

**AN ASSESSMENT OF THE NEED FOR SOCIAL WORK
SERVICES FOR PATIENTS AND THEIR FAMILY MEMBERS
ON THE NEUROSUPPORTIVE CARE UNIT AT DEER LODGE
CENTRE**

**A PRACTICUM REPORT
SUBMITTED TO
THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILLMENT
OF THE REQUIREMENT
FOR THE DEGREE
MASTER OF SOCIAL WORK**

**BY
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JULY 1997**



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by

LISA LLOYD-SCOTT

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

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ACKNOWLEDGMENTS

My sincere appreciation and heart felt thanks,

To my husband Jeff, my step daughter Ashley, my Nana, my parents and my siblings for their understanding, patience and constant encouragement.

To my colleagues at Deer Lodge Centre for their thoughtfulness and support.

To my advisor, Don Fuchs for his direction and patience.

To my advisory committee, Geri McGrath and Dr. Chris Engel for their time, support and perseverance.

I would also like to thank the family members and patients on the Neurosupportive Care Unit for completing the questionnaires and for sharing their ideas to further the development of providing support and counselling with family systems affected by the onset of severe acquired brain injury.

ABSTRACT

Survival following moderate or severe acquired brain injury is a recent phenomenon. Until the 1980s individuals who sustained moderate or severe acquired brain injury rarely survived the acute onset. Advances in medical research and medical technology have resulted in increased survival rates.

The Neurosupportive Care Unit was developed in 1991 at Deer Lodge Centre to serve the needs of younger Manitobans affected by severe neurological impairments who required chronic care. The Neurosupportive Care Unit is a family-centered chronic care program for younger adults with severe neurological impairment.

An evaluability assessment of the Neurosupportive Care Unit at Deer Lodge Centre was conducted to assist in the development of evaluation and assessment tools. The evaluation and assessment tools developed was a questionnaire. It was used in a program evaluation examining the need for Social Work services on the Neurosupportive Care Unit.

The goal of this practicum was to collect demographic data, to explore family members knowledge of acquired brain injury, to examine Social Work related needs and to explore the perceptions of support and counselling held by the family members. Through this practicum project and the data analysis results it has become clear that the traditional systems perspective in combination with the problem solving goal oriented support and counselling approach are insufficient tools to provide efficient and effective Social Work service to this unique patient population. There is an expressed need to utilize alternate assessment and intervention strategies. The writer believes that the results of this Practicum report will enhance Social Work service provision through information sharing, education, support and counselling.

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INTRODUCTION

Survival following moderate and severe acquired brain injury is a recent phenomenon. Until the 1980s, individuals who sustained moderate and severe acquired brain injuries rarely survived the acute onset. Advances in medical research and technology have resulted in increased survival rates:

The twentieth century is the age of automobiles and the age of speed. It is also the age of the road toll. Each year in developed countries about 20 people of each 100, 000 die in road accidents. However horrendous this death toll may be, it is only part of the picture. The hidden road toll, the effect on the drivers, passengers, and pedestrians who suffer head injuries but survive with disability is great. There are in addition head injuries from other sorts of accident; in sport, industry, and from violence on the streets....Over the past fifteen years there has been a surge of interest in the problem of head injury. Improved medical techniques have meant that many more people are surviving injuries which in the past would have been fatal.Yet families desperately want to know and understand what happens when one of them suffers a head injury. (Gronwall, Wrightson & Waddel, 1990, p. 1-2).

Health Care providers endeavor to help others through the provision of care, education and support to patients and their family members. Attaining and maintaining the highest level of functioning possible become the focus of care. The challenge in working with patients who have sustained severe

acquired brain injury and their family members is meeting the ongoing emotional needs of the family members who are grieving the loss of the individual they once knew for an extended period of time. The grieving process is not complete as death has not occurred. The unique emotional needs will be examined in detail through this practicum report. The writers experiences and the challenges encountered in providing Social Work services to the clients on the Neurosupportive Care Unit serve as the basis for this practicum. The practicum objectives that were chosen were:

- i) To begin a program evaluation of the Neurosupportive Care Unit at Deer Lodge Centre and to provide guidance in developing evaluation and assessment tools to be utilized.
- ii) To conduct a needs assessment related to the effectiveness of Social Work Services being provided to individuals and their families on the Neurosupportive Care Unit at Deer Lodge Centre.
- iii) Based on the needs assessment findings develop intervention goals and objectives to provide efficient and effective Social Work Services to the patients living on the Neurosupportive Care Unit and their family members.

The program evaluation process was initiated as a Practicum for the writer to obtain a Masters of Social Work. There are learning objectives that the writer identified at the outset.

- i) To develop skills in the area of program evaluation, particularly the skills and tools necessary to assess the needs of a specific client population.
- ii) To develop a specialized clinical base to provide therapeutic interventions to patients and their family members.

Organization of the Practicum Report

This Practicum report is organized as follows, to allow the reader to familiarize themselves with the various aspects of the practicum process.

Chapter 1 presents an extensive review of the literature in the area of acquired brain injury and program evaluation design. The attendant definitions, concepts and theoretical terminology formulate the context for the evaluability assessment and data analysis.

Chapter 2 presents the context, methods and procedures used in carrying out an evaluability assessment of the Neurosupportive Care Unit at Deer Lodge Centre. A questionnaire was developed to gather data from family members related to demographic information, health care system experiences and the meaning of support and counselling based, in part, upon the evaluability assessment results.

Chapter 3 presents the results of the evaluability assessment that was conducted. This process provided the interdisciplinary care team with an

opportunity to explore program goals and objectives providing a context for the writer to focus on specific program goals in the development of the evaluation and assessment tool.

Chapter 4 reports the questionnaire results. The section on data analysis describes a specific demographic population, clarifies knowledge base of family members related to acquired brain injury, explains family members' Social Work related needs and examines perceptions of support and counselling.

Chapter 5 probes the implications and recommendations for future research based on the data analysis and Chapter 6 joins the findings together providing the conclusions for this practicum report.

CHAPTER 1

LITERATURE REVIEW

Health care service provision to individuals and families affected by acquired brain injury is an emerging field. Individuals who sustained moderate and severe acquired brain injury rarely survived the initial trauma, until the 1980s. An extensive literature review was conducted over a five year time period by the writer to locate research and material on severe acquired brain injury and the impact on individuals and their family members. A preponderance of the research literature focuses on mild to moderate acquired brain injury and the need for rehabilitation and community based services and supports.

Statement of the Problem

Acquired brain injury is the number one killer and disabler of persons under the age of 44. The Surgeon Generals Report of the United States indicates that the number of persons left with disability after head injury far exceeds cerebral palsy, spinal cord injury and multiple sclerosis combined" (Manitoba Head Injury Association Information Sheet, 1991).

In the province of Manitoba approximately 2,000 persons per year sustain mild, moderate or severe acquired brain injury. Five individuals per day sustain mild, moderate or severe acquired brain injury. In a one year time period 210 people will die as the result of acquired brain injury and 360 persons are left with residual physical, cognitive, and/or behavioral sequelae following acquired brain injury. Acquired brain injury is sustained in many ways. Strokes, aneurysms, seizure activity and anoxia, when the oxygen supply to the brain is cut off for a period of time or from traumatic causes such as motor vehicle accidents, falls and assaults are the most common causes. Fifty percent of acquired brain injury is sustained in motor vehicle accidents (Manitoba Head Injury Association Inc., Information Sheet, 1991).

Victims of severe head injury do not form a random cross section of society. They tend to be young, economically active adults who have been involved in road traffic accident as driver or pedestrian, or who have been assaulted. Alcohol is commonly involved, and there is a higher incidence in men from lower socioeconomic groups (Livingston,. 1988, p. 6).

A study was conducted by the Neuropsychological Research Unit at the Health Sciences Centre and the St. Boniface General Hospital in Winnipeg from January 15, 1990 through to September 1, 1991. The study examined young adults admitted to these two facilities with acquired brain

injury. The statistical analysis investigated monthly admissions related to mild, moderate and severe acquired brain injury.

NUMBER OF ADMISSIONS TO HOSPITAL PER MONTH

	<u>MILD</u>	<u>MODERATE</u>	<u>SEVERE</u>
HEALTH SCIENCES CENTRE	23.13	4.56	2.72
ST. BONIFACE HOSPITAL	10.56	1.69	.82

(Neuropsychological Research Unit, 1993).

LENGTH OF STAY (DAYS)

	<u>MODERATE</u>	<u>SEVERE</u>
HEALTH SCIENCES CENTRE	22.17	72.83
ST. BONIFACE HOSPITAL	13.73	102.40

(Neuropsychological Research Unit, 1993).

Children under the age of 18 years who sustain brain injuries are not included in these statistics. Children are more likely to recover completely from acquired brain injury than adults. Young adults who sustain moderate and severe brain injuries are likely to have residual physical, cognitive and/or behavioral sequelae. "The increasing survival of persons with severe traumatic brain injury (TBI) raises fundamental questions about the obligation of society to meet their ongoing health care needs, especially as they apply to rehabilitative and long term care" (DeJong, 1989, p. 1).

Survival following moderate to severe acquired brain injury has repercussions for the individuals who have sustained acquired brain injury, their family members and health care providers. The individual who sustains a moderate or severe acquired brain injury may experience severe physical, cognitive and behavioral sequelae and they may or may not be aware of the changes. Since the onset of acquired brain injury usually occurs in young economically active adults there is an extensive family system including grandparents, parents, siblings, spouses and children who are affected. The family system experiences a profound alteration in roles, expectations, hopes and dreams with the onset of severe acquired brain injury. The unique needs of those effected by moderate and severe acquired brain injury pose a challenge for health care providers to meet the ongoing physical, psychological, social and spiritual needs of this client population.

Definitions, Concepts and Theoretical Terminology

This section of the Practicum Report will explore definitions, concepts and theoretical terminology that will frame the context for understanding the practicum organization, information gathering and data analysis.

Acquired Brain Injury

A head injury sets off a train of events. It can help to think of these events in three stages, beginning with the 'first injury', the direct effect of the accident. After this, within an hour or two, the 'second injury' can follow, and in the first day or two the 'third injury'. Each of these injuries can have a decisive effect on the quality of recovery and the success of rehabilitation (Gronwall, 1990, p. 7).

First Injury:

There are three types of first injury.

- i) **Closed head injury:** A closed head injury occurs when the head decelerates, accelerates or rotates. "The brain is forced to follow the movement of the skull, and as the brain is soft and jelly - like it gets twisted and distorted" (Gronwall, 1990, p. 8). In this process the nerve fibers, arteries and veins can be damaged. The brain can also be bruised in this process.
- ii) **Penetrating head injury:** "In this type of injury the scalp is cut through, the bone of the skull beneath it can be broken up, and the brain exposed to damage" (Gronwall, 1990, p. 8).
- iii) **Crushing head injury:** This is the least common form of injury. The skull is crushed resulting in brain injury.

Second injury

The second injury occurs after the initial injury when the individual may have their airway blocked or the blood pressure decreases with the loss of blood resulting in the oxygen supply to the brain being impaired for a period of time.

Third injury

The third injury occurs when there is bruising or swelling of the brain, seizure activity or blood clots. For many individuals with acquired brain injury and their families the first week following the event is a waiting game to see if more damage will be incurred.

Physical, Cognitive and Behavioral Sequelae of Acquired Brain Injury

It has only been in recent years that individuals with moderate and severe acquired brain injury have survived the onset of sudden disability.

Following a brain injury there are several physical, cognitive and behavioral sequelae that can emerge. These deficits are describe in detail by Beverly Slater in COPING WITH HEAD INJURY (1988).

Motor Deficits: This includes partial or total paralysis, poor balance, ataxia (poor coordination), apraxia (loss of ability to plan motor movements), spasticity (stiffness), and orthopedic involvement that can effect joint mobility.

Sensory Deficits: The result can be an increase or a decrease in sensitivity to touch, smell, sound or movement. Sensory deficits can effect an individual's ability to perceive their environment.

Visual Deficits: This area includes perceptual deficits such as decreased or increased visual attention, decrease in the visual field and visual neglect.

Speech and Language: If speech and language are affected then there is the potential for the individual to experience Aphasia (understand what is being said but can not verbally respond), Anomia (difficulty finding words), Dysarthria (difficulty in articulating words) and Dysphagia (swallowing difficulties).

Cognitive Deficits: This area includes disorientation to person, time and place, attention deficits, decreased concentration abilities, decreased problem solving abilities, impaired judgment, inflexibility, and a decreased ability to understand abstract concepts.

Denial of Deficits: The individual may be unaware that they have deficits in a variety of areas.

Regulatory Disturbances: This would include reduced stamina with increased fatigue, alteration of sleep patterns, loss of bladder and/or bowel control, and loss of ability to control body temperature.

Personality Changes: Families have the most difficulty coping with the apathy, rapid mood changes, irritability, depression and lack of ability to initiate interactions. Personality changes may include impulsive, aggressive and abusive behaviors. The individual with acquired brain injury can become easily frustrated.

Trauma Epilepsy: Seizure activity can be an ongoing concern for individuals who have sustained mild, moderate or severe acquired brain injury.

There are physical, cognitive and behavioral sequelae that can occur as a result of acquired brain injury. Outcome following acquired brain injury depends upon what areas of the brain have sustained injury and to what extent these areas have been damaged.

Post Coma Unawareness

Individuals who sustain the most severe acquired brain injuries can be left with severe cognitive, behavioral and physical deficits including being unaware of the environment around them following coma and being reliant on others to provide for all of their care needs. Post coma unawareness is often referred to as 'persistent vegetative state':

The post coma unawareness (PCU) patient exists in an indefinite transitional period whose duration and prognosis are both unknown. It can last from weeks to years, and the patient can either regain consciousness, usually with a certain degree of disability, or remain unconscious until his or her death. This uncertainty produces intense mental stress for the patients' relatives, who must cope with the physical injury and the anticipated disability, but also the threat of life itself (Tzidkiahu, 1994, p. 159).

Individuals who are in a state of post coma unawareness will respond, at a subcortical level, to the environment around them with responses including eye opening and some ability to follow stimuli with their eyes. They also display definite sleep wake rhythms. Some individuals may demonstrate a reflexive grasp or reflexive crying or laughing. Individuals in a state of post coma unawareness "have no meaningful responsiveness and spontaneously maintain levels of blood pressure and respiratory control" (Bartkowski, 1987, p. 3).

Evaluability Assessment

Rutman (1984) states that "an evaluability assessment establishes the extent to which the program is sufficiently defined to consider evaluating it". (p. 28). Rossi and Freeman (1993) elaborate on this definition to include seeking "to describe and understand the program in terms of the 'social

reality' as held by the program personnel and stakeholders interviewed" (p. 148). According to Corbeil (1992) "The evaluation assessment prepares for an ensuing evaluation, while the evaluability assessment determines if a program can be evaluated in terms of its' effectiveness" (p. 109-110).

Rutman (1984) and Rossi and Freeman (1993) both outline six steps to an evaluability assessment. The six steps outlined by each of the writers are similar in that the resulting information from questions asked will be similar. For the purposes of this paper I will utilize the six steps outlined by Rossi and Freeman (1993):

- 1) Preparing a program description
- 2) Interviewing program personnel
- 3) "Scouting" the program
- 4) Developing an evaluable program model
- 5) Identifying evaluation user
- 6) Achieving agreement to proceed

Needs Assessment

Determining the effectiveness of services currently being provided by the Social Worker on the Neurosupportive Care Unit will provide a basis for identification of problem areas. "Once problems have been identified and defined, they have to be translated into needs (eventually needs will be

translated into services that are to be addressed through the planning process)" (Kettner, 1990, p. 44).

Effectiveness

"Refers to the extent to which social programs and social services are successful in achieving positive changes in the lives of the clients they serve" (Kettner, 1990, p. 13).

Summary

An extensive literature review was conducted over several years and is essential in setting the context for this practicum report. The concepts, definitions and theoretical terminology will be referred to and utilized throughout the report as a basis for analyzing data, articulating outcomes and asserting recommendations.

