Patients' Perceptions of Their Roles in Goal Setting in a Spinal Cord Injury Regional Rehabilitation Program

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Abstract

This research study was conducted to explore patients' perceptions of their roles in setting goals in a spinal cord injury regional rehabilitation program. Goal setting is a common practice in rehabilitation, yet there is a paucity of literature exploring patients' perceptions of their roles in this process. The research was conducted using qualitative description methodology. Imogene King's theory of goal attainment was used to frame the study. Data were collected through individual interviews ($n = 13$). Transcripts of these interviews were analyzed using a content analysis process. The results of the study revealed four themes: *Visioning, Redefining, Brainstorming, and Rebuilding.* Participants envisioned their roles as setting an overarching priority goal, defining detailed rehabilitation goals, sharing knowledge with the team, and rebuilding skills to attain goals. Implications for nursing practice include the need to understand patients' experiences and perceptions, share knowledge, and support effective communication to promote collaborative goal setting.

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Table of Contents

List of Tables

List of Figures

Patients' Perceptions of Their Roles in Goal Setting in a Spinal Cord Injury Regional Rehabilitation Program

Chapter One

Introduction

Background

Spinal cord injury (SCI) is catastrophic and life altering, resulting in varying degrees of paralysis for the individuals involved. The incidence of SCI in Canada is approximately 4,529 cases yearly, with 1,786 of those resulting from traumatic external injuries (Rick Hansen Institute, 2011). Approximately 50% of those injured sustain an injury at the cervical level of the spinal cord, referred to as tetraplegia. Another 50% sustain an injury in the lower spinal cord referred to as paraplegia (Canadian Paraplegic Association [CPA], 2011a). Most traumatic SCI injuries occur due to motor vehicle accidents, sports injuries, or falls, while other causes include compression of the spinal cord related to metastatic lesions, abscesses and various degenerative changes (Rick Hansen Institute, 2011). Males represent 80% of those who sustain a SCI and at present 84% are under the age of 34 years (CPA, 2011a). While the unemployment rate for those who have sustained a SCI is 62% (CPA, 2011a), additional financial burdens are associated with significant increases in the cost of living and health care expenses directly related to SCI. United States statistics report a cost of $801,161.00 in expenses for persons with a C1-C4 (within the top four cervical segments of the spine vertebrae) level of injury in the first year following injury. The average yearly cost thereafter is predicted to be approximately $143,507.00 (National Spinal Cord Injury Statistical

Center [NSCISC], 2009). The life altering consequences of sustaining a SCI has significant impact on the individual involved, their family and resources. Rehabilitation following such an injury is necessary to allow individuals to return to community living in as full a capacity as possible.

Phenomenon of Interest

While rehabilitation may continue for SCI patients following discharge from the program, the phenomenon of interest in this study is the experiences of the interactive process of goal setting that occurs while they are inpatients in a rehabilitation setting. During rehabilitation, SCI patients are expected to act as partners with the health care team in identifying their goals, working towards achieving those goals, or modifying the goals as necessary (Holliday, Antoun & Playford, 2005; Hurn, Kneebone & Cropley, 2006; Khan, Pallant &Turner-Stokes, 2008).

The Research Team

Researcher

The researcher in this study has been actively involved in the SCI rehabilitation program for over 24 years, and has participated in initiatives to promote patient engagement. She began her career as a rehabilitation nurse, providing bedside care for patients who had sustained a SCI, and was moved by the many challenges faced by this patient population. She has also been amazed at the resiliency shown by these individuals as they worked to return to the community. Over the years of her practice, she has taken on various roles in the team, including acting as SCI physiatrist support for four years, and at present, filling the role of clinical education and development clinician within the team. Given the researcher's longstanding association with the SCI rehabilitation program, it was of vital importance to undertake the process of bracketing in the early process of data review and analysis. Bracketing was initially associated with the qualitative methodology of phenomenology, but has gained acceptance with other qualitative methodologies (Gearing, 2004). It is defined as "the process of identifying and holding in abeyance preconceived beliefs and opinions about the phenomenon under study" (Polit & Beck, 2008, p. 228). Field notes completed following participant interviews helped the researcher identify preconceptions. Bracketing was also enhanced by reflective journaling.

Co-investigators

The local research team was a group of individuals with connections to the SCI population. While the research was completed entirely by the researcher, and co-investigators did not have access to the transcription data, their input as representatives of the SCI rehabilitation community was invaluable. They were able to enhance the researcher's thought processes about the concepts emerging from the data by bringing a rich tapestry of both personal and professional experience to the discussion table. The hospital Chief of Nursing acted as the local scientific mentor. In this role, she guided the team in maintaining good clinical research practice principles and in maintaining the values that are integral to ethical research. The co-investigators included the local Canadian Paraplegic Association (CPA) peer support coordinator, a patient education specialist, and the SCI program social worker. A study volunteer who recruited participants for the study was also an active part of the research team. This study volunteer had personal experience with SCI and degenerative disease, as did the CPA peer support coordinator. They were able to offer valuable insight from both a professional and a personal viewpoint. Both the social worker, and the patient education specialist who had written much of the SCI patient education material, were able to offer insight from their professional viewpoints.

Research meetings were held with local co-investigators and the study volunteer on a regular basis to discuss the progress of the study and to allow the researcher to share an overview of the progress of the study to date. The team was able to support the researcher by offering suggestions from their unique perspectives. Given the researcher's long standing association with the program, and the potential for pre-conceptions about the research question, this was extremely valuable. It allowed the researcher to examine data with a fresh point of view and a perspective other than her own. It also strongly connected the research to the SCI community, allowing representation from both the health care team and the SCI peer population to acquire an element of ownership in the research and the utilization of the research findings.

Chapter Two

Literature Review

A literature review was conducted to understand a) current directions from government health bodies regarding expected standards for the provision of care, b) current practice of rehabilitation teams, c) the psychological impact of spinal cord injury for patients, and d) patient perspectives of goal setting in rehabilitation. A search of Health Canada, HealthForceOntario, Ministry of Health and Long-Term Care, and the World Health Organization websites allowed an overview of current directions in the promotion of patient, family and community involvement in health care. Computerized searches of CINAHL, and MEDLINE (Ovid) and (PubMed), using various combinations of keywords, 'goal setting', 'self-directed', 'patient engagement', 'spinal cord injury' and rehabilitation were conducted to search for relevant research evidence regarding patient directed goal setting in rehabilitation. The resulting information gave the researcher an understanding of factors understood to affect the patient and the social setting of rehabilitation as well as the guiding organizational factors in which the phenomenon of interest occurs.

