time I (the patient) had to wait between seeing people and having tests	1	2	3	4	5	8
6. Reasons given for delays (if you had to wait)	1	2	3	4	5	8
7. Concern expressed by clinic nurse for you and your family as persons (interest in your feelings)	1	2	3	4	5	8
8. How easy it was to contact the clinic nurse for help before or after the surgery	1	2	3	4	5	8
9. Courtesy of the clinic nurse	1	2	3	4	5	8
10. Did surgeon explain the risks and benefits of the surgery to you in a way that you could understand?	Not at all ----- Definitely					Does Not Apply
	1	2	3	4	5	8
11. Did the anaesthetist explain the anaesthesia and recovery in a way that you could understand?	Not at all ----- Definitely					Does Not Apply
	1	2	3	4	5	8
12. Did the doctors and staff tell you how you would feel after surgery?	Not at all ----- Definitely					Does Not Apply
	1	2	3	4	5	8

13. If I could change anything about the clinic, it would be (please describe):

(Please write on the other side of the page if there is not enough room)

B. CARE WHILE A PATIENT ON 7 SOUTH NEUROSCIENCE WARD

Please rate each item by circling the number that best describes your opinion. If you do not have an opinion, circle 8 (Does Not Apply).

	Poor	Fair	Good	Very Good	Excellent	Does Not Apply
1. Providing for your safety and the security of your belongings	1	2	3	4	5	8
2. How available your hospital doctors were	1	2	3	4	5	8
3. Courtesy, respect, friendliness, kindness of your hospital doctors	1	2	3	4	5	8
4. Your confidence and trust in your hospital doctors	1	2	3	4	5	8
5. The doctor's attention to your concerns or fears about your problems or treatments	1	2	3	4	5	8
6. How available the nursing staff were	1	2	3	4	5	8
7. Courtesy, respect, friendliness of nursing staff	1	2	3	4	5	8
8. Your confidence and trust in the nursing staff	1	2	3	4	5	8
9. Attention paid by nursing staff to your concerns or fears about your medical problem or treatment	1	2	3	4	5	8
10. How well the physiotherapists did their job and acted toward you	1	2	3	4	5	8

	Poor	Fair	Good	Very Good	Excellent	Does Not Apply
11. How well the occupational therapists did their job and acted toward you	1	2	3	4	5	8
12. How well the social workers did their job and acted toward you	1	2	3	4	5	8
13. How well the housekeeping staff did their job and acted toward you	1	2	3	4	5	8
14. How well the health care aides did their job and acted toward you	1	2	3	4	5	8
15. How well the staff worked together as a team	1	2	3	4	5	8
16. How consistent your care was across shifts	1	2	3	4	5	8

17. If I could change anything about the care I received on 7 South, Neuroscience Ward, it would be (please describe):

(Please write on the other side of the page if there is not enough room)

C. YOUR COMFORT AND CONCERNS

Please rate each item by circling the number that best describes your opinion. If you do not have an opinion, circle 8 (Does Not Apply).

	Poor	Fair	Good	Very Good	Excellent	Does Not Apply
1. Concern expressed by hospital staff for you as a person (interest in you and your feelings)	1	2	3	4	5	8
2. Cleanliness of washrooms	1	2	3	4	5	8
3. Ease of getting help to the bathroom	1	2	3	4	5	8
4. Response to the call bell by staff	1	2	3	4	5	8
5. The amount of privacy you had	1	2	3	4	5	8
6. Cleanliness, comfort, lighting and temperature of room	1	2	3	4	5	8
7. Adequacy of the supplies and furnishings in your room	1	2	3	4	5	8
8. How restful your room was	1	2	3	4	5	8
9. Quality of food	1	2	3	4	5	8
10. Visiting hours and facilities for family and friends	1	2	3	4	5	8
11. How friendly and helpful the staff were toward visitors	1	2	3	4	5	8

12. If I could change anything about the way the staff showed concern for me, my family and visitors, it would be (please describe):

(Please write on the other side of the page if there is not enough room)

13. If I could change anything about the way the staff maintained the cleanliness of the ward or the food that was served, it would be (please describe):

(Please write on the other side of the page if there is not enough room)

D. INFORMATION RECEIVED WHILE ON 7 SOUTH NEUROSCIENCE WARD

Please rate each item by circling the number that best describes your opinion. If you do not have an opinion, circle 8 (Does Not Apply).