CHAPTER 2

CONTEXT, METHODS AND PROCEDURES

Introduction

The Context, Methods and Procedures Chapter of this practicum report will describe the process involved in developing and carrying out an evaluability assessment of the Neurosupportive Care Unit at Deer Lodge Centre. The development of a questionnaire to gather data from family members related to demographic information, health care system experiences, Social Work needs and the meaning of support and counselling was based, in part, on the evaluability.

The Context

Deer Lodge Centre began to emerge in 1856 when John Rowand, a retired Chief Factor of the Hudson's Bay Company, built a log house on the north side of the Assiniboine River. The facility has evolved over time and has undergone many changes since its conception. In 1916 the facility was purchased by the Federal Government and became the Deer Lodge Hospital, a place where injured Veterans of World War I could return for medical treatment. Deer Lodge Hospital remained a Veterans Hospital until 1983. The Deer Lodge Hospital had operating rooms and acute care beds. The

facility was sold by the Federal Government to the Provincial Government in 1983. With the transfer, the facility became the Deer Lodge Centre, a long term care facility to serve the needs of the veterans and the elderly of Manitoba. Since 1985 Deer Lodge Centre has been reconstructed and modernized. The renovations were completed on June 7, 1989 (Historical Documents of Deer Lodge Centre).

Deer Lodge Centre is a long term care facility containing 155 Veteran Personal Care Home Beds, 43 Community Personal Care Home beds, Interim Placement beds, Assessment and Rehabilitation beds, Chronic Care beds and outreach services that:

Provide a wide range of specialized programs and skilled staff to provide holistic care to the elderly of Manitoba. Programs are geared to their special and changing needs and to assist them in reaching and maintaining optimum health and independence; or arriving at a dignified death. The Centre provides outreach services to its community, and is continually striving to become a Centre of excellence for innovation, research, outreach and education in the fields of Gerontology and Geriatrics (Deer Lodge Centre Mission Statement).

The philosophy of Deer Lodge Centre states that the:

Quality of life of the individuals we service is based upon the recognition of their uniqueness as a person. This includes fulfillment of their physical, psychosocial and spiritual needs, their need for creative activity, fellowship and privacy, and the right to be consulted and exercise choice in matters affecting their health and welfare (Deer Lodge Centre Mission Statement).

The size and bed capacity of Deer Lodge Centre has increased immensely since its conception. Currently, there are 461 beds in Deer Lodge Centre. In term of numbers of beds Deer Lodge Centre is the second largest health care facility in the province of Manitoba. The Centre has five personal care units, two interim placement units, five chronic care units, two assessment and rehabilitation units and a Psychogeriatric in-patient unit. Within the above specified programs there is a specialized care unit for elderly persons with Alzheimer Disease and other related Dementia's, chronic care beds for patients who rely on continuous oxygen, and twenty-one beds for young persons who have sustained severe acquired brain injuries.

Deer Lodge Centre has many outreach programs including the Amyotrophic Lateral Sclerosis (ALS) outreach team, an Outpatient Department, Day Hospital, Get Away Club and the Psychogeriatric Outreach

Team. All programs are operated based on the philosophy outlined in the Mission Statement of Deer Lodge Centre.

All Programs are operated utilizing the interdisciplinary team approach. The teams are composed of Dietitians, Nurses, Occupational Therapists, Pharmacists, Physicians, Physiotherapists, Recreation Therapists, Respiratory Therapists, Social Workers and Speech and Language Pathologists.

The Neurosupportive Care Program Developmental History

The proposal for Deer Lodge Centre Neurosupportive Care Unit had its' beginnings in the Task Force on Extended Treatment Bed Review (Manitoba Health, November 1990). Subsequently, Health Sciences Centre Neurological Unit proposal recommended, amongst others, the establishment of nursing units especially designed to care for the severely brain injured.

In November 1990 Manitoba Health Services Commission conducted a survey that identified 35 young adults with severe acquired brain injury who required chronic care, which means that their care needs were beyond what could be provided in a Personal Care Home (Manitoba Health, 1990). At the time that the survey was conducted 14 of these individuals identified were living in chronic care at the Municipal Hospitals (Riverview Health Centre)

and 21 remained in acute care hospitals, primarily at the Health Sciences Centre and the St. Boniface General Hospital.

On November 8, 1990 a meeting was held with representatives from Manitoba Health and Deer Lodge Centre Administration. With the recent renovations, Deer Lodge Centre had a 23 bed chronic care unit that was equipped to be opened. This Unit was not staffed. During the meeting an opening date and staffing issues were discussed. Subsequent to the meeting, Manitoba Health forwarded a list of potential patients to Deer Lodge Centre for review.

It became apparent that before Deer Lodge Centre could consider opening a specialized care unit for young adults with severe acquired brain injury, clear and concise program criteria needed to be developed. The criteria were developed by Deer Lodge Centre Administration, Nursing Services, and Social Work Services in conjunction with Manitoba Health (Deer Lodge Centre/Manitoba Health Services/Continuing Care Meeting Minutes. 1990.).

Neurosupportive Care Unit - Admission Criteria

The Neurosupportive Care Unit provides specialized care for young adults with severe neurological (brain) impairment.

The purpose of the Unit is to provide a home-like environment where social and recreational activities can be geared to the patients' special needs, and where rehabilitation therapies can be performed on the Unit either by families or staff under the guidance of professional therapists.

The Unit will also recognize the special commitment made by the families of these patients and will attempt to provide support and encouragement to them.

In order to be admitted to the Neurosupportive Care Unit patients must:

1. Qualify for chronic care placement in that:
 - a) they can no longer be cared for at home or in a Personal Care Home.
 - b) they require equipment, facilities, specialized professional expertise and treatment and/or continuous physician supervision not provided in a Personal Care Home.
 - c) they are not currently receiving active rehabilitation.
 - d) responsibility for chronic care charges has been assigned.
2. be 18 years of age or older.
3. have had a traumatic brain injury or brain damage.
4. be medically stable and at least six (6) months post event.
5. not require mechanical ventilation.

Patients who have severe behavioral problems such as aggressive behavior that present a physical risk to themselves, other patients or staff can not be accommodated (Deer Lodge Centre, 1991).

Program Description

The Neurosupportive Care Unit is a unique program within the Deer Lodge Centre that has been a geriatric long term care facility. The Neurosupportive Care Unit is a twenty one bed chronic care unit: "a family-centered chronic care program for younger adults with severe neurological impairment" (Deer Lodge Centre, 1991).

The interdisciplinary objectives include symptom management, prevention of complications, social and psychological adaptation to changes affecting the entire family and providing the opportunity to achieve the greatest level of functioning possible.

The care goals are intended to ameliorate the physical, emotional, social and spiritual needs of severely neurologically impaired young adults and their family members (Deer Lodge Centre, 1991).

Each Department represented on the interdisciplinary team was asked to develop goals and objectives to fit with the Neurosupportive Care Unit goals and objectives and the general mission statement and philosophy of Deer Lodge Centre.

There are no specific written documents titled goals and objectives for the Neurosupportive Care Unit of Deer Lodge Centre therefore the writer will extrapolate the goals and objectives from the program description and the Deer Lodge Centre Mission statement.

General Goals and Objectives

- 1) To operate a chronic care unit that is family-centered that will enhance quality of life for patients and their family members.
- 2) To provide interdisciplinary care that manages physical symptoms and prevents complications in patients.
- 3) To provide interdisciplinary care that enhances the ability of patients and family members to adapt socially and psychologically to changes.
- 4) To provide interdisciplinary care that will assist patients in attaining and maintaining the highest level of functioning possible given the physical and cognitive issues that they endure as a result of severe acquired brain injury.
- 5) To provide interdisciplinary care that is ameliorative in addressing physical, emotional, social and spiritual needs.

Deer Lodge Centre has a unique evolutionary history with expansion beginning with the provision of acute care services to injured Veterans through the phase where the focus was on the provision of care and service

to the elderly of Manitoba. The introduction of the Neurosupportive Care Unit with the younger client population served as an impetus for Deer Lodge to extend internal long term care services and outreach services to meet the changing needs of the community and to provide service to Manitobans of all ages with varying causes of disability. Staff experience and competence in providing services to younger clients and their extended family systems is continuing to grow and blossom.

The process of developing a family-centered chronic care program with an interdisciplinary team focus on addressing physical, social, emotional and spiritual needs has provided a basis for learning, growing and exploring ethical issues and patient and family needs.

Program development and implementation is not a static process. There is a need for ongoing evaluation of goals, objectives, clients and community needs to ensure services are maintaining pace with changes in many spheres.

Program Evaluation and Design

One of the objectives of this practicum was to begin a program evaluation with the focus on an evaluability assessment of the Neurosupportive Care Unit at Deer Lodge Centre and to provide guidance in developing evaluation and assessment tools to be utilized.

The limitations in the design of this evaluation were related to the lack of comparative data and the inaccessibility of instruments designed specifically to measure adaptation and coping abilities of family members affected by severe acquired brain injury where profound disability or post coma unawareness has resulted. The Neurosupportive Care Unit was the only unit of its' kind in Canada.

The writer engaged in an extensive literature review on the needs of patients and family members affected by severe acquired brain injury resulting in profound disability or post coma unawareness. The writer, with the assistance of the Crane Library at Deer Lodge Centre, was able to locate a limited number of articles on providing support and counselling for family members of individuals who have sustained severe acquired brain injury.

Given the fact that surviving severe traumatic brain injury with profound disability or post coma unawareness is a recent phenomenon it is difficult to locate comparative data on the effectiveness of Social Work interventions and emotional and psychological adaptation.

The Neurosupportive Care Unit at Deer Lodge Centre has been in operation since June of 1991. The writer was involved in the development of the Unit beginning in May of 1991 and continues to provide Social Work services to the Unit. The family members are grieving the loss of the loved one that they once knew while trying to keep their memories alive. They are

in a state of prolonged grieving where there is no end in sight. They will often ask "How long can this go on?" or make statements that "someone must know how long this will go on for and they are just not telling me". There is limited literature and information on providing support, counseling and therapeutic interventions for patients and their family members where severe acquired brain injury has impacted. The literature focuses on rehabilitation, which is no longer possible for this population. One objective of the practicum was to conduct a needs assessment related to the effectiveness of Social Work services being provided to individuals and their families on the Neurosupportive Care Unit to provide insight into the needs of family members through a formal evaluation process which will assist in the development of a professional approach that will serve the needs of the patients and family members of the Neurosupportive Care Unit.

It is premature to conduct a summative or outcome evaluation related to Social Work services and therapeutic interventions on the Neurosupportive Care Unit at Deer Lodge Centre. "The goal of a summative evaluation is to collect and to present information needed for summary statements and judgments about the program and its' value (Fitz-Gibbon, 1978, p. 16).

Rossi and Freeman (1993) state that a major prerequisite for assessing impacts of services being provided is that the program be sufficiently

implemented to ascertain that the appropriate services are being provided to the target population. This has not been ascertained in relation to the Neurosupportive Care Unit.

The writer chose to design a formative evaluation because "if the evaluation is formative, then inside staff are appropriate because they are in a position to understand the program or practice in great detail to facilitate feedback and to enhance the use of evaluation results" (Tripodi, 1983, p. 14). The goal of the evaluation process was "to collect and share with the program managers, planners and staff information that will lead to the modification or improvements of a program" (Fitz-Gibbon, 1978, p. 42).

The formative evaluation process was based upon an evaluability assessment that provided an opportunity to explore program goals and objectives and facilitate Interdisciplinary Team discussion to provide a context for evaluation assessment and tool design.

Evaluability Assessment

The evaluability assessment portion of this practicum will provide guidance in developing evaluation and assessment tools.

Rutman states that "an evaluability assessment establishes the extent to which the program is sufficiently defined to consider evaluating it". (Rutman 1984, p. 28). Rossi and Freeman elaborate on this definition to

include seeking "to describe and understand the program in terms of the 'social reality' as held by the program personnel and stakeholders interviewed" (Rossi & Freeman, 1993, p. 148). For the purposes of this paper I will utilize the six steps outlined by Rossi and Freeman (1993) (Practicum Report, 1997, p. 14)

These six steps, as they relate to the Neurosupportive Care Unit at Deer Lodge Centre, will be examined in detail in this practicum report.

Preparing a Program Description

A description of the program is written based on formal documents, such as legislation, administrative regulations, funding proposals, published brochures, administrative manuals, annual reports, meeting minutes, and completed evaluation studies (Rossi & Freeman, 1993). The program description was detailed at the beginning of Chapter 2.

Interviewing Program Personnel

The evaluability specialist interviews key people to gather their descriptions of the program's goals and rationales, as well as to identify actual program operations. From this information, the evaluator develops models of both the intentions and the actual operations of the program and

subsequently verifies them with the personnel interviewed (Rossi & Freeman, 1993).

The interviews with program personnel were carried out during an Interdisciplinary Team Conference held on March 14, 1994 on the Neurosupportive Care Unit. Prior to the meeting the Interdisciplinary Team members were provided with a set of questions to consider that would lead the discussion during the meeting.

The writer developed questions (Appendix A) to engage the Interdisciplinary Care Team in discussions related to program goals and objectives and to explore general understanding of Social Work skill and knowledge base. The purpose was to review and verify program goals and objectives to verify global team views and practices. The purpose of the Social Work information was to determine if Interdisciplinary Team members had a general understanding of Social Work skill and knowledge base that would enhance the referral process, as the Social Worker is not in daily contact with Neurosupportive Care Unit patients or family members. Often the nursing staff or other team members providing service may recognize changes in coping, grief reactions or practical concerns being expressed in many forms. The questions were provided in advance of the meeting for team members to review and contemplate. The outcomes from the program personnel interviewing process will be addressed in Chapter 3.

"Scouting" the Program

Although evaluability assessments do not include formal research in the sense of large-scale data collection, they do generally include site visits to obtain first hand impressions of how the programs actually operate. These impressions are collated with information from documents and interviews (Rossi & Freeman 1993). The review of formal and informal documents in conjunction with interviewing of program personnel meet the objective of "scouting" the program and will also be reviewed in Chapter 3.

Developing an Evaluable Program Model

From the various types of information obtained, the investigator explicates the program elements and objectives to be considered for inclusion in the evaluation plans (Rossi & Freeman. 1993. p. 148). Each individual program goal was examined based on interviewing program personnel. The results of this process are detailed in the results section of the practicum report.

Identifying Evaluation Users

The writer identified the purpose of evaluation activities to be undertaken, together with the key stakeholders to whom they are to be

directed. In addition, the writer determined the ways in which decisions or changes could be made (Rossi & Freeman, 1993).

The primary purpose behind this program evaluation was to clarify the role of the Social Worker on the Neurosupportive Care Unit and to determine if the interdisciplinary team members, patients and family members understand the areas of expertise that a Social Worker has. The writer wanted to receive feedback from patients and family members to determine what services have been most helpful and what services have not been helpful to them. The implementation of efficient and effective Social Work Services was supported on this Unit by Deer Lodge Centre Administration, the Department of Social Work and the interdisciplinary team members.

The interdisciplinary team members requested a copy of the program evaluation to gain an understanding of what a formal Neurosupportive Program evaluation could potentially address.

The evaluation process provided the family members with an opportunity to express concerns related to the Neurosupportive Care Program and to identify the services and interventions that are helpful to them and those that are not helpful or beneficial.

The evaluation process will lead to efficient and effective service delivery by all team members. In times of limited staffing and health care cutbacks the delivery of efficient and effective program services is essential.

Achieving Agreement to Proceed

The evaluation plan was reviewed with the various stakeholders. The process of information collection during the course of the evaluability assessment included dialogue with key individuals and groups. Thus, at this point most components of the plan have been accepted (Rossi & Freeman, 1993).

The primary goal of the evaluation was to determine if the Social Work Services being provided are efficient and effective. The Director of the Department of Social Work was enthusiastic about this project and hoped that the questions being answered could be applied to evaluate other programs within Deer Lodge Centre.

Questionnaire Development and Trial

The limited research and literature in the area of assessment of family education and knowledge related to severe acquired brain injury or family perceptions of support and counselling necessitated the need for the writer to develop a specific questionnaire. The questionnaire utilized for this practicum report was written and revised by the writer based upon an extensive literature review, information being sought to achieve practicum objectives and learning goals as well as input from the writer's Practicum

Advisory Committee and results of a questionnaire pre-test. The questionnaire received ethical approval through the Faculty of Social Work Research Ethics Committee on January 3, 1996. Approval to proceed within Deer Lodge Centre was obtained in March of 1996.