Direction from Government Health Bodies

Importance of patient involvement. Health care has focused on the importance of patient involvement in their health care and promoted "patients as decision- makers" (Coulter, Parsons & Askham, 2008, p. 5) and as an integral part of the health care team (Coulter et al. 2008; Health Canada, 2007; HealthForceOntario, 2007). In a policy brief, written for the World Health Organization (WHO) Ministerial Conference on Health

Systems, Coulter et al. (2008) outlined evidence of the benefits of patient engagement in their health care, supporting the concept that health outcomes are improved with increased levels of health literacy, treatment decision making, and self-management of chronic disease. The authors suggested that "shared decision-making" (p.3) is a process in which patients are actively involved as partners with health professionals in the clarification of acceptable health care options and in choosing preferred interventions in medical care. Further, they suggested that "recognizing their role and seeking to strengthen it is fundamental to securing a more patient-centred approach to health care delivery" (p.1).

Promoting collaborative care in Canada. Health care in Canada supports a process of collaborative care that enhances the involvement of the patient, family and community (Health Canada, 2007). It encourages health care practice in which patients are encouraged not only to be part of the health care team, but also to be the determiner of their own autonomy in their personal health care (Health Canada, 2007; HealthForceOntario, 2007). Promoting autonomy in decision-making in health care is proposed to improve the health of Canadians and reduce health care costs (Ontario Ministry of Health Promotion and Sport, 2010). These requirements indicate an imperative for health care professionals to understand and recognize SCI and other patient roles in order to promote collaborative care and decision making.

Current Practice in Rehabilitation

Seeking patient engagement. In rehabilitation, the focus on decision-making and collaboration with the health care team has resulted in the promotion of active patient participation in setting and enabling their personal goals. Current literature has suggested wide support for this process of rehabilitation, (Holliday, et al., 2005; Hurn, et al., 2006; Khan, et al., 2008) with the intent to "actively engage patients in their rehabilitation program" (Holliday et al., 2005, p. 227). While rehabilitation facilities promote goal setting as a collaborative practice involving the patient as a partner with the team, actual practice may differ (Bloom et al, 2006; Holliday et al., 2005; Young, Manmathan & Ward, 2008). Holliday et al. (2005) conducted a survey using a postal system design to approach members of the British Society of Rehabilitation Medicine (BSRM) across a broad geographical area. The survey's emphasis was on determining the involvement of rehabilitation patients in goal setting. The survey results indicated that most goals were defined, formulated and evaluated by the rehabilitation team with minimum involvement of patients. The authors suggested there was opportunity to develop and refine an approach to goal setting that would allow greater patient engagement in the process. While rehabilitation teams seek to promote patient engagement in goal setting, there are a number of factors that may inhibit this process.

Balance of power. The balance of power that is inherent in the acute care medical community may make autonomous decision making difficult for patients as they transfer to rehabilitation and prepare for re-entry to the community (Donnelly et al., 2004; Pellatt, 2004; Wagner, Austin, Davis, Hindmarsh, Schaefer & Bonomi, 2001). Wagner et al. (2001) suggested that while there is a need to promote self-management skills for individuals who live with chronic conditions, "the patient's role" (p 65) may tend to be "largely passive" (p 65) in the acute medical model of care. Donnelly et al.

(2004) pointed out that this potential for passivity may require a significant change in focus for patients as they move to rehabilitation. The balance in power created when patients assume passive roles in acute care may continue in rehabilitation. Pellatt (2004) presented findings from a larger ethnographic study to call attention to paternalism in rehabilitation. Data in this study were collected through interviews and observation to explore both health professionals' and SCI patients' perceptions of the level of patient participation in decision making. The study was conducted with 30 health professionals and 20 patients. Pellatt found that practice continued to be shaped by "professional paternalism" (p. 948) in varying layers, and concluded that while the perception of participation in decision making was evident, it was also apparent that it rarely occurs in equal partnership.

Lack of patient and health provider concordance. One reason for unequal decision-making may be that patient and health provider goals are not in concordance in their perceptions of the patient's rehabilitation goals. Bloom et al. (2006) conducted a prospective cohort study in a Canadian rehabilitation facility to determine the level of agreement between patients with multiple sclerosis and health professionals on the identification of rehabilitation goals. Patients and health care providers were given a preset list of 55 goals, asked to rate the goals according to importance and identify the five most important goals. They were also asked to identify the level of change that would be required for significant benefit and to rate the level of likelihood of success of reaching the goal. The results indicated that there was a lack of concordance between patients and health providers in the rated importance of goals, the amount of change required to create a significant benefit and the likelihood of success. It was suggested that these findings indicated a need to improve communication between health care providers and patients in setting rehabilitation goals.

Patients as part of the interprofessional team. Interprofessional team meetings with SCI patients to discuss their goals are common practice for rehabilitation teams (Pellatt, 2004; Sinclair, Lingard, & Mohabeer, 2009; Struhkamp, 2004). Provision of care is offered through a variety of disciplines who work together to achieve these goals within "a collaborative and coordinated care plan" (Sinclair et al., 2009, p. 1198). Individual team members work with the patient separately and then meet as a group in conference with the patient to discuss the progress towards achievement of the rehabilitation goals. In current practice at the rehabilitation facility where this research was conducted, patients meet with the interprofessional team in bi-weekly conferences to discuss their rehabilitation goals.

Seeking program efficiency. While the primary focus of rehabilitation is on achieving the patient's rehabilitation goals, another strong driver in this process is achieving efficiency of care to conserve limited health care funding. Efficiency of care is measured by the achievement of changes in patient functional independence within the shortest possible length of stay. Efficiency is used by the National Rehabilitation Reporting System (NRS) as a peer comparator among rehabilitation facilities in Canada (Canadian Institute of Health Information [CIHI], 2009). The focus on providing health care in the most fiscally responsible manner may affect the patient's involvement in goal setting as health care professionals struggle in balancing the provision of health expertise in a timely fashion, and encouraging patients to take an active participatory role in their rehabilitation.

Psychological Impact of Spinal Cord Injury for Patients

Initial reaction to SCI. The emotional impact on patients sustaining such a catastrophic injury may be a significant factor for consideration. Patients, who have sustained a SCI, are asked to be active participants in the rehabilitation process in the midst of a traumatic, and often emotionally chaotic, period of time in their lives (Belciug, 2001; Lohne & Severinsson, 2004; Sullivan, 2001). Sullivan (2001) led a grounded theory qualitative study to explore the patient and family experience after SCI. She described negative psychological processes experienced by patients in acute SCI as those of "shock, disbelief, grief, depression, and uncertainty" (p. 81). Lohne and Severinsson (2004) echoed these observations in describing the experience of *hope* in the study they completed with 10 participants who had recently sustained a SCI. The researchers described the many inner emotional fluctuations between hope and despair as participants described their feelings about the uncertainty of the future and their hopes for regaining what had been lost due to injury.