	Poor	Fair	Good	Very Good	Excellent	Does Not Apply
1. The nursing staff's ability to answer questions in a way you could understand	1	2	3	4	5	8
2. The physiotherapists ability to answer questions in a way you could understand	1	2	3	4	5	8
3. The occupational therapists ability to answer questions in a way you could understand	1	2	3	4	5	8
4. The hospital physician's ability to answer questions in a way you could understand	1	2	3	4	5	8
5. How much information you got from hospital staff about your problems or treatments	1	2	3	4	5	8
6. How easy it was to find a person to talk to about your concerns	1	2	3	4	5	8
7. How the test results were explained to you	1	2	3	4	5	8
8. How much say you had in deciding your care	1	2	3	4	5	8

9. If you could change anything about the information given to you by the staff and physicians, it would be (please describe):

(Please write on the other side of the page if there is not enough room)

E. STUDENT LEARNERS AND RESEARCH

1. Were student learners involved in your care at HHSC (medicine, nursing, occupational therapy or physiotherapy students, psychology or chaplaincy interns, or other kinds of students)?

- 1 Yes
- 2 No → *Please go to Question 4 on page 5*
- 3 Don't know → *Please go to Question 4 on page 5*

2. Was your permission asked before you saw the student learner?

- 1 Yes
- 2 No

Please rate each of the following items about your student learner contacts by circling the number that best describes your opinion. If you do not have an opinion, circle 8 (Does Not Apply).

	Poor	Fair	Good	Very Good	Excellent	Does Not Apply
3. Courtesy, respect, friendliness, kindness of students	1	2	3	4	5	8
4. Ability to answer your questions in a way you could understand	1	2	3	4	5	8
5. Contribution to your care	1	2	3	4	5	8

6. Were you (the patient) involved in (or asked to be in) a research project while receiving care at HHSC?

- 1 Yes
- 2 No → *Please go to Section E, on page 7*

Please rate each of the following items about your involvement in the research project by circling the number that best describes your opinion.

	Poor	Fair	Good	Very Good	Excellent	Does Not Apply
7. Courtesy, respect, friendliness, kindness of research team	1	2	3	4	5	8
8. Completeness of explanations concerning what was involved	1	2	3	4	5	8
9. Ability to answer your questions in a way you could understand	1	2	3	4	5	8
10. Contribution to your care	1	2	3	4	5	8

F. PAIN CONTROL ON 7 SOUTH NEUROSCIENCE WARD

Please circle the number which best describes your answer to each question. If you do not have an opinion, circle 8 (Does Not Apply).

1. Were you ever in pain while in the hospital?

- 1 Yes
- 2 No → *Please go to Section G, Leaving 7 South Ward, on page 8*

2. Did you have a machine you could use to give yourself pain medicine?

- 1 Yes
- 2 No

3. Did you ever ask for pain medicine?

- 1 Yes
- 2 No → *(Go to Question 5 below)*

4. How many minutes after you asked for pain medicine did it usually take before you got it? *(Please fill in the blank)*

_____ minutes

5. How severe was your pain? *(Circle one number please)*

No Pain ----- Worst Possible Pain
 0 1 2 3 4 5 6 7 8 9 10

6. Did the hospital staff help you with your pain? *(Circle one number please.)*

Not at all ----- Definitely
 1 2 3 4 5

7. If I could change anything about the way my pain was managed on 7 South Neuroscience Ward, it would be (please describe):

(Please write on the other side of the page if there is not enough room)

G. LEAVING 7 SOUTH NEUROSCIENCE WARD

Please rate each item by circling the number that best describes your opinion. If you do not have an opinion, circle 8 (Does Not Apply).