In April of 1996 the questionnaire was pre-tested by six family members of patients on the Neurosupportive Care Unit, (two parents, two siblings, one spouse, and one adult child). The pre-test provided feedback related to the usefulness of the tool and whether or not the tool was eliciting the information required. Feedback from the pretest group recommended no changes to the tool. The information received back was analyzed by the writer and deemed to be the information that was required. The questionnaire was divided into several sections to elicit demographic information related to patients and their family members, knowledge of severe acquired brain injury, opportunities for discussion within the health care system, care giving roles and a needs assessment of Social Work services being provided in acute care and at Deer Lodge Centre and family member perceptions of support and counselling (APPENDIX B).

Consent was obtained through a form letter developed to accompany all questionnaires that were mailed out (APPENDIX C).

The purpose of the writer's practicum was discussed at a general family and resident meeting on the Neurosupportive Care Unit in January of

1996. The writer indicated that a questionnaire would be sent to parents, spouses, siblings and adult children of clients residing on the Neurosupportive Care Unit. The cover letter and questionnaires were mailed out to forty eight clients in June of 1996 (15 to parents, six to spouses, 21 to siblings and six to adult children).

In order to ensure confidentiality while collecting necessary demographic data, prior to mailing out the questionnaires each was numbered from 001 through to 021 to reflect individual patients on the Neurosupportive Care Unit. For example, if resident number one has six family members then all questionnaires mailed out related to resident number one were coded as 001. There were twenty one questionnaires returned. The response rate was 47.35%. All completed questionnaires were grouped by code number to reflect the number of patients accounted for in the data. These 21 questionnaire responses represented thirteen out of the 21 patients residing on the Neurosupportive Care Unit at that time.

The questionnaire was developed based upon the information obtained through the evaluability assessment, the literature that was available and the practicum goal involving conducting a needs assessment related to the effectiveness of Social Work services in the Neurosupportive Care Unit. The demographic data was collected to ensure that the results and implications for practice are utilized where similar populations exist.

Summary

The Neurosupportive Care Unit at Deer Lodge Centre has been in operation since June of 1991. The family members are grieving the loss of the loved one that they once knew while trying to keep the memories of the individual alive. There is limited literature and information on providing support, counseling and therapeutic interventions for patients and their family members where severe acquired brain injury has impacted. A formal evaluation process provides insight and assistance in the development of a professional approach that will serve the needs of the patients and family members of the Neurosupportive Care Unit. The evaluability assessment assisted the writer in focusing on objectives. The evaluability assessment in conjunction with specific program goals and objectives, the literature review and practicum goals led to the development of the questionnaire that was utilized.

CHAPTER 3

REPORT ON EVALUABILITY ASSESSMENT RESULTS

Introduction

The evaluability assessment was conducted to determine "the extent to which the program is sufficiently defined to consider evaluating it". (Rutman, 1984, p.28) and "to describe and understand the program in terms of the 'social reality' as held by the program personnel and stakeholders interviewed" (Rossi & Freeman, 1993, p.148). The evaluability assessment process provided the Interdisciplinary care team with an opportunity to explore program goals and objectives facilitating feedback that provided a context for assessment tool design.

Interviewing Program Personnel

The Interdisciplinary team members were agreeable and enthusiastic about engaging in attempting to answer the questions (Appendix A). A majority of the team members, with the exclusion of Dietary, were present at the team meeting. The Physician, Recreation Therapist, Physiotherapist, Occupational Therapist, Pharmacist, Speech and Language Pathologist, and two nursing staff were present. The Respiratory Therapist was unable to

attend, but provided written responses and returned them to the writer. The results were as follows:

1) Describe the rationale for the development of the Neurosupportive Care Unit.

The Interdisciplinary team members had several perceptions on the rationale for the development of the Neurosupportive Care Unit. There was a general feeling amongst the team that the Unit was established as a result of a need in acute care to empty their beds of long term stay patients who were living in acute care for extended periods of time (up to seven and one half years). Advocates including Dr. Norman Hill, the Manitoba Head Injury Association Inc. and family members expressed a need for the development of a specialized care unit to better meet the needs of individuals with severe acquired brain injury who required long term care and professional staff input in an institutional setting. There was a general perception amongst the team members that it was financially cheaper to place the young adults with severe acquired brain injury in long term care as opposed to acute care.

The development of a specialized care unit provides the Interdisciplinary Team members with an opportunity to develop and provide specialized treatment approaches when responding to patient and family needs. With program specialization and staff training there was a belief that efficient and effective care and interventions can be provided.

2) Describe the Neurosupportive Care Units goals.

Prior to entering into a discussion related to goals we discussed the difference between goals and objectives. Goals are often abstract and general whereas objectives are how goals become operationalized. The goals were articulated by each team member from their professional stand point.

Nursing: The primary goal articulated by nursing was to maintain the best quality of life for the patients and their families given the functional and cognitive limitations experienced by the patients. Inherent in the philosophy of maintaining quality of life is the provision of care and comfort measures to patients and the provision of support and education to family members.

Pharmacy: A general goal of the Pharmacist was to monitor medications to ensure that individuals are only on medications that are medically necessary. This process requires continual reassessment to facilitate and maintain present level of functioning through the use of medications.

Physiotherapy/Occupational Therapy: The primary focus articulated was to facilitate and maintain a level of physical functioning that is as high as possible given the limitations that the individuals are facing as a result of severe acquired brain injury. A second focus is to facilitate and maintain

positioning techniques that will reduce or prevent further contractures. A third goal is to assess and facilitate the acquisition of seating that will facilitate mobility at wheelchair level.

Physician: Defining goals and objectives when the unit opened was clouded by many ethical issues and dilemmas. Over the lifetime of the unit the goals have come to be the provision of good medical care while respecting individual and family treatment choices. Another goal is to work with the families to assist them in understanding their family member's disability and possible outcomes.

Recreation: The goal is to meet social and recreational needs through the provision of normative activities on an individual basis or in a group setting that can be enjoyed by individuals at the level at which they are functioning.

Social Work: The general goal for Social Work is to provide assessment and intervention to meet practical, emotional and psychological needs of patients and their family members.

Following the above mentioned discussion there was a team discussion related to the general feeling that patients are receiving "better care" on the Neurosupportive Care Unit as quality of life and the provision of a "home like" environment are the primary focus of all care and treatments provided. Quality of life is enhanced through the environment being open with natural

light and common areas for socialization. Also, the patients are dressed, up in wheelchairs and are tub bathed regularly on the Neurosupportive Care Unit. The Unit philosophy is to provide a family-centered care approach that involves patients (if they are able) and family members in the daily decision making processes.

3) Describe the Neurosupportive Care Units objectives.

Nursing: Nursing staff, including Registered Nurses, Licensed Practical Nurses and Health Care Aids see patients and family members daily. They provided constant support through discussions and education when questions arise. The Nursing staff are the individuals who dress patients, get them up in their wheelchairs and bath them regularly.

Pharmacist: Monitoring the medications and the reasons why individuals are on medications is carried out regularly through a medication review. The Pharmacist also attends weekly rounds and annual Health Inventories on the individual patients.

Physician: The provision of medical care is facilitated through an introduction of medications that are essential. Any informed treatment choices made by patients and family members are respected and facilitated. The physician along with other team members enters into discussions with family members regularly to provide education on current level of function and on ethical issues related to treatment choices.

Physiotherapy/Occupational Therapy: When patients are admitted to the Neurosupportive Care Unit an interdisciplinary assessment occurs with the involvement of the Physiotherapist, the Occupational Therapist and the Speech and Language Pathologist. They use a screening tool called the Western Neurosensory Screening Profile that measures individual responses to a variety of stimuli, including touch, smell, sight, hearing and taste. This screening tool is used as a baseline for future evaluations. Physiotherapy and Occupational Therapy work together on the positioning of patients through the use of the PEP Program in an attempt to reduce or prevent further contractures in patients. Physiotherapy provides exercise programs and Occupational Therapy looks at seating through seating assessment. In 1993 Physiotherapy and Occupational Therapy in conjunction with Recreation established a Sensory Stimulation Pilot Project, which is no longer being formally provided although sensory stimulation is incorporated informally into all care being provided.

Recreation Therapist: Normative social and recreational programs are developed to be age appropriate, as a majority of the patients who reside on other Units at Deer Lodge Centre are elderly. Some examples of programs developed for the Neurosupportive Care Unit are outings to Oktoberfest and to Rumours Comedy Club. Internally, there is the provision of one to one visits, a sports group and a pub night with a live band. The

patients and families are encouraged to attend these social and recreational functions, but attendance is voluntary. Choice is paramount.

Social Work: The Social Worker initiates contact with the patient and family prior to admission and provides an opportunity to view the facility and the Neurosupportive Care Unit in particular. There is general information provided related to services that are available and the limitations of services. Social Work is involved in the admission process, as well. Throughout the patients stay, the Social Worker is responsible for providing education, support and counselling to patients and their family members based on assessment and team discussions.

4) In your opinion, are there barriers to achieving program goals and objectives.

There was a lengthy discussion related to this question. The primary concern was time limitations related to decreased staffing in all departments except nursing and the physician. In March of 1993 forty four new beds opened up in Deer Lodge Centre with no increase in staff from any of the other departments.

The team members referred to decreased energy and changes in the level of enthusiasm in general as being a barrier to meeting goals and objectives. The decreased energy and enthusiasm is tied closely to the fact that a majority of the twenty one patients do not respond consistently to

the environment around them. The lack of response from patients affects motivation and decreases the amount of services provided. There is also a frustration that emerges related to the teams inability to reduce spasticity and contractures.

There was a consensus of opinion amongst the team that they found family members "difficult" at times because of unrealistic expectations and hopes. Many family members were hoping that the creation of the Neurosupportive Care Unit would assist their family member in improving both physically and cognitively. They are continually grieving the loss of the family member that they once knew, but the grieving will go on and on until death occurs. It is emotionally draining to try and work with the families without taking their hope away. If they are challenged then they feel that we do not care about them or their family member. The team expends much energy educating the family members and trying to provide the best service possible with limited resources of time and energy. The difficulties expressed in dealing with family members was also related to team member's frustrations about not knowing the answers to the questions being asked and not understanding how to be supportive at times.

5) Describe your individual philosophy, beliefs and values as they relate to your professional involvement on the Neurosupportive Care Unit?

This question led to a discussion related to ethical issues. Are we doing the best that we can for the individuals and their family members? Why was there no re-evaluation when the tube feeding was inserted? Professionally, what do you do when you see no quality of life and no hope of recovery? How do you respond to family members when questioned on this issue? Since many of the patients are in a post coma unawareness who makes the decision related to treatment? What do you do if there is disagreement amongst various family members related to treatment choices? Working on the Neurosupportive Care Unit can create internal ethical dilemmas for team members and it can also be emotionally draining. As a professional, it is clear that we cannot decide who to keep alive through artificial means and who to let die, therefore what do we do and how can we best provide quality of life for the patients and assist the surviving family members? With consideration of ethical dilemmas and legal issues, there are no easy answers to these questions.

6) In what situations would you refer a patient or family member to Social Work or alert Social Worker of concerns?

There was a common theme that the Social Work Assessments that detail who the individual was prior to sustaining an acquired brain injury is

extremely helpful. It serves to 'humanize' the individual when there may be no responses or no remnants or who the individual was pre-injury. The assessments also provide information related to family dynamics, relationships and coping abilities.

Team members refer to the Social Worker when patients and families are in need of counseling. Indicators for a counseling referral would be if the patient and/or family members are having a difficult time coping and/or if depressive symptoms are appearing. A referral to the Social Worker for assistance would occur when there was a need to locate financial resources to purchase necessary medical equipment and to ensure that basic personal needs are being met. The Social Worker is also consulted when concerns related to financial abuse are raised. The Social Worker assists in facilitating and obtaining Orders of Committeeship or Orders of Supervision if necessary.

The Interdisciplinary team discussion and feedback was essential in obtaining the perceptions and opinions of the team members. Following the meeting there have been informal discussions that demonstrated that team members had similar ideas about goals, objectives and ethical issues related to working on the Neurosupportive Care Unit. The interviewing process served as an effective team building exercise.

The Interdisciplinary Team discussion highlighted the fact that the team members have goals and objectives that are similar to those outlined in the formal program description with a focus on family systems not just the patient. There have been many efforts to assist the patients and their family members in achieving the highest level of functioning possible with the realization that patients have severe neurological impairments that restrict physical and cognitive functioning. The plateau of progress in the patients has resulted in some emotional anguish for staff because when the Neurosupportive Care Unit initially opened there were changes in the patients and the family members seemed more content with the focus changed from an acute care orientation to creating a "home like environment" where patients were dressed and up daily as most patients are medically stable.

Developing an Evaluable Program Model

From the various types of information obtained, the investigator explicates the program elements and objectives to be considered for inclusion in the evaluation plans (Rossi & Freeman, 1993, p. 148).

The goals of the Neurosupportive Care Unit have objectives that are defined in global terms with no specific plan for operationalizing the

objectives or measuring outcomes. There was no specified protocol for evaluation after a period of time for the Neurosupportive Care Unit.

For the purposes of evaluation and assessment tool design, the writer will focus on three program goals as follows:

- 1) To operate a chronic care unit that is family-centered that will enhance quality of life for patients and their family members.
- 2) To provide interdisciplinary care that enhances the ability of patients and family members to adapt socially and psychologically to changes.
- 3) To provide interdisciplinary care that is ameliorative in addressing physical, emotional, social and spiritual needs.

"Scouting" the Program

The Neurosupportive Care Unit is "a family-centered chronic care program for younger adults with severe neurological impairment" (Deer Lodge Centre, 1991). Based upon interviewing of program personnel, ethical discussions that are ongoing at the interdisciplinary team level and the writer's personal experiences, the Neurosupportive Care Unit has become a family-centered chronic care program since its' inception in June of 1991. When the Unit first opened there were medical and care issues that needed to be addressed and assessments that needed to be completed by the interdisciplinary team members. An extensive staff educational process that

is ongoing that has assisted in the development of this family-centered chronic care program.

Over time the Unit has admitted patients who are over the age of sixty who otherwise meet the Neurosupportive Care Unit criteria and younger individuals who may have other neurological impairment including Multiple Sclerosis and Spinal Cord Injury.

The paramount importance of involving families in developing care plans, sharing information and providing support has become a focus of interdisciplinary team work with all team members working with the family members. This is facilitated through education and support.

Further measures have been taken to ensure family members are part of the team caring for patients. Adjustments have been made related to provision of care including increasing the number of baths that patients receive, providing instruction for family members to utilize bathing facilities with patients, mechanical lifts and other pieces of equipment to ensure that family members who choose so can be involved in as much care as possible. Where family members who do not choose to provide direct care on an ongoing basis the nursing staff will provide for the patient's needs. The involvement of family members in care decisions for those patients who are unable to express their needs has been a paramount function of the Interdisciplinary Team. Formal interdisciplinary case conferences and

informal sessions involving patients and family members are held on a regular basis to ensure ongoing communication and renegotiation.

The interdisciplinary care team strives to provide symptom management and prevention of complications (Deer Lodge Centre, 1991). From the perspective of the interdisciplinary team members, symptom management and the prevention of complications, that are within the control of team members, has been achieved. The introduction of specialized seating systems, a positioning program for patients, education of staff and family members related to passive range of motion exercise and supporting the use of alternative therapies have provided a medium for achieving this goal. One issue expressed in the evaluability assessment interview was the frustration of team members related to their inability to reduce or prevent contractures resulting from severe neurological impairment.

The interdisciplinary care team provides an opportunity for patients to attain and maintain the highest level of function possible given the physical and cognitive issues that they endure as a result of severe acquired brain injury (Deer Lodge Centre, 1991). This goal is achieved through ongoing interdisciplinary assessment and discussions with patients and their family members. Given the severity of the acquired brain injuries a majority of the patients have remained in post coma unawareness. For these patients maintenance involves the provision of good care, having them up in their

wheelchairs, dressed regularly and providing general sensory stimulation. There have been adjustments made for patients who have entertainment units, computers and unique needs to ensure that they can be as independent as possible given their profound physical limitations. The use of power mobility, augmentative communication devices and environmental controls are explored in depth with recommendations and purchases for patients who can benefit from the technology available.