Coping strategies. Belciug (2001) conducted a study with 24 patients with SCI, of which 17 were male and seven female (Mean age = 34.83 years). A measuring instrument, the *Coping Responses Inventory-Adult* developed by Moos in 1993, which measures cognitive and behavioural methods of coping was utilized. The instrument was administered approximately three months after injury while participants were in rehabilitation. The results showed that participants tended to have high scores in

"Cognitive Avoidance" and "Emotional Discharge" (p.158). This indicated that they avoided thinking about the injury and reacted to tension by exhibiting angry behavior or expressing negative comments. Belciug suggested that the coping strategies patients use to deal with "emotional loss and physiological disruptions" (p.157) during rehabilitation may create barriers to their ability to utilize the opportunities presented to them during this time.

The literature review indicates that there are inherent emotional and physiological factors that affect the patient during the period of inpatient rehabilitation which may affect their ability to engage fully in the rehabilitation process (Belciug, 2001; Holliday, Cano, Freeman & Playford, 2007; Struhkamp, 2004).

Patient's Perspective on Goal Setting

The literature review resulted in two journal articles in which researchers directly addressed the patient's perspective of goal setting. Both studies were conducted in the United Kingdom and involved a sample participant group with mixed neurological etiologies. Young, Manmathan and Ward (2008) conducted a research study, in a neurological setting, to explore perceptions of goal setting from patients, lay care givers, and staff. The research sample in the study included four groups of participants: 1) patients who were currently inpatients, 2) those who had been discharged in the last two years, 3) lay care givers, and 4) staff. Each group was comprised of 10 individuals. The researchers used content analysis to analyze data obtained through individual semi-structured interviews. They concluded that goal setting provided psychological benefit to both the patients and their caregivers.

Holliday, Ballinger and Playford (2007) used focus groups to conduct a study of patients' perspectives of goal setting using groups of patients with a variety of neurological etiologies. Six focus groups were conducted, with three focus groups attended by patients who used the facility's current standard of goal setting, and three attended by participants who had been involved in an approach that encouraged increased involvement on the part of the patient. A total of 28 participants were included in the study. The researchers suggested there was significant importance attached to the "key worker" (p. 393) involved in assisting the patient with goal setting. They concluded that there is a necessity for health professionals to explore patients' understanding of their experiences and expectations of goal setting to ensure that it is a meaningful activity.

These studies offer evidence that the goal setting process is of benefit to patients and their caregivers. The benefit is qualified by the need to clearly communicate the process and ensure that health professionals are aware of the patients' understandings and expectations of goal setting.

In summary, a gap in knowledge was identified in reviewing the literature of the patients' perspectives of goal setting. While much has been written about the benefits of goal setting from the perspective of health professionals, the researcher found a paucity of literature describing the perspective of goal setting from the SCI patient's point of view. Research that explored the patients' perspectives of goal setting used a sample of participants with different neurological etiologies and was conducted in the United Kingdom health care system (Holliday, Ballinger & Playford, 2007; Young, et al., 2008).

Significance of this Study

The literature review identified the current federal and provincial government health care bodies' foci on the provision of care that supports active patient and family participation in decision-making, while requiring efficiency in achievement of goals within the shortest length of stay (CIHI, 2009; Health Canada, 2007; HealthForceOntario, 2007; Ontario Ministry of Health Promotion and Sport, 2010). There was evidence that goal setting in rehabilitation is a widely accepted method of practice. However, research reviewed indicated that there may be incongruence between the intent of encouraging active patient participation and self-determination in goal setting and the actual practice of interprofessional teams (Holliday et al., 2005; Hurn et al., 2006; Khan et al.,2008). While there was documented evidence of the benefit of goal setting from the clinician's perspective, there was limited information about the patient's perception of this activity.

In summary, a review of the literature supported the need to explore the specific perceptions of SCI patients regarding their roles in rehabilitation, and in particular the process of goal setting, within a Canadian health care system and rehabilitation facility context. This study has potential to add valuable information to the research that has been conducted to date.

Chapter Three

Nursing Theoretical Framework

The theory which guided this research project was Imogene King's theory of goal attainment. King proposed a theory based on a conceptual framework of "dynamic interacting systems" (King 1997, p.180) which encompasses personal, interpersonal and social systems. These systems represent the individual, dyad or larger group, and social organizations, all of which interact and are impacted by their environment. King (2007) identified the environment in which these systems function as both social and physical, and stated that environment is an "essential factor in one's adaptation to life and health" (p. 5). In the rehabilitation setting, the personal system can be seen as the patient and individual health care professional, and the interpersonal system as the patient interacting with members of the rehabilitation team. The governing health bodies and social resources that impact on the patient's community reintegration can be seen as the social systems. The basic unit in each of the systems is the human being (King, 1981).

King's theory emphasizes the interaction between humans, in particular the nurse and patient, in a process of mutual goal setting (King 1981). When the health professional and patient share an understanding of the events, agree on mutually valued goals and the means of achieving those goals, it will result in a transaction. King (1981) defined transaction as "a process of interaction in which human beings communicate with the environment to achieve goals that are valued" (p. 82), and stated that successful transactions result in goal attainment.

Personal System

King (1981) identified basic concepts required to understand the personal system which she identified as the human individual. These concepts include body image, growth and development, perception, self, space and time. Body image, an individual's perspective of his or her personal body, is dynamic, changing with time and events. In this context, a traumatic event, such as a SCI, can have a significant effect on the individual's body image. Individuals' perceptions of how family and friends view them will also have an impact on their body image. Perception of self can be influenced by environmental social factors of culture, and religious and social beliefs, both of the individual and the community. Awareness of the individual's body image is a vital consideration for the health professional if the interaction with the patient is to lead to successful outcomes.

The growth and development stage of an individual is also an important factor from this theoretical perspective. King (1981) identified growth and development as "the processes that take place in an individual's life that help the individual move from potential capacity for achievement to self actualization" (p. 31). From this perspective, it is apparent that a SCI, with the high potential for lifelong loss of function, may have a detrimental effect on the individual's growth and development. For example, the requirement of care for basic functions of life can be expected to have a significant effect on a young SCI adult patient's move to greater levels of independent living. In mature adults this loss of function may result in changes in established relationships with a spouse or children, or in functioning within their established roles in society.