	Poor	Fair	Good	Very Good	Excellent	Does Not Apply
1. Advice about how to take medicines	1	2	3	4	5	8
2. Advice about exercise	1	2	3	4	5	8
3. Advice about care of my incision or wound site	1	2	3	4	5	8
4. Advice about what changes/problems to watch for at home	1	2	3	4	5	8
5. Attention paid to family or living situation in planning for your leave	1	2	3	4	5	8

3. Overall, how would you rate the care and services you got at this hospital?

Poor ----- Excellent
1 2 3 4 5

4. If there was one thing you could change about your hospital experience that would have improved your stay, what would it be?

(Please write on the other side of the page if there is not enough room)

5. If there was one thing you could change on 7 South, Neurosciences, that would have made your stay easier for your family, what would that be?

I. INFORMATION ABOUT YOU

(Or about the patient if you are completing the questions on behalf of the patient.)

1. In general, compared to other persons your age, would you say that your health (the patient's health) is: *(Circle one please)*

- 1 Excellent
- 2 Very Good
- 3 Good
- 4 Fair
- 5 Poor

2. Your (the patient's) sex:

- 1 Male
- 2 Female

3. Postal Code _____

4. The year you (the patient) were born: 19_____

5. Were you (the patient) born in Canada?

- 1 Yes
- 2 No

6. What language do you (the patient) usually speak at home?

1 English

2 French

3 Other (*Please specify*) _____

7. How long did you (the patient) stay in hospital this time? (*Please write in your answer.*)

_____ days

8. Have you (the patient) ever used other services at this hospital before?

1 Yes

2 No

9. Completed by: (*Please circle only one*)

1 Myself, as the patient

2 Parent of the patient

2 Other family member of the patient

3 Other (*Please describe*) _____

Thank You For Helping Us to Provide the Best Care Possible!

APPENDIX 8:

NEUROSCIENCE PATIENT SATISFACTION
QUALITY INDICATORS

Measurement, Evaluation and Quality

Hamilton Health Science Corporation

1998

Patient Survey

Dimension/Attribute

Patient Satisfaction Scales		Responsiveness	System Competency	Communication
NEUROSCIENCE PREOPERATIVE CARE				
Question #	Page #			
A1	1			
A2	1			
A3	1			
A4	1		Appropriateness	
A5	1	Timeliness		
A6	1			
A7	1			
A8	1	Accessibility		
A9	1		Caring	
A10	1	Appropriateness		
A11	1	Appropriateness		
A12	1	Appropriateness		
CARE ON WARD 7 SOUTH NEUROSCIENCE WARD				
B1	1		Caring	
B2	1	Accessibility		
B3	1			Courtesy & Respect
B4	1		Caring	
B5	1		Caring	
B6	1	Accessibility		
B7	1			Courtesy & Respect
B8	1		Caring	
B9	1	Appropriateness		
B10	1	Appropriateness		
B11	3	Appropriateness		
B12	3	Appropriateness		
B13	3	Appropriateness		
B14	3	Appropriateness		
B15	3	Appropriateness		
B16	3	Appropriateness		
COMFORT AND CONCERNS				
C1	4		Caring	
C2	4		Appropriateness	
C3	4	Accessibility		
C4	4	Timeliness		
C5	4		Caring	
C6	4		Caring	
C7	4		Caring	
C8	4		Caring	
C9	4		Caring	

Dimension/Attribute				
Patient Satisfaction Scales		Responsiveness	System Competency	Communication
Question #	Page #			
C10	4		Caring	
C11	4			Courtesy & Respect
INFORMATION RECEIVED				
D1	5			Courtesy & Respect
D2	5			Courtesy & Respect
D3	5			Courtesy & Respect
D4	5			Courtesy & Respect
D5	5			Courtesy & Respect
D6	5	Accessibility		
D7	5			Courtesy & Respect
D8	5		Legitimacy	
STUDENT LEARNERS AND RESEARCH				
E1	6			
E2	6		Legitimacy	
E3	6			Courtesy & Respect
E4	6			Courtesy & Respect
E5	6			
E6	7			
E7	7			Courtesy & Respect
E8	7		Legitimacy	
E9	7		Legitimacy	
E10	7			
PAIN CONTROL MANAGEMENT				
F1	7			
F2	7			
F3	7			
F4	7	Timeliness		
F5	8			
F6	8			
LEAVING WARD 7 SOUTH				
G1	8		Appropriateness	
G2	8		Appropriateness	
G3	8		Appropriateness	
G4	8			Courtesy & Respect
G5	8			Courtesy & Respect
G6	9	Continuity		
G7	9			
G8	9	Continuity		
G9	9	Continuity		
G10	9	Continuity		