The provision of interdisciplinary care that enhances the ability of patients and family members to adapt socially and psychologically to change (Deer Lodge Centre, 1991) is an area that will be examined more closely in this practicum report. The patients and family members are at different stages of the grieving process and many coping mechanisms and styles are being utilized. The question of whether acceptance means adaptation results in ongoing discussion within the interdisciplinary team. When the team attempts to clarify the potential expectations for recovery many families interpret this as 'taking away their hope'. This hampers trust and relationships and often makes the families feel that no one is listening to them or hearing them. Families require hope in order to go on.

Encouraging family members to take time for themselves has also proven to be a difficult task. Many feel a need to visit frequently. Some visit up to eight hours per day. Others have never visited. Many professionals

will maintain that the family members 'need to get on with their own lives'. In many counseling sessions it has become apparent that this is extremely hurtful to family members who will maintain that this person is a part of their life. How does one go on grieving indefinitely with no end in sight? For the family members on the Neurosupportive Care Unit the grieving process is prolonged.

The provision of interdisciplinary care that is ameliorative in addressing physical, emotional social and spiritual needs (Deer Lodge , 1991) has been and continues to be the most difficult to evaluate and will form a portion of the evaluation and assessment tool design. The term ameliorative means " to make or become better" (Websters II, 1984, p. 25). Operationalizing and evaluating the provision of the opportunity to achieve the greatest level of functioning possible, in the team's experience, has different meanings for family members and patients than it does for the interdisciplinary team members.

Based on the interview with program personnel, the interdisciplinary team believes that although all patients have not improved physically their living situation has improved as their care needs are primary and methods of enhancing quality of life have been addressed and introduced. Spiritual and emotional support is available to family members from a variety of team members with referral to outside sources if necessary. The families also

receive support from each other, as they have been enduring similar experiences and can understand one another implicitly. By placing individuals with similar disabilities and needs in one area the effect on family members and on staff has been a positive growing experience.

Each Department represented on the interdisciplinary team was asked to develop goals and objectives to fit with the Neurosupportive Care Unit and the general mission statement and philosophy of Deer Lodge Centre. Based upon practicum implications and conclusions the writer will articulate clear goals and objectives for the Department of Social Work related to the provision of service for the Neurosupportive Care Unit. The evaluation question was utilized in developing the assessment tool to determine the types of Social Work Services that have been provided, those that family members identify as being the most helpful and those that are required.

Based upon the results from the Interviewing of Program Personnel, ongoing Interdisciplinary Team Work, discussion and education from the perspective of the Interdisciplinary Team the formal goals and objectives have been achieved at a basic level, but more exploration related to client perceptions will evolve from this practicum report.

Summary

The evaluability assessment process provided the writer and the interdisciplinary care team with an opportunity to explore program goals and objectives. The interdisciplinary team interviewing process illustrated that the team members have goals and objectives that are similar to those outlined in the formal program description, with a focus on broader family system not just the patient. The emotional and ethical issues that arise for individual team members were brought into the open. The results of the evaluability assessment provided a context for the writer to focus on specific program objectives to guide the program evaluation process.

CHAPTER 4

REPORT ON SURVEY RESULTS

Introduction

This Chapter of the practicum report is composed of the data collected using the questionnaire (Appendix B). This Chapter will report on the analysis of responses obtained to create a specific demographic profile, to clarify the knowledge base of family members related to acquired brain injury, to explain family members' Social Work related needs and to examine perceptions of support and counselling.

Data Analysis

The questionnaire elicited information related to demographics about the patients and the family members, knowledge of acquired brain injury and the subsequent effect on the patient, experiences in gathering and receiving information within the health care system, experiences related to Social Work in particular and the family members perceptions of support and counselling.

The cover letter and questionnaires were mailed out to 48 clients in June of 1996. There were 15 questionnaires mailed to parents (31.25%), 6 questionnaires mailed to spouses (12.5%), 21 questionnaires mailed to

siblings (43.75%) and 6 questionnaires mailed to adult children (12.5%). The writer received 21 completed questionnaires (43.75%). All completed questionnaires were grouped by code number to reflect the number of patients accounted for in the data. The 21 questionnaire responses represented 13 of the 21 patients residing on the Neurosupportive Care Unit at that time. Of the patients on the Neurosupportive Care Unit 61.9% are represented in the sample.

The data analysis will be based on 21 questionnaire responses reflecting information related to 13 patients of the Neurosupportive Care Unit and 21 family members. Of the 21 questionnaire responses received four were completed by a Client Administration Officer from the Office of the Public Trustee who serves as the Committee/Guardian of the client. The demographic data collected provides a description of the patient and family member population on the Neurosupportive Care Unit. It is the writer's hope that where similar populations exist the findings can be utilized.

Data Related to Neurosupportive Care Unit Patients

The demographic data collected on the patients represents 61.9% of the patients on the Neurosupportive Care Unit. Section One - Part A (APPENDIX B) of the questionnaire gathered data related to the Neurosupportive Care Unit patient. Information related to demographics and

severe acquired brain injury are presented in Tables 1 -5 with the accompanying analysis.

TABLE 1
DEMOGRAPHIC DATA RELATED TO THE NEUROSUPPORTIVE
CARE UNIT PATIENTS

MEASURE	MALE	FEMALE	TOTAL
Number in Sample	8	5	13
Age Range	23 - 61 years	34 - 61 years	23 - 61 years
Mean Age	41.25 years	47 years	44.125 years
Median Age	42 years	47.5 years	44.75 years
Marital Status			
Single	4	1	5
Common law	1		1
Married	2	2	4
Divorced	1	2	3
Education Level			
Highschool	6	3	9
Community College		1	1
Trade School	2		2
University		1	1

The literature refers to individuals with severe acquired brain injury being a somewhat homogeneous group. "Victims of severe head injury do

not form a random cross section of society ... They tend to be young, economically active adults ... and there is a higher incidence in men from lower socio-economic groups (Livingston, 1988, p. 6):

Table 1 indicates that the patients on the Neurosupportive Care Unit have completed grade twelve education or higher and eight (61.5%) resided in an apartment while five (39.5%) were residing in houses prior to hospitalization. The survey responses indicated that the average age of the patients was 44 years of age. Information related to socioeconomic status prior to hospitalization was not obtained.

The demographic data collected depicts profiles similar to that portrayed in the literature. The data portrayed in Table 1 reflects a homogeneous group of young economically active adults sustaining acquired brain injury. Thus the financial, social and psychological implications to the patients and their family members will result in profound changes within the family system in terms of roles and expectations.

TABLE 2**RESIDENCE AND ACCOMMODATION PRIOR TO HOSPITALIZATION**

Residence prior to Injury			
Winnipeg	5	4	9
Rural	2	1	3
Manitoba			
Other	1		1
Housing Prior to Injury			
House	3	2	5
Apartment	5	3	8
Owned	5	2	7
Rented	3	3	6

The data gathered indicates that 69.2% of patients were residing in Winnipeg prior to hospitalization. Three patients were living outside of Winnipeg. The writer is curious about the number of patients residing in rural areas that may be appropriate for the Neurosupportive Care Unit but to be near families they remain in their own communities. The statistics related to housing do not appear to indicate anything unusual. The data in Table 2 serves to raise questions about the potential need to have specialized care for young adults with acquired brain injury in other areas throughout the province of Manitoba.

The data presented in Table 3 (Practicum Report, 1997, p. 65), Table 4 (Practicum Report, 1997, p. 67) and Table 5 (Practicum Report, 1997,p.69) in combination with the narrative responses from Questionnaire Part One - Question number 13 (APPENDIX B) that stated "PLEASE DESCRIBE THE ABILITIES AND LIMITATIONS OF YOUR FAMILY MEMBER RELATED TO COGNITIVE, PHYSICAL AND PSYCHOLOGICAL FUNCTIONING" obtained data related to the knowledge base of family members as it relates to severe acquired brain injury and how it affected their family member living on the Neurosupportive Care Unit. This data was collected to determine the current level of understanding of the family members related to the patient, as providing information and education is a major component of a Social Worker's role.

TABLE 3

**DESCRIPTION OF SEVERE ACQUIRED BRAIN INJURY AS IT RELATES
TO THE NEUROSUPPORTIVE CARE UNIT PATIENTS**

MEASURE	MALE	FEMALE	TOTAL
Cause of Injury			
<i>Traumatic</i>			
MVA	1		1
Assault	1		1
Fall	2		2
Other		1	1
<i>Anoxic</i>			
Cardiac			
Arrest		1	1
Stroke	1		1
Other	3	3	6

In the province of Manitoba 50 percent of acquired brain injury is sustained in motor vehicle accidents (Manitoba Head Injury Association Inc., 1991). In general the literature on acquired brain injury and prevention programs focuses on involvement in road traffic accident as driver or pedestrian or individuals who have been assaulted (Livingston, 1988). The issue of alcohol consumption prior to sustaining acquired brain injury is highlighted through prevention campaigns and in the media.

The population on the Neurosupportive Care Unit portrays a different picture related to onset for acquired brain injury. The data in Table 3

indicates 7.69% of patients on the Neurosupportive Care Unit sustained acquired brain injury in a motor vehicle accidents with a further 38.46% sustaining acquired brain injury from assaults, falls or other traumatic causes. 69.23% of patients sustained acquired brain injury from strokes, cardiac arrests or other anoxic causes. For the writer the most startling and frightening statistic emerged in the Anoxic Other category with four of the six patients sustaining acquired brain injury through suicide attempts. This indicates that 30.77% of the patients sustained acquired brain injury from suicide attempts. Data related to alcohol consumption was not gathered for the purposes of this practicum report. The data that emerged through analysis brings about unsettled feelings in the writer related to the randomness at which profound stroke, cardiac arrests accidents and violence can lead to severe disability. The issues emerging in the area of survival after suicide have far-reaching implications for intervention within the family system and the health care system.

TABLE 4**LENGTH OF TIME SINCE INJURY AND LOCATION PRIOR TO DEER****LODGE CENTRE ADMISSION**

Months since Onset	Male	Female	Total
Range	34 - 116	57 - 152	34 - 152
Mean	57.7	101	59.7
Median	75	105.5	90.25
Location prior to admission			
Acute Care	6	4	10
Other	2	1	3

A study conducted by the Neuropsychological Research Unit at the Health Sciences Centre and the St. Boniface General Hospital in Winnipeg from January 15, 1990 through to September 1, 1991 on young adults admitted with acquired brain injury:

LENGTH OF STAY (DAYS)

	<u>MODERATE</u>	<u>SEVERE</u>
HEALTH SCIENCES CENTRE	22.17	72.83
ST. BONIFACE HOSPITAL	13.73	102.40

(Unpublished Paper. Neuropsychological Research Unit at Health Sciences Centre. 1993).

The average length of life since severe acquired brain injury onset is seven and one half years (2700 days). The Neurosupportive Care Unit

opened in June 1991 which means that it has been open for approximately 1,890 days as of August 1996. The Neurosupportive Care Unit patients spent more time in acute care than the research demonstrates. The Unit criteria outlines admission as six months post trauma which is 180 days at a minimum, recognizing low turnover due to young age of clients.

The data gathered on length of stay in acute health care settings portrays a sad commentary on the existing health care system. Patients and their family members were forced into dealing with an acute care system that is based upon the medical model with the focus on diagnosis, treatment and discharge once medical care is no longer required.

TABLE 5
DESCRIPTION OF COGNITIVE AND BEHAVIORAL SEQUELAE AS
PERCEIVED BY FAMILY MEMBERS

MEASURE	TOTAL BASED ON 21 RESPONSES
Tube Feeding	12
Tracheotomy	4
Incontinence	13
Spasticity	9
Pain	6
Fatigue	7
Visual Deficits	12
Auditory Deficits	6
Swallowing Deficits	11
Communication Deficits	11
Cognitive Deficits	9
Wheelchair Dependent	13
Consistent Response to Environment	2
Consistent Form of Communication	2

The narrative responses to the question "PLEASE DESCRIBE THE ABILITIES AND LIMITATIONS OF YOUR FAMILY MEMBER RELATED TO COGNITIVE, PHYSICAL AND PSYCHOLOGICAL FUNCTIONING" were summarized by the writer.

Cognitive: A majority of respondents acknowledged that their family member did not respond consistently to environmental stimuli, but felt that awareness was present as family member becomes relaxed in their

presence. Many of the respondents felt that there were inconsistent responses to sound and touch:

"My son responds to me occasionally but then lapses into his own world again".

"My sister is brain dead. The only responses she has are reflexive, like those of a baby".

"My son's long term memory is intact but his short term memory is sometimes poor. He is able to communicate with us using eye blinks and a switch hooked up to a communication device" (Quotations from Questionnaire Responses. 1996).

Physical: All respondents acknowledged that their family members are totally reliant on others to provide for all of their care needs. There was recognition of lack of controlled movements at the physical level.

"Being a former athlete (cyclist) she had a strong body. She experiences spasticity of all her muscles - they are stiff from not being used".

"My brother is very dependent on us and the nurses. He is not able to walk, talk or go to the bathroom". (Quotations from Questionnaire Responses. 1996).

Psychological: The responses varied from emotional responses being in tact and depression being present to acknowledgment that there was no psychological functioning with reflexive laughing, smiling and crying being noted.

“My sister can cry, yawn and blink - they are all reflexive actions”.

Usually patient is able to cope with an accept the condition while maintaining a sense of humour in dealing with other”. (Quotations from Questionnaire Responses. 1996).

The patients on the Neurosupportive Care Unit have sustained severe acquired brain injury as opposed to moderate or mild acquired brain injury. Eleven of the thirteen (84.6%) of the patients were described as not responding consistently to environmental stimulation and having no consistent form of communication. All of the patients rely on staff and family members to provide for all of their care needs. All patients require tube feeding for nutrition and hydration.

Individuals who sustain the most severe acquired brain injuries are left with severe cognitive, behavioral and physical deficits including being unaware of the environment around them following coma and being reliant on others to provide for all of their care needs. Individuals who are in a state of post coma unawareness will respond at a subcortical level to the environment around them with responses including eye opening and some ability to follow stimuli with their eyes. They also display definitive sleep wake rhythms. Some individuals may demonstrate a reflexive grasp or reflexive crying or laughing. Individuals in a state of post coma unawareness.

Based on the response data 84.6% of the patients on the Neurosupportive Care Unit would be considered to be in post coma unawareness. This data is not consistent with general literature that focuses on mild to moderate acquired brain injury, rehabilitation and community living. The writer questions whether cause of onset, with 61.5% of patients sustaining acquired brain injury from non - traumatic causes, has an effect on post coma unawareness.

One of the objectives of this practicum report was to conduct a needs assessment related to the effectiveness of Social Work Services being provided to individuals and their family members on the Neurosupportive Care Unit at Deer Lodge Centre. As a Social Worker, the writer has an obligation to meet the multiple needs of clients receiving service. As a Social Worker "an important part of acting as a broker, enabler, advocate, and educator is to increase the client's knowledge about aspects that he or she may not know about (Compton & Galaway, 1994, p. 465).

The data displayed in Table 3 (Practicum Report, 1997, p. 65), Table 4 (Practicum Report, 1997, p. 67) and Table 5 (Practicum Report, 1997, p.69) demonstrates understanding and incorporation of basic knowledge related to the cause and subsequent effect that severe acquired brain injury has had on the patient on the Neurosupportive Care Unit. The respondents did acknowledge profound impairment in all spheres where questioned

directly about consistent responses, consistent communication and in the narrative portion of the question:

“She is able to track with her eyes. Some people feel she is occasionally able to respond to verbal communication by moving her thumb” (Quotations from Questionnaire Responses. 1996).

The data reflects an understanding and incorporation on a basic level of information related to the cause and subsequent effect that severe acquired brain injury has had on the patient. The respondents acknowledged profound impairment in all spheres where questioned directly about consistent responses, consistent communication. 61.5% of the patients sustained acquired brain injury from anoxia related to cardiac arrests, strokes and suicide attempts. The patient population on the Neurosupportive Care Unit as described in the response data have sustained severe acquired brain injury as opposed to moderate or mild acquired brain injury. 84.6% of the patients do not respond consistently to environmental stimulation and have no consistent form of communication. For the writer the challenge becomes providing Social Work services including support and counselling to family members who have a loved one in a state of post coma unawareness. This Issue will be explored in the data analysis later in Chapter 5.