Perception is reality as defined by the individual, and is related to a number of factors including the person's prior experience, socioeconomic status and personal values (King 1981). Perception "gives meaning" (King 1981, p. 24) to the individual's experience and is an important consideration when providing care. The concepts of self, space and time are strongly related to the person's perception of an interaction. Individuals' perceptions of self, their personal strengths and their ability to adjust and change with changing conditions are a "key to understanding human behavior" (King, 1981, p. 26). The perception of personal space and of a time frame or period all contribute to the individual's judgment and perceptions of an interaction with health professionals. As Sieloff (1991) pointed out, time perception for a nurse may be very different than it is for the patient, particularly if the patient is the one who is waiting!

Interpersonal System

The interpersonal system reflects the interaction that occurs between two or more individuals. King (1995) identified this interaction in the nurse-patient relationship as a reciprocal relationship with the purpose of setting mutual goals and determining the means by which these goals will be achieved. This process is referred to as a "transaction process" (King, 1999, p. 295). The interpersonal system is reflected in the concepts of communication, interaction, roles, stress, and transaction (King, 1981).

King (1981) described communication as "information processing, a change of information from one state to another" (p.69), and stated that it is the "means by which social interaction and learning takes place" (p. 62). Communication can be verbal or non-verbal and must be based on mutual respect to be effective. There is a strong element of perception in communication and individuals in the interaction may view the communication quite differently. The judgment that each individual brings to the interaction, both of the situation and of the individuals involved, gives meaning to their perceptions and impacts on communication. King pointed out that there are a number of factors involved in communication including the situation, expectations and goals of the individuals, and barriers to communication (King, 1981). Health professionals must be prepared to adjust their communication methods, while keeping these factors in mind, in order to meet the needs of the individual. King stressed the importance of offering accurate health information stating individuals have a fundamental need for "usable health information at a time when he/she needs it and is able to use it" (King, 1971, p. 83).

King (1981) described how goal setting occurs in the interaction between nurse and patient. If the interaction is successful, a transaction of value will result, and the potential for successful goal attainment will be accomplished. A number of assumptions are important to the process of interaction. King identified the right of individuals to obtain knowledge, participate in decision-making, and accept or refuse health care. She stated that it was the health professional's responsibility to share information to assist patients in making informed decisions about their health care, while acknowledging that the goals of the health professional and individuals' goals may be "incongruent" (King, 1981, p. 144). King (1999) expounded on the ethical implications of her theory and pointed out the importance of acknowledging patients' rights to informed decision making, and of the preservation of the autonomy of both patient and nurse in the transaction process.

Individuals bring perceptions of their roles to an interaction. These roles are learned through previous experiences in functioning within the social system. King (2007) stated that "role knowledge" (p.8) is essential for both the health professional and patient to understand the environment and stress that is part of their interaction. Stress is a constant for all individuals and can be increased in changing or traumatic events. King (1981) stated that an increase in stress can interfere with the individual's ability to accurately perceive the situation and make rational decisions. This may affect the interaction between the health professional and the patient. King suggested that stress can be reduced through the provision of information and attention to physiological needs. In addition, facilitating goal setting by the individual and suggesting alternative ways of attaining those goals can reduce the patient's level of stress. Using skills to promote effective interactions will result in successful transactions and ultimately goal attainment (King, 1981).

Social system

King (1981) defined the social system as "an organized boundary system of social roles, behaviors and practices developed to maintain values and the mechanisms to regulate the practices and rules" (p. 115). She suggested social systems can be any organization that has elements of authority, decision making, organization, power, and status. The social system is a vital component of the interrelated systems as individuals within the social system have power to set standards and have the authority to maintain those standards. Decisions made by those in authority are made to achieve goals. King identified a number of social systems that may affect health professionals and patients. In addition to governing health care systems, these included families, public health agencies, educational and other community organizations.

In health care systems, hospital organizations reflect the supportive social systems that determine standards of practice, and have the power to make decisions that affect individual patients and hospital programs. King (1981) identified that participation in decision making, in areas that affect health care, may lead to decreased resistance to the implementation of those decisions. Power is crucial to health organizations as there is a need to manage budgets and make organizational decisions that will affect all the interconnecting systems. On the individual level, power is also evident as nurses and patients, in their respective roles, make decisions that lead to goal attainment. King stated that it is important for nurses to be aware of the power associated with their status because of their roles in health care, as this status can be beneficial as they seek to assist their patients in goal attainment.

Application to Research Study

King's theory of goal attainment, chosen as the foundation for this research study was selected for its ability to explain the interrelated personal, interpersonal and social systems within health care and, more specifically, within the context of SCI rehabilitation. The theory was useful for this study as the researcher sought to reflect on the SCI patients' perceptions of their roles in goal setting and goal attainment within the rehabilitation setting. Rehabilitation is conducted in an environment where the patient is expected to interact with individual health professionals and the health team in an interprofessional health care process. The process is impacted by the directives of the health care system which utilizes length of stay and improved functional outcomes to evaluate program efficiency. Both patients and the health care team are impacted by environmental stressors which affect their day by day performances.

Health care professionals and patients gather information from each other throughout the rehabilitation process. This information provides the foundation on which to base their plan of care, set goals, modify these goals as necessary and determine how goals can be attained. Understanding and successfully performing in this collaborative process is an important factor for patients in the recovery process throughout rehabilitation.

Effective interactions between the SCI patient and the rehabilitation team has the potential to lead to agreement on mutually set goals resulting in a transaction. Following King's theory, this transaction will lead to goal attainment and SCI patient satisfaction. In this research, the researcher examined the SCI study participants' perceptions of their roles as collaborative partners in setting and working to attain goals. King stated that the perceptions of individuals "give meaning to a person's experiences and represent an individual's image of the real world" (King 1971, p. 87). This research allowed the researcher to explore the reality of the rehabilitation experience from the SCI patients' perspectives.

Chapter Four

Research Methods

This chapter will identify the purpose of the study and the research question emerging from the review of current literature. It will outline the setting, the methodology, the sampling and the data analysis used in the study.

Statement of Purpose

The purpose of this study was to explore the experiences of patients who had taken part in a SCI rehabilitation inpatient program. In this qualitative description research study the researcher sought to explore and identify the patients' perceptions of their roles in setting personal rehabilitation goals as members of the interprofessional rehabilitation health care team.

Research Question

The research question that guided this study was: What are the patients' perceptions of their roles in goal setting within an inpatient rehabilitation program?