APPENDIX 9:

PATIENT'S INTERVIEW GUIDE: CENTRAL QUESTIONS

By

Norman, Redfern, Tomalin & Oliver

1992,p.600

PATIENT'S INTERVIEW GUIDE: CENTRAL QUESTIONS

1. What has struck you most about being in hospital?
 - 1.1 What else has struck you? (Repeat as often as responses are forthcoming.)

2. Has anything happened concerning your care that has been particularly important to you?
 - 2.1 Has anything else happened that has been particularly important? (Repeat as often as responses are forthcoming.)

3. Has anything struck you as being particularly impressive about the care that you have received?
 - 3.1 Has anything else struck you as being particularly impressive? (Repeat as often as responses are forthcoming.)

4. Have you seen any care here that you thought was not quite what it should be; when you thought "that piece of nursing care is not quite up to par"?
 - 4.1 Have you seen any other care that you thought was not quite as it should be? (Repeat as often as responses are forthcoming.)

APPENDIX 10:

PATIENT INTERVIEW QUESTIONNAIRE

By

Cox, Bergen & Norman

1993,p.411.

CENTRAL QUESTIONS IN THE PATIENT'S INTERVIEW

1. What has struck you most about being cared for in your own home?
(If response is anything to do with nursing or Macmillan nurse:)
 - 1.1 Can you tell me a bit more about that?
(If not:)
2. What has struck you most about being cared for in your own home by the Macmillan nurse?
(Repeat as often as responses are forthcoming.)
3. Has anything particularly impressed you about the care you received from the Macmillan nurse?
 - 3.1 Can you tell me about a specific time when that happened?
(Repeat as often as responses are forthcoming)
4. Have you seen any care here when you thought that was not quite as it should be; when you thought that bit of nursing care was not quite up to par?
 - 4.1 Can you tell me about a specific time when that happened?
(Repeat as often as responses are forthcoming)
(Pursue meanings in relation to happenings).

APPENDIX 11:

STUDY RESULTS

By

Kent, Faulkner, Parry, Whipp & Coleman

1996,p.189.

NUMBER OF PATIENTS CITING SITUATIONS
IN WHICH THEY FELT UNSUPPORTED BY THE NURSING STAFF

CATEGORY	NUMBER OF PATIENTS
Treatment issues	7
Specific needs	5
Inadequate communication	5
Lack of emotional support	4
Total	21

APPENDIX 12:

CONSENT FORM

CONSENT FORM

I understand that the Neuroscience Program at the Hamilton Health Science Corporation is examining the patient's and/or families satisfaction with the communication, information and education provided to the patient and/or family member during their inpatient stay on the Neuroscience patient care unit (i.e. 7 South).

I agree to participate in an interview in my home or current living environment four weeks after discharge from the hospital, or at a later date, as agreed upon by the patient and/or family member. A non-employee of the Neuroscience program will conduct the interview. The information collected will pertain to the care on the Neuroscience patient care unit (i.e. 7 South) or be related to the transfer of information, communication and education between 7 South and other patient care areas. The data will be used to improve the way in which we provide care to our patients and families.

I understand that the study might not benefit me specifically but it will advance the understanding of how the neuroscience health care team can improve the way in which we communicate, provide information and plan for education to the patient and their family.

I have had the opportunity to discuss this study with the interviewer and my questions have been answered to my satisfaction.

Any information learned about me during this study will be confidential and neither my name nor any other identifying particulars will be made available to anyone other than the interviewer and the research investigators, nor will it appear in any publications.

I, the patient or the family member (please circle appropriately), consent to take part in the study with the understanding that I may withdraw at any time without prejudice to my future care.

Name (Print)	Signature	Date
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I have explained the nature of the study to the participant and believe that he/she understood.

Name (Print)	Signature	Date
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