Data Related to Neurosupportive Care Unit Family Members

There were 15 questionnaires mailed to parents (31.25%), 6 questionnaires mailed to spouses (12.5%), 21 questionnaires mailed to siblings (43.75%) and 6 questionnaires to adult children (12.5%). Of the mailed out questionnaires 21 completed questionnaires were returned resulting in a 43.75% response rate with four questionnaires being completed by the Client Administration Officer who serves as the Committee/guardian of the client. One (6.25%) questionnaire response contained patient related data only. Sixteen (33.33%) of mailed out questionnaires were available for data analysis related to family members.

The questionnaire was divided into sections with Part One - Section B of the questionnaire being written to gather demographic information related to family members (APPENDIX B).

TABLE 6

DEMOGRAPHIC DATA RELATED TO THE NEUROSUPPORTIVE CARE**UNIT FAMILY MEMBERS**

MEASURE	MALE	FEMALE	TOTAL
Number of Responses	5	11	16
Age Range	33 - 64 years	23 - 68 years	23 - 68 years
Mean Age	55.40 years	43.09 years	47.50 years
Median Age	50 years	45.40 years	47.40 years
Relation to Patient			
Parent	2	4	6
Spouse			
Sibling	1	6	7
Adult	2	1	3
Child			

The data depicted in Table 6 presents indicates that 37.5% of respondents were parents, 43.75% siblings, 18.75% were adult children and none of the respondents were spouses. There were six questionnaires mailed to spouses with no responses. These findings related to siblings and adult children are unique as the literature tends to focus on parents and spouses with some reference to younger children. The results suggest ongoing involvement and contact from siblings and adult children. The data on parent and spousal responses is consistent with the literature. The

results of Table 6 related to parents and spouses is consistent with the literature:

Clinical evidence suggests that wives of men with traumatic brain injury have more difficulties with the impact than do other family members ... spouses difficulty in accepting regressive behavior of the injured person ... Parents may find it easier to accept these changes because dependency is a natural part of the relationship between parents and children (Florian & Katz, 1991, p. 269).

Although the literature focuses on mild and moderate acquired brain injury the findings can be logically extrapolated to the population on the Neurosupportive Care Unit and their family members.

TABLE 7**MARITAL STATUS, RESIDENCE AND ACCOMMODATION OF FAMILY****MEMBERS**

Marital Status			
Single		1	1
Common law		1	1
Married	4	8	12
Divorced	1		1
Education Level			
Highschool	2		2
Community College		4	4
Trade School	1	1	2
University	2	6	8
Residence			
Winnipeg	3	4	7
Rural			
Manitoba	2	6	8
Other		1	1
Housing			
House	5	10	15
Apartment		1	1
Owned	5	9	14
Rented		2	2

The demographic data from Table 7 creates a picture of a somewhat homogeneous group. The data indicates that 75% of respondents are married and 87.5% have higher than grade 12 educational level. 93.75% of

respondents lived in houses with 87.5% owning their house. 6.25% lived in an apartment and 12.5% rented their living accommodation.

The data suggests that the family member respondents have a support network within their home and potentially outside of the home given the education levels attained.

The writer was intrigued by 56.25% of respondents residing outside of Winnipeg when only 23% of patients resided outside of Winnipeg prior to hospitalization.

The demographic data related to family members creates a context for exploring caregiving roles of the family members. The six questionnaires mailed to spouses with no responses, the findings related to siblings and adult children, parents and spouses suggest limited involvement from spouses and ongoing involvement from parents, siblings and adult children. The data on parent and spousal responses is consistent with the literature. The data also suggests that the family member respondents have a support network within their home and potentially outside of the home given the education levels attained. This demographic data serves as a basis for exploring visiting patterns and care provision.

Data Related to Visitation Patterns and Provision of Care

The analysis of questionnaire responses provided data related to family members' visiting patterns and the types of interactions that occur during visits. Part One Section B question 8 (APPENDIX B) asked "HOW OFTEN DO YOU VISIT YOUR FAMILY MEMBER?" The responses received are summarized in Table 8.

TABLE 8

DESCRIPTION OF INVOLVEMENT BY FAMILY MEMBERS

FREQUENCY OF VISITS	NUMBER OUT OF 16
Daily	1
5 - 6 Times Per Week	2
2 - 3 Times Per Week	2
Weekly	7
Bi-Weekly	1
Weekend Visits to Family Home	2
4 Times Per Year	2
Annually (when Possible)	1

Some family members visit regularly plus provide care for weekend visits home. The data indicates that 68.75% of family members visit at least once per week. This data combined with the average length of time since injury being seven and one half years indicates an unwavering dedication to their loved one. The visiting patterns addressed in Table in conjunction with Table 9 (Practicum Report, 1997, p. 80.) delineate a portrait of the family members caregiving roles.

Part One Section B question 9 asked "DO YOU PROVIDE DIRECT CARE (HANDS ON CARE) TO YOUR FAMILY MEMBER? PLEASE DESCRIBE THE NATURE OF THE CARE NEEDS THAT YOU ASSIST WITH."

TABLE 9

NATURE OF CARE PROVIDED BY FAMILY MEMBERS

NATURE OF CARE PROVIDED	NUMBER
No Care Provided	6
Mouth Care	10
Tracheotomy Care	2
Gastrostomy Care	5
Bathing	4
Facial and Lip Care	3
Transfers	6
Range Of Motion Exercises	6
Massage	8
Walks	10
Communication	8

There are varying degrees of family involvement, both in visiting and in the provision of hands on care. In terms of direct care 37.5% of respondents were providing no care with 62.5% providing mouth care, taking the patient for walks. The data suggest varying comfort levels in care provision with a focus on comfort and stimulation. The variations may be related to the nature of the relationship within the family system prior to the event resulting in acquired brain injury.

There is limited literature available on family members' roles, coping and adjustment following severe acquired brain injury. The writer has chosen to utilize grief and coping literature to add some understanding in this area. The writer speculates that grief and coping reactions may account for decreased questionnaire responses, the varied visiting patterns and the varying degrees of hands on care being provided. The onset of post coma unawareness leads to a series of psychological responses for family members. The stages of grief are set into motion without total resolution because death does not occur:

Guilt is most often related to the perceived role of the family in the patients injury and present status ... **Denial** is most frequently noted as a coping response that helps a family to adjust to the patients present state but it can be pathological if the need to see improvement fosters severe delusions ... **Accommodation** occurs over time as the family learns to accept the patients disability and works towards meeting the needs of the patient and the separate needs of the other family members ... **Disengagement**, often a result of accommodation, is frequently related to the patients level of disability and its' interference with family function. Although still considering the patient a family member, the rest of the family might find a need to distance themselves so that they can meet their own personal needs over the long term ... **Rejection** is considered an extreme form of disengagement

(similar to abandonment) which might occur after a prolonged period of vegetative state which interferes with other family functions (Jacobs, 1987, p. 56).

Each individual family member experiences grief and will cope in a different manner, which may account for varying levels and patterns of involvement. The literature focuses on mild and moderate acquired brain injury and spousal, parental and child reaction and involvement patterns. General literature on grief and coping with loss in critical illness has been utilized to explore this area in more detail:

The sudden onset of a major disability, with the attending physical and psychological changes and losses affecting every aspect of the person's and family's life, often result in an interruption of lifestyles and goals, and expectations of crisis proportions, causing disruption of the family's homeostasis on which the usual problem solving means are inadequate to restore balance....Thus, the onset of disability, which often means prolonged hospitalization and separation of the individuals from the family, has an impact on the lifestyle of the children and parents and interferes with the physical and emotional routines of daily living, plans, and expectations of all family members (Glass, 1985, p. 145).

Coping when Life is Threatened (Buchanan, 1987.) addresses the issue of stress, loss and coping as they impact upon patients, their family members and significant others. Patients "span the whole spectrum of health - there is the black of death, the white of cure and the great gray of

disability.... they also cover the full emotional spectrum from desperation and dissolution to growth" (Buchanan, 1987, p. 1).

Karin Buchanan (1987) has summarized many of the factors, influences and reactions that the writer utilizes in working with individuals and their families. Therefore the writer has chosen to use excerpts of her work for the purposes of this practicum report.

The theory of loss outlined by Karin Buchanan will be adapted to focus on the experience of loss by individuals and their families affected by severe acquired brain injury "All change, even good change, threatens the status quo, and hence our sense of security, of order, of expectation, of future fulfillment, and of purpose in our world (Buchanan, 1987, p. 9).

Karin Buchanan (1987) outlines several areas of loss that can create sources of stress for individuals and their family members that will impact upon coping styles.

Financial

The onset of severe acquired brain injury and the associated losses usually leads to financial concerns or a disruption in receipt of income. Disability can mean a direct loss of income or decrease in income. The process of determining what benefits are available and applying for disability benefits can be an arduous task for families who are grieving. The

Social Work intervention role at this point in time is clearly to assist family members in accessing benefits and resources available to them to ensure that the process of accessing financial resources does not become overwhelming.

Health Care System

Professionals who work within the health care system see themselves as “helpers” who are there to provide comfort, care and support to the patients and their family members. However, the health care system and staff can be a source of frustration and anxiety for many patients and their family members where sudden onset of disability has occurred.

Until the 1980s survival following severe acquired brain injury was not likely. Therefore, physicians and other health care professionals often have no clear answers related to prognosis or outcome. This is a source of anxiety, frustration and stress for individuals because people believe that physicians have all the answers and that they just are not telling them ‘what is going on’ or ‘what the outcome will be’.

When a loved one is admitted to hospital with severe acquired brain injury the family members are faced with life and death decisions following a sudden traumatic event. Individuals often opt for the choice of life as the outcome is unknown. When an individual sustains a severe acquired brain

injury the family members are faced with the awesome responsibility of continually making life and death treatment choices.

The provision of health care to this unique population needs to incorporate an understanding of the responsibility placed on family members to make life and death decisions in a state of shock:

Family members tell of extremely strong emotions, a feeling of physical exhaustion to the point of near collapse. They describe the first month of onset after the illness as a time of anxiety - filled waiting for the patient to wake up. Many families refer to this period as a 'bad dream', as though it were not really happening to them (Tzidkiah, 1994, p. 160).

The writer has encountered many family members who maintain that the doctors provided them with a poor prognosis upon initial hospital admission and that over time their loved one continued to survive and outlive the prognosis. This provides a source of hope.

The data collected and the literature suggest a need to provide consistent and honest information in a caring and compassionate manner to ensure that the decision maker has all the information and support they need to make an informed decision recognizing various grief and shock reactions.

Family Role Changes

The onset of severe acquired brain injury always necessitates role changes and most often role reversals for extended periods of time, if not indefinitely. The writer will use a fictitious case example to articulate familial role changes. Mary is a 41 year old woman who has been married to Harry for 20 years. They have two daughters, Caroline (19 years of age) and Susan (17 years of age). Mary sustained severe acquired brain injury following a cardiac arrest. Mary remains unresponsive to environmental stimulation. Harry has lost the mother of his children, his companion, his lover and his best friend. Caroline and Susan have lost their mother, their confidant and their friend. The losses go far beyond those of family roles and relationships.

Loss is a unique experience that is affected by past relationships and roles. Mary contributed financially to household maintenance, she managed the household through shopping, cooking and cleaning and dividing up household tasks, she provided emotional support to her husband and daughters and Mary also played the mediator within the family system, mediating disputes and disagreements amongst family members.

In this case scenario Harry was forced into a position where he was trying to manage the household on decreased income until disability benefits could be straightened out. He also had to take over the role of household manager and provide support to his daughters. This role reversal was taking

place at a time when the outcome of Mary's acquired brain injury was unknown.

The impact of role changes within the family system is an area of focus for Social Work intervention. The literature notes role change issues as having a profound impact between spouses, with parents making the transition to caregiving more easily. The impact on siblings and adult children is discussed in general in this practicum report.

Survivor Guilt

Survivor guilt following the onset of severe disability or death is extremely common even years after the initial event has occurred. For the family members that the writer works with the events preceding and following the onset of severe acquired brain injury are rehashed over and over again, often triggered by another traumatic event has occurred, such as the death of another individual or reports of a similar accident.

It is the writers professional opinion that the guilt felt by many family members hits at the core of their varying abilities to cope. Many individuals will say that they can not discuss the accident because it is "too painful". Guilt is a powerful emotion that requires constant monitoring and intervention. The data collected did not address the issue of guilt directly but there were guilt reactions expressed. There was hostility expressed

towards staff in acute care and at Deer Lodge Centre. The interdisciplinary team and the Social Work interventions need to incorporate an understanding that guilt is not a static state and that it may disappear and then reemerge as the prolonged grieving process continues:

Since the family of the post coma unawareness patient does not go through the bereavement process in completion, it can not adjust to the situation fully ... Lack of adjustment can be seen in the family's clinging to both the patient and denial. This persistence tends to be strongest among family members who have not extricated themselves from their sense of guilt (Tzidkiah, 1994, p. 164).

Reactions of Others

"Patients and families are parts of networks, not just sets of isolated individuals, everyone must deal with reactions of others, extended family members, friends, fellow workers and staff" (Buchanan, 1987, p. 21).

The sudden onset of acquired brain injury will either bring networks together or push them apart. "Seldom does it leave family dynamics unaltered" (Buchanan, 1984, p. 22). People tend to be critical of the coping strategies used by others. As human beings we tend to see our way of doing things as the 'right way and the most helpful way'. Severe acquired brain injury has long lasting effects on the family members for many years. Many families of those with severe acquired brain have discussed a scenario

where professionals, family, friends and co-workers have encouraged them to 'get on with their lives' as it has been a long time since the onset of sudden disability. The family members' response to the writer has always been 'how can I get on with my life when this person was a part of my life and they are still here?'.

Isolation

The onset of severe acquired brain injury tends to lead to emotional and social isolation for many patients and their family members. The results indicated in Table 9 (Practicum Report, 1997, p 80.), in conjunction with narrative responses of the family members related to the description of their support network demonstrate there is a decrease in the size of their support network as the length of time since injury onset increases. The increased isolation stems from an initial disruption in social interaction during the acute phase to the reactions of others noted above. One of the thoughts on the development of a specialized care unit for young adults with acquired brain injury was to place individuals with experiencing similar issues in one area in hopes of developing an extended support network.

Coping Styles

Coping means many different things to people. Each individual has their own individual coping style that may or may not be healthy. Coping styles are influenced by individual circumstances related to financial concerns, health care system experiences, family role changes, survivor guilt, reactions of others and isolation and previous coping experiences.

Coping styles can be examined through a division into the effectiveness of the coping style utilized. The least effective coping mechanisms are regression, prolonged blaming, complete denial and extreme projection. The use of "these primitive coping mechanisms will, if used consistently, distort reality and inevitably create more problems" (Buchanan, 1987, p. 80). The moderately effective and most commonly used coping mechanisms are reaction formation, rationalization/intellectualization, withdrawal/avoidance and inappropriate humor. These moderately effective coping mechanisms are helpful if used short term in conjunction with highly effective coping mechanisms which are confrontation, redefinition, suppression, differential compliance with authority, some sharing with others and appropriate humor. The highly effective coping mechanisms are "conscious, planned and chosen. All require some level of successful confrontation first" (Buchanan, 1987, p. 82).

Social Work intervention involves an exploration of coping styles and can extend to an intervention related to altering and utilizing the most effective coping mechanisms to enhance adaptation and coping in general.

Increased understanding of utilization of coping mechanisms obtained through a literature review and data collected helps to explain the variations in family visitation and care provision. Each individual has a unique relationship with the patient on the Neurosupportive Care Unit both prior to and subsequent to the onset of severe acquired brain injury. The nature of the relationships, health care system experiences, role alteration and coping styles determine visitation and care provision patterns.

Onset of Disability: The Effects on Children

The literature on acquired brain injury focuses on parent and spouse reactions. Since 43.75% of respondents were adult children the writer attempted to locate information on the effects of acquired brain injury on children. Dorthea Glass (1985) in *"Onset of disability in a parent: impact on child and family"* examines how the many losses outlined by Karin Buchanan affect children at various life stages.