Research setting

The regional rehabilitation facility in which this research was conducted offers both inpatient and outpatient rehabilitation and is associated with a tertiary care, academic teaching hospital. It is one of five regional centers in Ontario offering comprehensive rehabilitation services for adults with SCI. These regional facilities all promote individualized, goal directed care supported by an interprofessional rehabilitation team (Hamilton Health Sciences, 2009; St. Joseph's hospital, 2010; Ottawa hospital, 2010; Providence Care, 2007; Toronto Rehab, 2011). The inpatient SCI rehabilitation unit at the study centre has a 13-bed capacity. Patients who have recently sustained a SCI are admitted from an acute care unit and attend the inpatient rehabilitation program for an average of eight to 12 weeks, depending on the level of injury, before returning to some form of community living.

Methodology

Qualitative description was chosen as the most appropriate research methodology for this study as it allowed for a straightforward description of the phenomenon under focus (Sandelowski, 2000). It provided an opportunity for a simple description of the SCI participants' perceptions of their roles in goal setting in rehabilitation. Sandelowski (2000) identified the distinguishing features of qualitative description including the theoretical location, the preferred methods of sampling, data collection and data analysis. She stated that qualitative description is a research methodology that requires limited interpretation. It permits the *voice* of the collective group of participants to be clearly heard in such a way that it does not move far from what is actually stated by individual members (Sandelowski, 2000; Thorne, 2008). While interpretation of data is inevitable in qualitative research, qualitative description is less interpretive than other methodologies. It identifies patterns in the collected data without focusing on the interpretation of those patterns. Thorne, Kirkham, and MacDonald- Emes (1997) suggested that acknowledging that patterns exist is often more important to application in clinical practice than explaining those patterns in theory.

Qualitative description methodology lies within the naturalistic paradigm of research which views reality as fluid, being constructed by the individual's perception.

This allows for “multiple interpretations of reality” (Polit & Beck, 2008, p. 15). The theoretical location is well suited for this research, as the purpose of the study was to explore the role of the SCI patient from the participant’s perspective. Since the naturalistic perspective reflects reality from a subjective rather than an objective perspective, it acknowledges the validity of the participant’s view of the interactive process in rehabilitation, regardless of whether that reality fits with another’s perspective of *truth* or not.

Using qualitative description methodology allowed the researcher to explore the participants’ perceptions of their roles in setting and enacting goals as members of the rehabilitation team. It also validated that perspective as the collective truth of the interactive process that occurred to facilitate or inhibit the realization of that role within the rehabilitation team. By using a methodology that encourages straightforward description and requires limited interpretation, the researcher was able to offer a clear descriptive picture of the participants’ perceptions of their roles and ensure the greatest potential for the research findings to find concordance with the SCI population and health professionals interested in SCI rehabilitation.

Study Design

Recruitment

Participants were recruited in a face-to-face communicative process. Potential participants were approached by a health professional within their circle of care to ask if they were interested in hearing about the research study. If they expressed interest, a study volunteer met with them to explain the study and ask if they would be willing to participate. To ensure SCI patients did not feel any obligation or concern about possible repercussions to their care should they refuse to participate in the study, this study volunteer was not a member of the patients' inner circle of care. If individuals agreed to be involved in the study, a date and time at their convenience was arranged for the participant to meet with the researcher. In order to explore a full range of experiences, recruitment continued until no new concepts or themes were noted. Thirteen individuals were included in the study over a period of eight months.

Inclusion criteria. In this study, the sample was drawn from patients above the ages of 16 who had sustained a SCI and were admitted to the facility's inpatient rehabilitation program following discharge from acute care. Eligibility for the study included patients with either traumatic or non traumatic injuries. Patients who had sustained a SCI within the last six months that was expected to result in permanent disability and who were expected to remain in the rehabilitation program for at least four weeks were eligible to be included as participants.

Exclusion criteria. Patients who were expected to be discharged from inpatient rehabilitation within a period of four weeks were excluded. Based on experience the researcher decided that four weeks was the minimum amount of time required for a participant to experience a substantive interaction with the health care team in the areas of the research focus. SCI patients at the study site rehabilitation centre routinely meet with the entire team in bi-weekly patient conferences. Patients who were expected to stay less than four weeks would attend only one conference and would not be able to experience the progress of interactions with the team in this venue over a period of time.

Those who had great difficulty understanding and communicating in the English language or who had co-morbid neurological injuries resulting in significant cognitive impairments were excluded from the study. It was felt that a severe language or cognitive barrier would result in their inability to fully participate and understand the interview questions.

Purposive Sampling

Purposive sampling using maximum variation was utilized as the sample method in this study. Sandelowski (2000) suggested maximum variation as the sampling method for qualitative description research, stating that it allows the researcher to explore both "the common and unique manifestations" (p. 338) of the researched phenomenon. Maximum variation is appropriate when the sample size is relatively small, but the researcher seeks to capture data that reflects the whole population of an aggregate (List, 2004). It includes the widest possible range of participants and allows the researcher to determine if what is observed is "anomalous or an artifact of some unexplained characteristic of [the] current sample or study design" (Thorne, 2008, p. 91-92).

The sample included both participants with tetraplegia and those with paraplegia. Participants included seven individuals who had sustained a SCI through traumatic injury; five with SCI related degenerative disease; and one individual with a SCI disease process etiology. Including participants with a wide variation of level of injury and etiology provided maximum variation of the various sequelae seen in SCI. The participants included seven males and six females with of varied ages and education levels. Marital status was included to assess personal support systems.

Ethical Considerations

Approval for this study was obtained from the local university and health care facility's joint Research Ethics Board and the York University Office of Research Ethics. Steps were taken to ensure the privacy of all potential participants. All collected data related to individual participants were identified only by alphabetical and numeric codes. In the documentation of the study, care was taken to offer no identifying information about participants that might be recognizable to those who were familiar with them.

All participants were informed that they could withdraw from the study at any time and that it would not impact on their care. They received a copy of their consent forms immediately after the interviews. They were also assured that they would have an opportunity to hear the results of the study after it was completed. Documentation relating to the study and contact information for the participants is secured in a locked filing cabinet. It will be transferred to a secure location at the hospital facility, stored for ten years following the study, and then destroyed using a confidential waste process. These considerations ensured protection of the participants' right to privacy at recruitment and during the interview, and will secure the privacy of the study data.

Data Collection

Data were collected through audio-recorded, semi-structured interviews with individual participants. The participants met with the researcher while they were in the inpatient rehabilitation program, shortly before they were discharged. Interviews were conducted in a private interview room at a time convenient to the individual. Participants were given an opportunity to read the consent form, and were then asked if they had any questions about the research study. The researcher answered any questions prior to the participant signing the consent form. If the individual was physically not able to sign the consent form, a study volunteer witnessed his or her verbal consent. Demographics including, SCI level, etiology, age, gender, marital status, and last level of completed education were collected to allow an overview of the variations among the participants. The researcher then asked for permission to turn on the audio recorder and the interview proceeded.

Questions that guided the discussion are identified in Appendix A on page 114. They focused on the participant's perception of how they identified their goals, how they visualized their role within the team, and what promoted or inhibited their participation as members of the team in setting and enacting their rehabilitation goals. These questions related to King's theory of goal attainment in their foci on roles, interactions in mutual goal setting and goal attainment within the SCI rehabilitation setting. They allowed the exploration of the individuals' perceptions of their interactions with the rehabilitation team, the meaning those interactions and resulting transactions had for the participants, and the impact hospital and community systems had on their roles. Following the completion of the interview, participants were asked if they would agree to be contacted at a later date should the researcher have further questions. All agreed to allow further contact if necessary. Contact information was obtained and each individual was given a card thanking them for their involvement in the study. A beverage voucher offered as a small stipend was enclosed in the card. Field notes and memos were written immediately following the interview to capture personal thoughts and observations made by the researcher.

Seven participants were contacted for further clarification of the collected data after they had been discharged. Five of the participant interviews were conducted by telephone and two were conducted in a private interview room in the research facility outpatient clinic. All interviews were audio recorded. These interviews gave the researcher an opportunity to ask the participants to reflect on their inpatient rehabilitation experience after they had been discharged.

Data Analysis

A transcriptionist or the researcher transcribed the collected data as soon as possible after each interview was completed. The researcher reviewed each transcript while listening to the taped interview to ensure the transcript accurately captured, verbatim, what was stated by the individuals. Field notes and memos were reviewed to note any observations not captured by the transcripts. Prior to the initiation of coding, transcripts and field notes were read and re-read four to five times. Immersion in the data is an important step prior to the initiation of coding, allowing the researcher to absorb the whole meaning of the participant's communication (Hsieh &Shannon, 2005; Thorne, 2008). Data collection and analysis were conducted simultaneously, and data emerging from each new interview were compared with those from preceding interviews. Differences and similarities were identified as new data were generated. Sandelowski (2000) suggested that the treatment of data is continuously modified to "accommodate new data and new insights about those data" (p.338).

Content analysis, using an inductive approach, was the method used for data analysis. Content analysis is a process that reduces information from specific to greater abstraction, resulting in "a condensed and broad description of the phenomenon" (Elo & Kyngäs, 2008, p. 108). Graneheim and Lundman (2004) identified that the process of content analysis starts with the identification of the unit of analysis. They suggested a complete interview as an appropriate unit of analysis, stating this unit is "large enough to be considered a whole and small enough to be possible to keep in mind as a context for the meaning unit" (p. 106). In this study, the unit of analysis was the transcription of the conducted interview and the associated field note completed after each interview.

In qualitative content analysis, an inductive approach is used to allow concepts to be generated from the data as it is collected (Sandelowski, 2000; Waltz, Strickland & Lenz, 2010). The use of this approach allowed initial concepts and patterns of meaning found in the study transcripts to surface and be identified. Coding was completed in a process described by Elo and Kyngäs (2008) and Hseih and Shannon (2005). Words or statements with similar meanings were coded using NVIVO 8, a computer software program (QSR International, 2007). The NVIVO 8 program assists researchers in organizing unstructured data and reducing it to manageable components for analysis. Initial codes were generated openly, without grouping, allowing all concepts expressed within the transcribed data and field notes to be captured.

In order to understand the emerging concepts, the open codes were initially grouped under headings that reflected the time of occurrence related by participants at the time of interview. Elo and Kyngäs (2008) suggested the use of "higher order headings" (p.111) to allow the researcher greater clarity in grouping codes into similar and dissimilar categories. The initial headings in this study were identified: 'Before Rehabilitation', 'Early Rehabilitation', and 'Fully in Rehabilitation'. Grouping the codes into these headings gave the researcher a sense of the context in time within which the participants' understanding of their roles occurred. Codes were merged into categories to reflect similar concepts. Categories were examined for overall consistency among the participants and for *outliers*. New data were analyzed and emerging codes were added to the existing categories if the data fit in that category. A new category was created if the data had not been previously observed. Categories were merged or deleted if they were seen as addressing the same information or as being irrelevant to the research question.

As new data emerged it became evident that it would be useful to re-examine the codes using the research interview questions as headings to gain greater clarity of understanding. The research questions were grouped to reflect the focus areas of the questions under headings: 'Priorities for Rehabilitation', 'Experience of Patient Conference', 'Experience of Goal Setting', and 'Acting on Identified Goals'. The codes were re-grouped under these headings. Transcripts were re-examined to ensure the codes were appropriate and no data related to these new headings had been missed. Examining the codes from these different perspectives allowed a clear understanding of the participants' perceptions of their roles, and the time context in which the understanding of their roles occurred.

Categories emerging from the two sets of headings were compared and merged or deleted according to their relevance to the research question in order to produce a final set of subcategories. Subcategories identified through this process were included because they corresponded either directly or indirectly to the research question. They revealed the context in which participants began the process of identifying their roles, identified the participants' perceptions of their roles in setting and enacting their personal rehabilitation goals, or reflected factors that promoted or inhibited those roles. These subcategories were analyzed, revealing an emerging set of categories that captured an overall view of the identified concepts. In the content analysis process, generated data leads to greater abstraction of the categories (Elo and Kyngäs, 2008). In this study, further levels of abstraction generated final themes that reflected the participants' perceptions of their roles in setting and enacting their personal rehabilitation goals. Final themes were identified: *Visioning, Redefining, Brainstorming and Rebuilding.*

Chapter Five

Results

This chapter will review the results of the data analysis. Descriptions of the study sample, the categories that emerged, and the themes reflective of participants' perceptions of their roles in setting and enacting their goals within the rehabilitation team are provided. Concepts identified in the final subcategories are explored within each theme section. These concepts reflect important factors to consider within each facet of the participants' roles. The context in which the participants' perceptions of their roles unfolded is explained to allow greater understanding of the interactions and resulting transactions between the participants and the health care team.

Introduction of Participants

The participants in the study included 13 patients who had sustained a SCI through a trauma, disease process, or degenerative conditions. Ethical considerations do not allow a detailed description of individual participants, however, a composite description of the participant group is provided.