1) Very Young Child: "The very young child's thinking is primitive and magical" (p. 146). This means that the abstract concepts surrounding change and the onset of sudden disability can not be handled and are often

overwhelming for the very young child. The experience is frightening for adults so imagine how it would feel if you did not understand any of the changes or the disability.

2) Older Child: "The older child who is able to think in rational and conceptual terms identifies with the parents and their troubles and feels the same loneliness, helplessness, apprehension, anger and perhaps guilt" (p.147).

The written works of Karin Buchanan, Dorthea Glass and Harvey Jacobs begin to provide insight for health care providers to understand family system issues in experiences and coping that affect interactions with the individual who has sustained severe acquired brain injury. The writer believes that the incorporation of grief and coping based therapeutic interventions would benefit family members who have been affected by severe acquired brain injury.

Data Related to Existing Support Networks

The analysis of data gathered from Part One Section B Question 10 (APPENDIX B) addresses the issue of existing support networks accessible to family members. "WHO DO YOU RECEIVE EITHER PRACTICAL AND/OR EMOTIONAL SUPPORT FROM? INCLUDING FAMILY (PARENT, SPOUSE, SIBLINGS OR CHILDREN), FRIENDS OR OTHER FAMILY MEMBERS. PLEASE

DESCRIBE YOUR SUPPORT NETWORK INDICATING WHAT KIND OF SUPPORT IS MOST HELPFUL TO YOU.

TABLE 10
TYPE AND SOURCE OF INFORMAL SUPPORT NETWORK

TYPE AND SOURCE OF SUPPORT	NUMBER
Practical Support	16
Emotional Support	3
Church Community	1
Spouse	13
Sibling	6
Parents	13
Deer Lodge Centre Staff	16

The data in Table 10 indicates that 100% of respondents have received practical support yet only 18.75% feel that they have received emotional support. The research in the area of perceived burden presented in *The Effects of Severe Head Injury on Patient and Relative within Seven Years of Injury* (Brook, 1987) indicates that "the distribution of scores is skewed towards the high burden end, with 89% of relatives reporting either medium (37%) of high (52%) burden and only (11%) low. This suggest that the strain of the injury for close relatives does not reduce over seven years (Brooks, 1987, p. 6)

Given the devastating effects of severe acquired brain injury on the family system the 81.25% of respondents who felt that emotional support has not been provided is an unexpected result. The writer believes that the perceived burden scores for the population on the Neurosupportive Care Unit would be similar to those noted by Brooks (1987) especially since 81.25% of the family members feel that no emotional support has been provided. The data obtained related to family perceptions of support and counselling is invaluable in terms of clarifying family members needs to increase the percentage of family members who receive emotional support and counselling.

Respondents noted a decrease in scope of their support network as length of time from initial accident increased. This suggests increased isolation and highlights the need for increased emotional support.

The area of support from staff reflected some dissatisfaction in some respondents. There was frustration expressed related to staff responses to concerns expressed by family members, including minimizing issues resulting in decreased effective communication:

"I don't feel we get much if any support from the staff on his ward"

"We have the perception that our concerns are minimized and chalked up to emotional responses because we aren't coping."

"There are some health care issues that need to be dealt with on his ward before we would ever feel comfortable to not check on him daily" (Summary of Questionnaire Responses. 1996.).

As providers of health care the data from the survey would indicate that there is a need to remember and respect individual grieving and coping styles because in long term care the facility becomes an extension of the system that the family must interact with:

For most families the vigil over the patient begins at the time of injury and they do not give up hope for recovery even if they are pragmatic about the patients present condition. They are, after all, frequently the patients best advocates and generally view the situation from broader perspective than medical prognosis and management. Families react to the patient as a person with whom they have a long and intimate history (Jacobs, 1987, p. 59).

Harvey Jacobs (1987) examines family reactions to staff treatment where post coma unawareness has affected family functioning. The questionnaire responses outlining dissatisfaction with care are similar to reactions of family members noted in the literature:

Family reactions to staff treatment and the facility will generally be related to their interpretation of the patient's progress ... When the patient shows no specific markers of progress, the family will often focus on some concrete aspect of treatment as the "cause" for the patient's failure to continue recovery. Frequently the cause will have no direct relationship to treatment but will be selected because of its' conspicuous or correlative nature ... In other cases families may search for problems within the facility that can be blamed for lack of progress. This can include the frequency of therapeutic protocols, physician visits, a special diagnostic procedure that they recently heard about, diet or other external issues ... Few families are willing or able to accept the role of fate, inconclusive medical evidence or their own lack of control over the patient's destiny (Jacobs, 1987, p. 59-60).

The writer believes that the data collected from family members expressing dissatisfaction with care is related to grief and loss issues as indicated in the quotation above. There is a need to utilize practicum data related to family perceptions of support and counselling to develop increased skill in assisting family members to cope and deal with emotional and psychological issues that emerge and re-emerge over time.

Data Related to Knowledge of Acquired Brain Injury

Part Two - Section A of the questionnaire (APPENDIX B) was designed to gather data related to knowledge of acquired brain injury as well as exploring the current information and education needs of family members related to acquired brain injury.

TABLE 11

SOURCES OF INFORMATION UTILIZED BY FAMILY MEMBERS

SOURCE OF INFORMATION	NUMBER USING SOURCE
No Information Provided	4
Doctors with no Follow-Up	8
Manitoba Head Injury Association	8
Own Research (library/internet)	12
Deer Lodge Centre	4
Word of Mouth	2
Nurse	1
Physiotherapist	1
Occupational Therapist	1
Social Worker	3
Family	4
Friends	1
Not Applicable	2

The questionnaire responses indicated that 75% of respondents carried out their own research with 50% using information from doctors and the Manitoba Head Injury Association Incorporated and 25% accessing information through Deer Lodge Centre staff or family members. The data

suggests that they received general information related to acquired brain injury that was vague and for the most part inadequate, as the focus was on acute crisis state with poor follow-up in relation to long term care and outcomes. Family members recognized that it must be "depressing" for hospital staff to articulate expected outcome. "I felt abandoned after the crisis phase in Intensive Care" (Summary of Questionnaire Responses, 1996). The family members are continuing to search for more information on long term outcomes for individuals with severe acquired brain injury:

 Serious brain injury is an unwelcome and uninvited event not only for the person incurring it but for that persons family. The injury may take only an instant to occur, while the recovery process may take months or years and never be complete ... Thus traumatic brain injury is both an acute and chronic impairment, with attendant difficulties affecting both the designated patient and that person's significant others (Romano, 1989, p. 33).

 There is a need to ensure that information is provided repeatedly to family members as they are often in a state of shock for a prolonged period of time. When faced with tragedy and adversity individuals may or may not incorporate information shared:

Be honest with family members but keep in mind that what we have to say may be very painful to hear and therefore be misunderstood or repressed); Their eternal hope for the patients recovery may be a necessary ingredient for their emotional survival (Jacobs, 1987, p 61).

Based upon the data displayed in Table 11 health care professionals need to enhance individual and family adjustment and coping through increasing knowledge of family members. This will ensure that family members are not operating on myths or hearsay information. This is an area of health care practice that needs to be developed.

Follow-Up on information sharing experiences

DID YOU HAVE AN OPPORTUNITY TO ASK QUESTIONS OR RAISE CONCERNS AFTER YOU HAD LISTENED TO OR REVIEWED THE INFORMATION?

The follow-up on information sharing experiences is crucial to ensure effective open communication. Without follow-up the family members may perceive the door to be closed. There is a need to recognize that the family members are unlikely to bring forth questions if they are afraid of what the answers might be. Two (12.5%) of the respondents indicated that this information and education portion was not applicable to their situation. The data analysis will be based upon fourteen respondents for whom this

question was applicable. When asked if they had an opportunity to raise questions or concerns after listening to and reviewing information eleven (78.57%) of respondents received follow-up with three (21.4%) receiving no follow-up.

When asked about comfort levels in terms of asking questions or raising concerns during follow-up two (12.5%) provided no response, eleven (78.57%) indicated a comfort level in raising questions and one (6.25%) did not feel comfortable asking questions or raising concerns.

The tables and narrative responses highlight family members' experiences in the area of information gathering and sharing experiences:

"Information given only if you ask, that is assuming you know what to ask".

"I don't know what to ask".

"It's easy to talk to Deer Lodge Centre Social Worker".

I am a health care professional so I am not afraid to ask questions, but I know what to ask".

"At Deer Lodge I feel free to ask questions, but not the same in acute care"

(Quotations from Questionnaire Responses. 1996).

The data displayed in Table 11 (Practicum Report, 1997, p. 97) in conjunction with the data analysis and narrative responses indicate that 78.57% of respondents are receiving the information and education related to acquired. 21.43% are not receiving the information that they require.

Ongoing information sharing and education are essential as the patients condition is maintained or changes. The data collected in the area information gathering and sharing experiences will be utilized as a portion of the development of an ongoing information sharing and educational strategy.

The second portion of the data to be utilized in developing an information and educational strategy was gathered through the narrative responses to the question "IS THERE ANY INFORMATION OR EDUCATION RELATED TO ACQUIRED BRAIN INJURY OR OTHER HEALTH CARE ISSUES AFFECTING YOUR FAMILY MEMBER THAT YOU HAVE QUESTIONS ABOUT AT THE PRESENT TIME?". Six (37.5%) respondents indicated that they required no more information or education and there was no written response on one (6.25%) questionnaire:

"I would like to have a better understanding of mom's state of mind".

"I want to know how to prevent a brain aneurysm in myself and in my family".

"Are there any new treatments or cures in Europe or the United States".

"Are there any new exercises to reconnect the brain nerves".

"Why is there no rehabilitation for brain injury to prevent deterioration not as a cure".

"Poor treatment available in Manitoba".

"Will my mom's condition improve".

"I see an improvement in my son, but Deer Lodge Centre does not therefore no rehabilitation. This is not fair".

"Can miracles happen and if they can why can't one happen for my mom".

"The future for our son is bleak at best. The most we can offer as a family is our love in making him as comfortable as possible".(Quotations from Questionnaire Responses, 1996).

The narrative responses from family members request answers that are not available. There is a sense of helplessness, fear and anger expressed in the responses. The issues of prevention, treatment, ongoing rehabilitation and hopes are brought to the forefront by the narrative responses. The difficulty in addressing the questions and concerns emerges because the literature and research in the area of severe acquired brain injury resulting in post coma unawareness is almost non-existent. Therefore there are no concrete answers. The manner in which information and education are shared needs to consider the hopes and dreams of the family members. The family members who have a patient on the Neurosupportive Care Unit have had extensive experience with the medical system since the time of injury onset in particular, but they also know that there are "no sure things" when it comes to acquired brain injury recovery; there are only educated guesses based on clinical findings and diagnostic tests:

The persistent vegetative state diagnosis is also unlikely to affect the positive family expectations that have been shaped by earlier medical experiences. Most notably, the patient is likely to have already beaten insurmountable odds and earlier predictions of survival. Hence the new diagnosis becomes another challenge to overcome (Jacobs, 1987, p.57).

The development of an information and educational strategy will be based upon data collected and analyzed in conjunction with narrative responses from family members. The development of such a strategy will pose a challenge due to limited and inconclusive research in the area of survival following severe acquired brain injury combined with family members hopes, dreams and previous health care system experiences.

Needs Assessment of Social Work Services

One of the objectives of this practicum report involved conducting a needs assessment related to the effectiveness of Social Work Services being provided to individuals and their families on the Neurosupportive Care Unit at Deer Lodge Centre. Part Two - Section B (Appendix B) of the questionnaire was focused on gathering data related to this objective. Data has been based upon 16 responses from family members whose demographics have been reported.

1) SOCIAL WORKERS CAN OFFER BOTH PRACTICAL AND EMOTIONAL SUPPORT. WHEN YOUR FAMILY MEMBER WAS INITIALLY HOSPITALIZED DID YOU HAVE CONTACT WITH A SOCIAL WORKER? IF YES PLEASE DESCRIBE THE NATURE OF YOUR INTERACTION(S) AND WHAT WAS HELPFUL OR NOT.

TABLE 12

SUMMARY OF SOCIAL WORK INTERACTIONS IN ACUTE CARE

RESPONSE	NUMBER
No Response	2
No Contact in Acute Care	3
No Contact Long Term Care	2
Contact in Acute Care	9

Written responses focused on the practical nature of Social Work in acute care. The respondents noted minimal support after practical issues (finances and placement) were resolved. There was no mention of counselling. The data displayed in Table 12 portrays similar experiences to the data presented in Table 10 (Practicum Report, 1997, p. 93). The formal support network in the health care system is providing the practical support required but there is no emotional support being perceived by family members. The perceptions have implications for provision of support in acute care and long term care facilities and for the interdisciplinary teams providing care to patients with severe acquired brain injury and their family

members. The data collected in relationship to family members perceptions of support and counselling will provide guidance in meeting the emotional needs more effectively.

2) IN RETROSPECT, WAS THERE SOME SORT OF SOCIAL WORK ASSISTANCE THAT COULD HAVE BEEN PROVIDED THAT WAS NOT MADE AVAILABLE TO YOU WHEN YOUR FAMILY MEMBER WAS INITIALLY HOSPITALIZED?

The narrative responses in relation to this question were limited with two (12.5%) respondents stating "I don't know" and three (18.75%) respondents providing no data.

"Once Social Work involved at Deer Lodge felt feelings of desperation were acknowledged"

"Patient became focus at Deer Lodge , not injury"

(Quotations from Questionnaire Responses. 1996).

Respondents in general noted the need for individual as opposed to family counselling. There was a strong indication for a need to actively follow-up and encourage counselling as opposed to client coming forward alone once initial offer has been made for counselling. The provision of effective Social Work service can be enhanced based upon results obtained

for limited responses and results of perceptions of support and counselling data analysis.

3) WHEN YOUR FAMILY MEMBER WAS ADMITTED TO THE NEUROSUPPORTIVE CARE UNIT AT DEER LODGE CENTRE DID YOU HAVE CONTACT WITH A SOCIAL WORKER? IF YES PLEASE DESCRIBE THE NATURE OF YOUR INTERACTION(S) AND WHAT WAS HELPFUL AND WHAT WAS NOT.

I) PRACTICAL ASSISTANCE (FOR EXAMPLE ACCESSING RESOURCES, COMPLETING DOCUMENTS)

TABLE 13

**SOCIAL WORK RELATED PRACTICAL ASSISTANCE EXPERIENCES AT
DEER LODGE CENTRE**

RESPONSE	NUMBER
No Response	2
Accessed Government Assistance	10
General Tours and Orientation	6
Accessed Unemployment Insurance	3
Decreased Feeling Burden	5

The data indicates that 81.25% of family members were still in the process of accessing financial assistance through government and

unemployment benefits after a median length of time since injury onset being seven and one half years. Since financial concerns are a source of stress that affect coping styles, these issues need to be addressed in an expedient manner to decrease stress and burden in this area. The data indicates that 37.5% of family members spontaneously noted general tours and orientation contact experiences. 31.25% of respondents expressed decreased feelings of burden. The data displayed in Table 13 suggests Social Work interventions related to practical assistance issues were provided.

II) EMOTIONAL/PSYCHOLOGICAL SUPPORT

TABLE 14

**SOCIAL WORK RELATED EMOTIONAL AND PSYCHOLOGICAL
SUPPORT EXPERIENCES AT DEER LODGE CENTRE**

RESPONSE	NUMBER
No Response	2
Written Responses	14

"Our Social Worker shows genuine love and care for patients and their family members on 5E"

"Compassion tremendous support to our family"

"No contact since before admission to Deer Lodge Centre"

"I have received no emotional or psychological support from Social Worker"

"Offsets poor image of nursing staff"

"Always available when sought out"

"Made us feel at ease"

"I have received no emotional or psychological support from Social Worker"

"No contact with Social Worker since before admission"

"Social Worker provided much emotional support. She was always sincere,
friendly and dependable"

"I did not receive or seek out support"

"I did not seek out any support and I was not sought out"

"Limited support only"

"Genuine caring and support provided"

"I was supported through both formal and casual discussions"

(Quotations from Questionnaire Responses. 1996).