The participants in this study group represented the maximum variation possible within the available sample pool. Demographic data were gathered from each participant to describe the variations in SCI etiology and injury level, gender, age, marital status, and education levels within the sample group. Table 5.1 provides an outline of the variations among the participants. Identifiers were removed to protect the privacy of the individuals. Central cord etiology in the cervical category under 'Level of Injury' was included as relevant information. The overall functional loss between those with central cord etiology and other cervical level injuries may be quite different. Individuals who sustain a central cord injury are usually able to walk but have very limited use of their hands. Cervical injuries are more often associated with paralysis of all four limbs (Hickey, 1997).

Table 5.1
Demographics and Variations Among Study Participants

Identifiers Removed	Level of Impairment	Etiology	Age Category	Gender	Marital Status	Level of Education
...	Thoracic	Disease Process	>55	F	Divorced	Post-Secondary
...	Thoracic	Degenerative	>55	F	Single	Secondary
...	Cervical Central cord	Degenerative	>55	M	Married	Secondary
...	Cervical Central cord	Trauma	>55	M	Divorced	Elementary
...	Cervical	Degenerative	>55	F	Married	Secondary
...	Cervical Central cord	Trauma	>55	M	Married	Post-Secondary
...	Thoracic	Trauma	36-45	M	Single	Secondary
...	Lumbar	Degenerative	>55	F	Single	Secondary
...	Lumbar	Trauma	46-55	F	Married	Post-Secondary
...	Cervical	Degenerative	>55	F	Married	Elementary
...	Thoracic	Trauma	16-25	M	Single	Secondary
...	Cervical	Trauma	16-25	M	Single	Secondary
...	Thoracic	Trauma	>55	M	Married	Post-Secondary

Participants' ages ranged from 21 to 74 years. Two participants were young adults who had sustained their injury through sports activities. Both were in post-secondary education at the time of injury and hoped to resume their education after rehabilitation. Their plans for returning to school required goals to achieve modification in physical transportation and in manual dexterity skills. One participant, who had completed only elementary education, described how he had not been able to complete formal education, but had continued to take courses at different periods of his life. The occupations of those who were employed varied. One individual was a businessman who took pride in the fact that his customers were always satisfied. He had high expectations of himself and had a strong confidence in his ability to overcome any hardship through hard work. Another participant was a homemaker. A concern for her was her ability to return to cooking for her family. Several of the participants were retired. Lifestyles and activities planned for retirement years were disrupted and difficult goal changes were required.

Traumatic injuries had occurred through falls, sports, or motor vehicle accidents. Degenerative conditions resulting in SCI were often longstanding conditions with which the individual had struggled for some time. Functional loss ranged from those who were not able to perform most of their own care needs, to those who were able to perform most personal care needs although with significant difficulty. Bodily functions, like voiding or defecating, long taken for granted, often became an issue with the need for bowel routines and regular catheterizations. The participants spoke about disruptions to plans they had made with their friends or families and to activities they enjoyed in the community.

Lifestyles were disrupted. One participant spoke about the fact that he loved outdoor activities and now was unable to use his hands at all. Another wept as she described the need to sell a home she loved but was now inaccessible for her. Several expressed concerns about the amount of care they would require, or in some cases, the fact that they now did not have an income or accessible housing, and did not know where they would be living when they were discharged. Some were married or had families to support them while others had very limited community support. Those participants faced increased stress, returning to the community with little support. Most faced an uncertain future at the time of their admission to rehabilitation. Two examples of participants who were typical of this group were Paul (pseudonym) and Irene (pseudonym). Their rehabilitation experience is given to provide a picture of the continuum of the perceptions and differences in levels of satisfaction with rehabilitation, among the participants.

Paul gave a detailed description of the traumatic events that resulted in a SCI. He described the sense of disconnect, or loss of control he felt while in the intensive care unit, stating that, in his perception, he did not realize what was happening for about a month and a half. Although he did not know what to expect of rehabilitation, he embraced entering the program with enthusiasm, hoping for a good level of recovery. He was given an opportunity to identify his goals, but stated that lack of knowledge about his prognosis kept him from realistically setting goals. A consideration for him was the importance of reducing the burden of care for his loved ones.

In rehabilitation, Paul attended patient conference, but felt that there was a lack of communication with the team. He identified that communication in the conference was primarily between him and the physician. He felt that a concern he had brought to the conference was not addressed. This concern involved his ability to transfer from one surface to another. In day to day rehabilitation activities, he cooperated to fullest extent possible with the rehabilitation team, however, the unattended concern he had identified in conference continued to prevent him from attaining his envisioned goal. There were aspects of the environment that left him uncomfortable. He was upset about patients who were in isolation rooms, yet came out of their rooms and shared equipment and dining facilities with him. He also felt that the nursing staff was not considerate of his discomfort with the cold environment. On discharge, he stated he had not achieved his goal and expressed dissatisfaction with his rehabilitation.

Irene experienced a disease process which resulted in a spontaneous SCI. She described the experience in detail, stating that she felt first one leg give way, and then the other. Although she was transferred to a number of different facilities before being admitted to the rehabilitation facility, she did not identify this as a confusing or upsetting experience. She had knowledge of what to expect in rehabilitation and stated she did not realistically expect to walk again, identifying the goal of transferring as her overall priority. When speaking of her input in goal setting, she identified that she had been assisted by a health care professional and stated that she found goal setting difficult. She explained that goal setting was not a normal activity for her, stating that she simply did not think that way. Despite that, she was able to clearly articulate setting priorities in goal setting, identifying her most important goal as transferring because it represented freedom for her. She was concentrating on this goal and explained that since she required assistance for personal care such as catheterization to empty her urinary bladder, learning to dress herself was not a priority.

When speaking about the patient conference, Irene identified her role as sharing knowledge about her progress with the team. She stated this was different than what she had anticipated. She expected the team to give information to her rather than receive information from her. She accommodated this by writing down any questions she had and taking them with her to the conferences. In day to day rehabilitation, she attempted to achieve the skills suggested even though she found the required actions frightening. She also pushed herself to attempt skills that would allow greater access to the community once she was discharged.

In speaking about her experience in rehabilitation, Irene acknowledged great satisfaction, despite continuing to struggle with consistently managing her transfers. She stated that she felt the communication within the team was “incredible” and that she had been well supported by individual members of the team throughout her stay in rehabilitation. She acknowledged that she saw the other patients and the team as her family and that she would miss everyone when she was discharged. Paul and Irene are given as examples of individuals in the study to provide a frame of reference for understanding the data obtained through transcripts of participants’ interviews.