Feedback received in this question will assist the writer in ensuring that family members are approached individually and repeatedly by the writer to ensure issues do not go unresolved.

The practicum objective involving conducting a needs assessment related to the effectiveness of Social Work Services being provided to individuals and their families on the Neurosupportive Care Unit at Deer

Lodge Centre was addressed partially through Table 13 (Practicum Report, 1997, p. 106) and Table 14 (Practicum Report, 1997, 107) in conjunction with the narrative responses and data analysis. This practicum objective will be explored in more detail through family perceptions of support and counselling that will be utilized to develop efficient and effective Social Work services.

4) IN YOUR OWN WORDS, PLEASE DESCRIBE WHAT SUPPORT MEANS TO YOU?

There were 15 (93.75%) responses articulating perceptions of support received. One (6.25%) respondent did not address this question:

"Support means showing concern. Support means providing information about care, about long term well being (non-medical). Support means answering or finding answers to questions we might have about what is available etc."

"My idea of support is help that you can rely on or can turn to when you need to. It is also being able to trust those who are your support and know that your concerns and pains are confidential"

"Listen to me, not necessarily give me advice. Be there when needed"

"Support means help with (and not necessarily physical) the tasks at hand. Support can be advice, backing etc."

"Support to me is someone you can talk to and they will listen. Also offer you advice. Someone who is there to provide you with answers for questions you may have. It's like someone who is on your side instead of against you."

"Support means to me is to have someone there for you to boost your morale. For example:

- a) to have someone sitting with you while you are waiting in the sitting room of the Intensive Care Unit taking turns seeing your loved one.
- b) To have that someone who is willing to give.
- c) That someone who is willing to drive you to the hospital when you are beyond exhaustion
- d) To get a phone call and know that someone does care."

"Support is being there to provide a listening and empathetic ear."

"Taking time to inform me of progression or regression especially telling us that family member is content to know that his son is well cared for. Nurses being helpful in terms of family."

"An opportunity to share feelings, vent frustrations, ask questions, reaffirm coping strategies, shed feelings of helplessness and receive information about community resources where one can continue to do above on a regular basis."

"Being able to talk to doctor, nurses, Social Worker, friends and family."

"A willingness to be involved by listening and speaking , and knowing when to do and not do both."

"Support to me is when a person freely gives of their time to help, whether it is to talk or listen and knowing when to do either or just 'BE THERE'."

"Friends and family listening to your feelings and emotions. Someone who can relate or understand."

"To me support means a person or a group of people who assist a person or family in coping with a particular problem in order to gain a better understanding to better grasp the reality of the situation at hand. In assisting, the person is kind, compassionate, understanding, listening to all sides of the problem, taking into consideration the possible effects of the situation (trauma) may have on individual family members. Support is someone explaining the whole truth of the problem step by step in layman's terms to people concerned. Being there for the family someone when they request support or even if they don't request support."

"Support comes in many forms. I believe it means to be there for someone else in a way which would help them to cope with a situation. Being a friend or confidant or a shoulder to lean on are all supportive."

(Quotations from Questionnaire Responses. 1996.).

The narrative responses related to the perception of support suggest that support involves someone to listen, to talk to and to share information and feelings with in an non-threatening manner. Advice, recommendations, resolution and problem solving were mentioned in some narrative responses but were not a consistent thread throughout

the responses. Addressing issues related to advice, recommendations, resolutions and problem solving may be dealt with on an individual issue scale. Often the health care system aims to provide answers and to assist others to 'feel better', to help them cope and move forward in their lives. This may or may not be what the family members need. Some of the narrative responses suggest a need for unconditional acceptance to facilitate their ability to cope and function in the face of profound loss. The narrative responses indicate a changing need for support over time as the support required does not remain in a static state. A recognition of changing needs and reclarification of support perception over the length of time of the professional relationship with family members is necessary to ensure the provision of efficient and effective Social Work services. One quotation in particular summarizes the perceptions for the writer, a willingness to be involved by listening and speaking, and knowing when to do and not to do both (Quotation from Questionnaire Responses, 1996).

5) IN YOUR OWN WORDS, PLEASE DESCRIBE WHAT
COUNSELLING MEANS TO YOU?

There were 15 (93.75%) responses articulating perceptions of counselling received. One (6.25%) respondent did not address this question

"Counselling helps to provide an understanding. Counselling provides a means to help individuals to reach an understanding and satisfaction with that understanding"

"Counselling is talking about problems that you have to deal with in the context of solving them."

"To listen to me; to show me different ways of looking at situations; to give me advice as needed or asked for. Also providing me information to help me make decisions."

"Counselling is a bit more abstract. It could be guidance/suggestions to help change troubling or unreasonable responses to events/situations by qualified people."

"Counselling is someone talking to you and educating you."

"Counselling means to me someone who gives you advice. Counseling was offered to me in the acute care center but I had not attended any meetings. My best counsel was my loving family and extended family. Their advice kept my sanity and helped me to take one day at a time. Advice from some caring nursing staff and Social Worker was also helpful."

"Counselling is provision of strategies to deal with grief loss and rebuilding."

"Never received any counselling."

"An occasion to share feelings, vent frustration, ask questions and reaffirm coping strategies with professional guidance relative to how one can deal with these issues in the most positive way."

"Counselling helped with all my mixed feelings and gave me courage to carry on."

"Listening to and understanding problems, offering advice, guidance and possible solutions. Provide direction to available services."

"Counselling to me means firstly to listen, secondly to offer advice if possible and thirdly - if not advice - perhaps just guidance in the right direction."

"Sorting out your feelings and emotions."

"Counselling means assisting a person/family in coping with their grief related to the accident/death/situation of their loved one. To listen to guide the person/family towards a state of well being and understanding of the reality of the situation and it's repercussions over a period of time on the lives of those involved. To console those most hurt emotionally by the tragedy of losing a loved one in such a distasteful disaster. Counselling is gathering all the immediate family and explaining step by step the best ways to go on living and dealing with the tragedy in a healthy and caring manner. To be available to individuals in time of need and to help them go beyond blame and to grasp the reality of the situation and its' long term tentacles of emotional grief which are so far reaching."

"Counselling is verbal communication you give to another individual to assist or advise someone on a subject for which they require more information."

"(Quotations from Questionnaire Responses, 1996).

The narrative responses obtained and analyzed provide a foundation for understanding the counselling perceptions of family members which will assist in the development of intervention strategies. The family members perceptions of counselling depict a picture of moving beyond support to resolution and coping skill development. The narrative responses indicate that counselling involves active listening in relation to multiple feelings being experienced, providing alternative frameworks for interacting and coping with multiple systems and emotions. The respondents also noted education and information sharing as being part of the counselling experience. Throughout responses grief and loss issues were articulated as areas of need for intervention. One family member noted a counselling experience involving "Counselling is provision of strategies to deal with grief loss and rebuilding" (Quotation from Questionnaire Responses, 1996).

The narrative responses related to counselling perceptions reinforced the need for using grief, loss and coping theoretical perspectives in intervention strategies.

6) IS THERE SOME TYPE OF SOCIAL WORK ASSISTANCE THAT COULD HAVE BEEN PROVIDED TO YOU AT DEER LODGE CENTRE THAT HAS NOT BEEN PROVIDED? PLEASE DESCRIBE.

There were six (37.5%) questionnaires returned with no responses and ten (62.5%) questionnaire responses for this question.

"I think in our case we received adequate Social Work assistance."

"In my personal opinion, I do not feel there is Social Work assistance that could have been provided to me that was not provided, but I know that our family has been very independent and has not sought out external support."

"Not that I am aware of at this time."

"Maybe more support to family members who are trying to cope with this. I would like to see more programs geared for brain injured patients instead of just writing them off."

"I have no idea what was available to me or what should have been provided for me at time of admission or at a later date."

"I am unable to comment on this as I am unaware of what is available. I personally do not require input from Social Worker at this time related to support or counselling."

"No not at the present time. We are satisfied with the assistance to date."

"Independent counseling may have helped but I don't know how responsive I would have been at the time of my mother illness."

"It would have been helpful if all family members had been informed when my sister was moved to Deer Lodge Centre. Ongoing updates to family would have

been helpful as there is not free flowing communication within our family system."

"Not that I am aware of."

(Quotations from Questionnaire Responses, 1996).

The narrative responses indicated a lack of knowledge as to what services could be provided by a Social Worker which is an area that could be addressed through the information and educational strategy. The issue of Social Work service provision was addressed in detail in Table 12 (Practicum Report, 1997, 104), Table 13 (Practicum Report, 1997, 106) and Table 14 (Practicum Report, 1997, p. 107.). The narrative responses provided limited information in this area but did highlight a need for individualized as opposed to family oriented services.

Summary

The data reported on in the Chapter 4 portrays a specific demographic population, clarifies the knowledge base of family members related to acquired brain injury, examines family members Social Work related experiences and needs and summarizes perceptions of support and counselling. The questionnaire data analysis leads to the development of approaches for provision of information and education. The data indicates a need to provide specific Social Work interventions utilizing grief and loss

theories and interventions to meet changing and ongoing needs of family members on an individuals basis.

CHAPTER 5

IMPLICATIONS AND RECOMMENDATIONS

Introduction

The implications of the program evaluation, the data collected and analyzed and their relationship to the practicum objectives will be summarized and compared to existing research and literature throughout this chapter. The writer hopes that the findings can be utilized by other Social Workers and health care providers where severe acquired brain injury has had a profound impact on both patients and family functioning:

Traumatic brain injury is both acute and chronic impairment with long term difficulties affecting both the patients and members of the patients family ... Because of the impressive advances in the fields of medicine and technology in the last decade, there has been a significant increase in the number of survivors with traumatic brain injury (Florian & Katz, 1991, p. 267).

Implications of Demographic Data

The data collected from survey responses indicates that the patients on the Neurosupportive Care Unit were young economically active adults with a majority being men (61.5%) which is consistent with literature. The demographic data collected depicts profiles similar to that portrayed in the

literature. In future research endeavors the writer would recommend collecting data related to socio-economic status prior to the onset of acquired brain injury.

The data indicates that 69.2% of patients were residing in Winnipeg prior to hospitalization. There were 50% of the family members residing in rural Manitoba at the time that the survey was conducted when only 23% of patients resided outside of Winnipeg prior to injury onset. The logical research opportunity that emerges involves exploring the need for specialized programs in rural Manitoba.

The population on the Neurosupportive Care Unit creates a unique pattern related to the cause of acquired brain injury indicating that only 7.69% of patients on the Neurosupportive Care Unit sustained acquired brain injury in a motor vehicle accidents with a further 23.07% sustaining acquired brain injury from assaults, falls or other traumatic causes. An additional 61.5% of patients sustained acquired brain injury from strokes, cardiac arrests or other anoxic causes. The cause of acquired brain injury for the patients on the Neurosupportive Care Unit is different than the causes delineated in the literature with the focus on motor vehicle accidents, assaults and the role of alcohol in injury onset. Future research endeavor could examine the role of alcohol or other chemicals in relation to the onset of acquired brain injury to elicit more comparative data.

The most startling and frightening statistic emerged in the Anoxic Other category with four out of the six or 30.77% of the total patient population sustaining acquired brain injury through suicide attempts:

Whether suicide is preceded by threats or is totally without prior clues, it usually wreaks havoc among the survivors because the mind is not prepared for such a destructive event. Not only is it difficult to conceive of a family member taking his or her own life, but society as a whole provides few guidelines about how to perceive or grapple with such an event....By its very nature suicide is violent...Survivors are blatantly confronted with suicide's destructive nature (Hauser, 1987, p 62-63).

The issues emerging in the area of survival after suicide have far reaching implications for intervention within the family system and the health care system. Several clinical themes emerge when working with suicide survivors. These themes could be used in working with family members when suicide attempts have resulted in profound disability or post coma unawareness.

- 1) Surviving suicide establishes in the survivor a perpetual need to search for both physical and psychological clues as to the reason for the suicide attempt.
- 2) Whether irrational or appropriate, surviving suicide leaves a legacy of inexorable guilt.

- 3) **Surviving suicide profoundly alters one's own social relationships as a consequence of real or imagined stigma.**
- 4) **Grief following suicide is always complex and likely to be incomplete.**
- 5) **The idea of suicide as a solution to a problem becomes implanted in the mind of the survivor.**
- 6) **Suicide erodes the capacity to trust other.**
- 7) **There is a tendency to blame other family members through scapegoating behavior.**
- 8) **There is a tendency towards social isolation within the community.**
- 9) **There is a tendency towards the development of emotional estrangement's or cutoffs within the family system.**

(Dunne, 1987).

The themes presented serve as a reminder for Social Workers and other health care professionals providing support and counselling to family members. "The family is a powerful factor in recovery from suicide grief" (Dunne, 1987, p. 206).

The Neurosupportive Care Unit patients spent more time in acute care than the research demonstrates. Patients and their family members were forced into dealing with an acute care system that is based upon the medical model with the focus on diagnosis, treatment and discharge once

medical care is no longer required. Future program development strategies could consider the appropriateness of 'living' in acute care settings from both a financial and quality of life point of view.

The patient population on the Neurosupportive Care data sustained severe acquired brain injury as opposed to moderate or mild acquired brain injury. Based on the response data 84.6% of the patients on the Neurosupportive Care Unit would be considered to be in a state of post coma unawareness. This data is not consistent with general literature that focuses on mild to moderate acquired brain injury, rehabilitation and community living. Future research may examine whether cause of onset being non - traumatic causes has an effect on post coma unawareness.

The response patterns in questionnaire completion related to parents and spouses was consistent with the literature, but the findings related to sibling and adult children are unique. The results suggest ongoing involvement and contact from siblings and adult children. Future research endeavors could explore the issue of sibling and adult child reactions to severe acquired brain injury.

The demographic data related to the family members suggests that the family members who responded have a support network within their home and potentially outside of the home given the education levels attained.

The family members' visiting patterns and caregiving roles data suggests varying comfort levels in care provision, with a focus on comfort and stimulation. The writer speculates that grief and coping reactions may account for decreased questionnaire responses, the varied visiting patterns and the varying degrees of hands on care being provided. The stages of grief are set into motion without total resolution because death does not occur. The writer believes that the incorporation of grief, loss, coping and suicide based therapeutic interventions would benefit family members who have been affected by severe acquired brain injury.

Implications of Findings Related to Educational and Support Needs

One of the objectives of this practicum report was to conduct a needs assessment related to the effectiveness of Social Work Services being provided to individuals and their family members on the Neurosupportive Care Unit at Deer Lodge Centre. To begin this process the writer collected data on family perceptions of practical and emotional support provided through informal and formal networks and discovered that 81.25% of respondents felt that emotional support had not been provided through their family, their church community or through Deer Lodge Centre staff.

In terms of Social Work provision of practical and emotional support in acute care the responses focused on the practical nature of Social Work

interventions. There was no mention of emotional support being provided. This finding is consistent with the research that examines perceived burden in family members following acquired brain injury. The writer believes that the perceived burden could be explored for future research.

The data indicated that family members experienced a decrease in scope of their support network as length of time from initial accident increased. This finding is consistent with the disability literature in general and highlights the need for the development of alternative and continuing support networks.

The data suggests that the family members received general information related to acquired brain injury that was vague and for the most part inadequate as the focus was on acute crisis state with poor follow-up in relation to long term care and expectations. The family members are continuing to search for more information on long term expectations and prognosis for individuals with severe acquired brain injury.

There is a need to ensure that information is provided repeatedly to family members as the family members are often in a in a state of shock for a prolonged period of time. When faced with tragedy and adversity individuals may not incorporate information shared. The follow-up on information sharing experiences is crucial to ensure effective open communication. The current educational needs of the family members were

explored with the issues of prevention, treatment, ongoing rehabilitation and hopes being brought to the forefront. The development of an information and educational strategy will pose a challenge due to limited and inconclusive research in the area of survival following severe acquired brain injury when combined with family members' hopes, dreams and previous health care system experiences. Ongoing assessment of need for education could occur to ensure effective service provision in order to enhance individual and family adjustment and coping through increasing knowledge.

Implications of Needs Assessment Related Social Work Services at Deer Lodge Centre

The data indicates that 81.25% of family members were still in the process of accessing financial assistance through government and unemployment benefits upon admission to Deer Lodge Centre. Financial concerns are a source of stress that affect coping styles. The issues need to be addressed in an expedient manner to decrease stress and burden in this area. The data suggests Social Work interventions related to practical assistance issues were provided and found to be helpful.

The responses related to the provision of emotional support provided by the Social Worker at Deer Lodge Centre further highlights the perception of limited emotional and psychological support being provided.

The data suggests a need for individual as opposed to family counselling and a need for active follow-up and initiation of support and counselling as opposed to client requesting. The provision of effective Social Work service can be enhanced based upon results obtained.

The narrative responses related to the perception of support suggest that support involves someone to listen, to talk to and to share information and feelings with in a non-threatening manner. Some of the narrative responses suggest a need for unconditional acceptance to facilitate their ability to cope and function in the face of profound loss and a changing need for support over time. Exploring support perception and needs over time would enhance Social Work service provision.

The data collected on counselling perceptions will be invaluable in creating intervention strategies. The perceptions expressed articulate movement beyond support to resolution and coping skill development, education and information sharing. The family members referred grief and loss issues as areas of need for intervention. The narrative responses related to counselling perceptions reinforced the need for using grief, loss and coping theoretical perspectives in intervention strategies.

The responses obtained in relation to current support and counselling needs suggest a lack of knowledge in relation to what services could be

provided by a Social Worker. This is an area that should be addressed through the information and educational strategy.

Summary

The age of onset for the Neurosupportive Care Unit patients was similar to the profiles delineated in the literature yet the cause of the severe acquired brain injury, the profound physical and cognitive sequelae and the length of stay in acute care different from the literature in this area.

There are varying degrees of family involvement both in visiting patterns and in the provision of hands on care. Each individual family member will grieve, adjust and cope in a different manner which may account for varying levels and patterns of involvement.

The development of an educational strategy related to severe acquired brain injury resulting in post coma unawareness poses a challenge as there are no concrete simple answers related to outcome and prognosis. Educated guesses are the best that can be provided.

The questionnaire data provides a basis for developing specialized approaches to assist patients and family members affected by severe acquired brain injury. Social Work interventions utilizing theoretical perspectives on grief, loss, coping and suicide could be used to meet changing and ongoing needs of family members on an individuals basis.

CHAPTER 6

CONCLUSIONS

Introduction

The purpose of Social Work is to mediate person in environment interaction through enhancement of problem solving coping and developmental capacities of individuals. There is an inherent belief within the Social Work profession that shifts focus from cause and effect relationships to "the person and the situation as an interrelated whole " (Compton & Galaway, 1994, p. 118). There is a problem solving nature to the relationship between the client and Social Worker composed of a series of interactions involving integration of feeling, thinking and doing with an expressed end goal. It has become clear that the systems perspective and problem solving goal oriented support and counselling alone are insufficient tools to provide efficient and effective Social Work service. The " families with traumatically brain injured (TBI) family member are a very difficult population to deal with because of the devastating sequelae to the TBI, because family dynamics are always changed for the worse (Solomon, 1991, p. 255).

The writer believes that the objectives of this practicum report have been met. The primary purpose behind the program evaluation was to clarify

the Social Work related needs of the family members. A formative evaluation design was used because the writer is an employee of Deer Lodge Centre. The evaluability assessment process led to an exploration of interdisciplinary ethical dilemmas that affect service provision and assisted the writer in focusing on specific program goals to be evaluated. This process led to the development of an evaluation and assessment tool design. The writer believes that skill development in the area of program evaluation, particularly the skills and tools necessary to assess the needs of a specific client population, has occurred.

The benefits of the evaluation design emerge from the narrative responses received. The written words of the family members provide insight and clarity that facilitates the development of alternate ways to provide service. The limitations in the evaluation design were related to lack of comparative data and key information related to socio-economic status and alcohol or other chemicals involvement in injury onset not being collected.

A needs assessment related to the effectiveness of Social Work Services being provided to individuals and their families on the Neurosupportive Care Unit at Deer Lodge Centre was conducted. The data collected reflects a need for emotional support and counselling. The family members felt that minimal emotional support was provided. The major

limitations in this portion of the practicum report are related to comparative data and the fact that there are no instruments designed specifically to measure knowledge of severe acquired brain injury or family needs related to support and counselling where severe acquired brain injury has impacted. Thus the writer devised, pretested and used a questionnaire to gather data related to these areas. Demographic data was also collected to ensure that information is used in relation to similar population groups.

The needs assessment findings were utilized to explore and develop intervention goals and objectives to facilitate efficient and effective Social Work services for the patients living on the Neurosupportive Care Unit and their family members. The writer developed specialized clinical skill base to enhance therapeutic interventions. Social Work interventions utilizing theoretical perspectives on grief, loss, coping and suicide will be used to meet the ongoing needs of family members on an individual basis.

The writer used the loss model (Buchanan, 1984) to explore financial concerns, health care system experiences, family role changes, reactions of others, feelings of isolation and survivor guilt. This approach facilitates increased understanding of coping skills being used and opens the door to explore coping skill development.

The writer believes that the provision of efficient and effective Social Work services to family members of individuals who have sustained severe

acquired brain injury resulting in profound disability or post coma unawareness requires using new intervention strategies.

Based the literature, the data analysis, the implications and the conclusions, the writer has chosen to create a model for Social Work assessment and intervention.

SOCIAL WORK ASSESSMENT AND INTERVENTION MODEL
FOR FAMILY MEMBERS AFFECTED BY SEVERE ACQUIRED BRAIN
INJURY

- 1) Exploration of perceived burden.
- 2) Exploration of existing support networks
- 3) Development of alternative support networks
- 4) Provision of information and education with active follow-up
- 5) Ongoing assessment of information and educational needs
- 6) Expedient provision of assistance to access financial resources.
- 7) Provision of individual support and counselling, with active follow-up
- 8) Utilization of grief, loss, coping and suicidal theoretical perspectives in intervention

The writer believes that this model will assist Social Workers and other health care providers in working with families where severe acquired brain injury resulting in profound disability or post coma unawareness has resulted.

Summary

It has become clear that the traditional systems perspective and problem solving, goal oriented support and counselling are insufficient tools to provide efficient and effective Social Work service.

There was an expressed need for individual as opposed to family counselling. There was also a strong indication for a need to actively follow-up and initiate support and counselling interventions as opposed to clients requesting assistance once an initial offer has been made for counselling. Feedback received in this area will assist the writer in changing style of approach from a laid back perspective where the writer makes an initial offer for support and counseling to a more active seeking out of clients at regular intervals to ensure that issues are addressed as time goes on.

One of the most valuable parts of the program evaluation was the realization that there are no simple answers in working with patients and family members where severe acquired brain injury has resulted in profound disability or post coma unawareness. This was reaffirmed through the

interdisciplinary team discussions where ethical questions and issues emerged. The ethical dilemmas and overriding legal issues pose a constant struggle for the interdisciplinary team and family members of the Neurosupportive Care Unit.

Based on the literature and data collected and analyzed it has become apparent that this writer needs to alter Social Work Intervention strategies to provided service to family members of the Neurosupportive Care Unit patients. Social Work assessment from a systems perspective would continue to serve as a basis for developing intervention strategies. The problem focused interventions would still be utilized in relation to practical issues but grief and loss exploration and resolution interventions would be incorporated to assist in other issues identified.

As a result of this practicum, the writer will employ new intervention techniques in the provision of efficient and effective Social Work services to family members of individuals who have sustained severe acquired brain injury resulting in profound disability or post coma unawareness

In closing this writer would like to share a poem written by a spouse of a young man who sustained severe acquired brain injury.

HEAR MY LAMENT

I can not believe it happened to ... the man I love
Oh How I pleaded that they save him!

They certainly did alright
But then I am told he will never walk or talk

I vow we will prove them wrong
Oh, How I am enraged for I have hope.

They persist in saying "Your efforts are to no avail."
But without hope I can not rationalize my sacrifices.

I visit and beg for the most expert care.
And I demand special attention and complain bitterly if they do not
comply.

They negate my perceptions of his accomplishments
But instead shatter me with "You imagine these".

I, along with the staff, grow hostile as the days linger on.
And I become sad and weary of my predicament.

They then tell me therapy is discontinued.
But he can stay while awaiting placement.

I become painfully aware I am a married widow
Left to watch him vegetate and assume his responsibilities.

My family and friends have abandoned me by now
But though I need a listening ear I know you have no time to spare

I begin to realize that there is no hope
And now I begin to scream "Why did they save him?"

Written by a spouse of a young man who died after seven years in
post coma unawareness.

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APPENDIX A**QUESTIONS USED TO FACILITATE INTERDISCIPLINARY TEAM
DISCUSSIONS RELATED TO THE EVALUABILITY ASSESSMENT -
INTERVIEWING PROGRAM PERSONNEL**

- 1) Describe the rationale for the development of the Neurosupportive Care Unit.
- 2) Describe the Neurosupportive Care Units goals.
- 3) Describe the Neurosupportive Care Units objectives.
- 4) In your opinion, are there barriers to achieving program goals and objectives.
- 5) Describe your philosophy, beliefs, and values as they relate to your professional involvement on the Neurosupportive Care Unit?
- 6) In what situation would you refer a patient or family member to a Social Worker or alert a Social Worker of concerns?

APPENDIX B

QUESTIONNAIRE
NEUROSUPPLEMENTARY CARE UNIT REVIEW OF SOCIAL WORK SERVICES

PART ONE: DEMOGRAPHIC INFORMATION

A) THE NEUROSUPPLEMENTARY CARE UNIT PATIENT

1. WHAT IS THE SEX OF YOUR FAMILY MEMBER? -----
2. WHAT YEAR WAS YOUR FAMILY MEMBER BORN IN? -----
3. WHAT IS YOUR FAMILY MEMBERS MARITAL STATUS?

SINGLE	-----	(1)
COMMON LAW	-----	(2)
MARRIED	-----	(3)
DIVORCED	-----	(4)
WIDOWED	-----	(5)

4. WHAT IS THE HIGHEST LEVEL OF EDUCATION ATTAINED BY YOUR FAMILY MEMBER?

HIGHSCHOOL	-----	(1)
COMMUNITY COLLEGE	-----	(2)
TRADE SCHOOL	-----	(3)
UNIVERSITY	-----	(4)

5. WHERE WAS YOUR FAMILY MEMBER RESIDING PRIOR TO HOSPITALIZATION?
WINNIPEG -----
RURAL, MANITOBA -----
OTHER (PLEASE SPECIFY) -----

5. WHERE WAS YOUR FAMILY MEMBER LIVING PRIOR TO HOSPITALIZATION (CHECK THOSE THAT APPLY)

HOUSE	-----	RENTED	-----
APARTMENT	-----	OWNED	-----
	-----	WITH FAMILY	-----
	-----	INDEPENDENTLY	-----

OTHER (PLEASE SPECIFY)

7. WHEN WAS YOUR FAMILY MEMBER HOSPITALIZED RELATED TO ACQUIRED BRAIN INJURY?
MONTH -----
YEAR -----

8. WHAT WAS THE CAUSE OF THE SEVERE ACQUIRED BRAIN INJURY?

- 1) TRAUMATIC
MOTOR VEHICLE ACCIDENT -----
ASSAULT -----
FALL -----
OTHER -----
- 2) ANOXIC
CARDIAC ARREST -----
STROKE -----
OTHER -----
- 3) OTHER (PLEASE DESCRIBE)

9. HOW LONG DID YOUR FAMILY MEMBER REMAIN IN ACUTE CARE BEFORE BEING TRANSFERRED TO LONG TERM CARE (NEUROSUPPORTIVE CARE)

YEARS ----- MONTHS -----

10. DID YOUR FAMILY MEMBER RESIDE IN ANOTHER LONG TERM CARE FACILITY PRIOR TO ADMISSION TO NEUROSUPPORTIVE CARE?

WHERE -----
HOW LONG -----

11. AT THE CURRENT TIME, WHAT ARE THE PHYSICAL AND COGNITIVE ISSUES BEING COPEDED WITH BY THE NEUROSUPPORTIVE CARE UNIT RESIDENT (PLEASE CHECK THOSE THAT APPLY):

TUBE FEEDING	----	VISUAL DEFICITS	----
TRACHEOSTOMY	----	AUDITORY DEFICITS	----
INCONTINENCE	----	SWALLOWING DEFICITS	----
SPASTICITY	----	COMMUNICATION DEFICITS	----
PAIN	----	COGNITIVE DEFICITS	----
FATIGUE	----	WHEELCHAIR DEPENDENT	----
CONSISTANT RESPONSE TO ENVIRONMENT	----		----
CONSISTANT FORM OF COMMUNICATION	----		----

12. IS YOUR FAMILY MEMBER RECEIVING INCOME FROM:

- MANITOBA PUBLIC INSURANCE -----
- WORKER COMPENSATION -----
- CRIMINAL INJURIES COMPENSATION -----
- PROVINCIAL INCOME SECURITY -----
- CANADA PENSION PLAN -----
- OTHER (PLEASE SPECIFY) -----

8) NEUROSUPPORTIVE CARE UNIT FAMILY MEMBER

1. WHAT IS YOUR SEX? -----

2. WHAT YEAR WERE YOU BORN IN? -----

3. WHAT IS YOUR MARITAL STATUS?

- SINGLE ----- (1)
- COMMON LAW ----- (2)
- MARRIED ----- (3)
- DIVORCED ----- (4)
- WIDOWED ----- (5)

4. WHAT IS YOUR RELATIONSHIP TO YOUR RELATIVE LIVING ON NEUROSUPPORTIVE CARE AT DEER LODGE CENTRE?

- PARENT ----- (1)
- SPOUSE ----- (2)
- SIBLING ----- (3)
- ADULT CHILD ----- (4)

5. WHAT IS THE HIGHEST LEVEL OF EDUCATION YOU ATTAINED?

- HIGHSCHOOL ----- (1)
- COMMUNITY COLLEGE ----- (2)
- TRADE SCHOOL ----- (3)
- UNIVERSITY ----- (4)

6. WHERE ARE YOU CURRENTLY RESIDING?

- WINNIPEG -----
- RURAL, MANITOBA -----
- OTHER (PLEASE SPECIFY) -----

7. ARE YOU LIVING IN (CHECK THOSE THAT APPLY)

- HOUSE ----- RENTED -----
- APARTMENT ----- OWNED -----

- WITH FAMILY -----
- INDEPENDENTLY -----

OTHER (PLEASE SPECIFY)

8. HOW OFTEN DO YOU VISIT YOUR FAMILY MEMBER?

- MONTHLY -----
- DAILY -----
- OTHER (PLEASE SPECIFY) -----

APPENDIX C**TO WHO IT MAY CONCERN:**

I am Lisa Lloyd-Scott and I have been the Social Worker providing services to the Neurosupportive Care Unit at Deer Lodge Centre since May of 1991.

I am currently studying towards a Masters degree in Social Work through the University of Manitoba. To date I have completed the necessary course work and the final step that I need to qualify for my degree is to complete a Practicum. The project I have chosen is to evaluate the Social Work related needs of the patients of the Neurosupportive Care Unit and their family members.

I have prepared a series of questions related to demographic information about you and your family member as well as specific questions related to your knowledge related to acquired brain injury and Social Work service and your needs.

In order to ensure anonymity of those who complete the questionnaires I have enclosed two separate envelopes. One to contain the demographic data and another to contain service needs information that can be sent back

to me. The data collected will be treated confidentially and all returned questionnaires will be destroyed once the data has been analyzed.

Please understand that your participation in completing the questionnaires is strictly voluntary. You are under no obligation to complete the questionnaire and there will be no adverse effects for not returning the questionnaire.

The information collected will be utilized to provide efficient and effective Social Work interventions to the patients and family members of the Neurosupportive Care Unit.

Once the practicum report has been completed the information collected will be made available to all patients and family members either in writing or through meetings on the Unit that will be posted in advance.

If you agree to participate please complete the two sections of the questionnaire and return them in the self addressed envelopes.

If you have any questions or concerns please do not hesitate to contact me at 831-2194.

Thank you for your assistance in this project.

Sincerely,

Lisa Lloyd-Scott