Emerging Themes

Categories and Subcategories

Data analysis of the categories emerging from the two sets of headings described in the previous chapter, produced a group of subcategories which were further reduced to categories and finally to themes. The subcategories were included because they corresponded, either directly or indirectly, to the research question. They revealed the context in which participants began the process of identifying their roles, identified the participants' perceptions of their roles in setting and enacting personal rehabilitation goals, or reflected factors that promoted or created barriers to fulfilling those roles. Final categories reflected the overall concepts captured by the analysis of the subcategories. As the data analysis proceeded, further levels of abstraction were generated with final themes emerging as the concepts captured in each category were explored.

Themes

Final themes to reflect the participants' perceptions of their roles in setting and enacting their personal rehabilitation goals as participants in the health care team were identified: Visioning, Redefining, Brainstorming, and Rebuilding. The theme of Visioning reflects the participants' perceptions of the overarching priority goals they hoped to achieve through rehabilitation. It is reflective of both the participants' early perceptions of their roles in goal setting, and the foundation upon which they continued to build those roles throughout the rehabilitation process. The themes of Refining, Brainstorming, and Rebuilding build upon the foundation of Visioning. These themes reflect the participants' growing awareness of their roles in setting manageable steps towards achieving their envisioned goals, in modifying the goals through collaboration with the health care team, and in the difficult work involved in rebuilding skills for daily living. Figure 5.1 is provided to allow a visualization of the interconnecting themes and their relationship in the participants' interactions with the rehabilitation health care team.

Figure 5.1
Themes Relationship

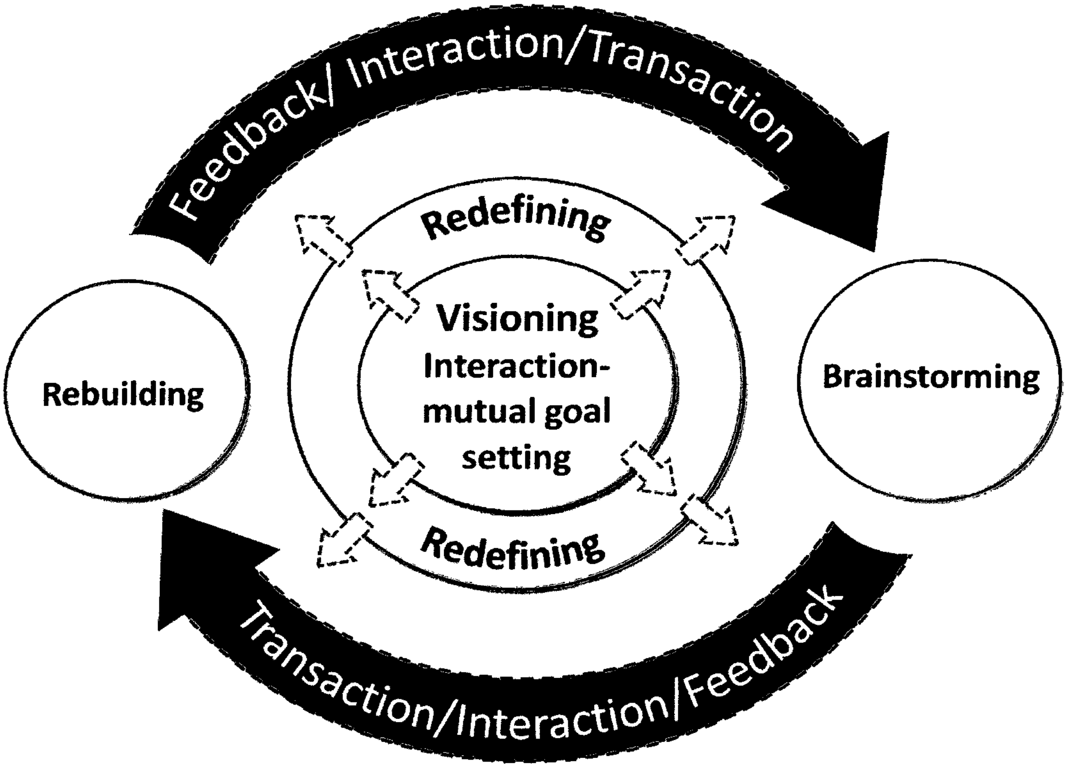

Figure 5.1: Themes Relationship. The figure illustrates the relationship of Visioning with the themes of Redefining, Brainstorming, and Rebuilding. The themes were interconnected. Redefining, Brainstorming, and Rebuilding built upon the foundational theme of Visioning. Redefining expanded on the overarching priority goal identified in Visioning to set defined incremental steps to achieve mutually identified goals. Brainstorming and Rebuilding are continued in cyclic interactions and transactions. Dashed arrows represent the interactions and resulting transactions that occurred between participants and health professionals in either individual or group venues in the rehabilitation interpersonal system (King, 1981). The arrows are dashed to represent the fluid nature of the interactive process.

Visioning

Context of Visioning

Patients who have been admitted to an acute care hospital setting for SCI related health concerns are assessed by a nurse clinician to determine appropriateness of the referral and readiness for admission to the regional SCI rehabilitation program. Rehabilitation goals are necessary criteria for admission. During the clinician's assessment, patients are asked to articulate their goals for rehabilitation. For some, this may be the first time they have been asked to consider this question. As the study participants expressed thoughts about goals they had hoped to accomplish, they identified their vision of regaining some level of control of functional abilities lost through traumatic injury, degenerative disease or disease process, and of reconstructing the lives that had been disrupted. Throughout the rehabilitation process, they continued to work with this vision. This interaction may be explained by King's theory of goal attainment as the clinician and potential patient set a mutually agreed upon goal of entering into rehabilitation. Transaction in this step occurs when the patient is admitted and prepared to engage in the rehabilitation process.

Definition and Factors for Consideration in Visioning

Visioning can be defined as the participants' perceptions of their roles in setting overarching priority goals for rehabilitation. These goals were initially articulated in acute care as their reasons for entering the program and were the foundational goals upon which they continued to build their hopes for levels of recovery that were acceptable to them. There are five important factors for consideration in Visioning. They include 1) establishing an overarching priority goal, 2) levels of hope, 3) the impact of injury, 4) loss of control, and 5) lack of knowledge about rehabilitation. Establishing overarching priority goals and the ability to have hope were seen as promoting the participants' roles in Visioning. The impact of injury, loss of control and the lack of knowledge about rehabilitation prior to their admissions were seen as barriers.

Overarching priority goal. Participants expressed their envisioned goals with key words such as "self-sufficient" (PA01; PA06), "independence" (PA04; PA13), and the desire to be their "old self" (PA06). Some articulated their goals in words and expressions that reflected an action. A number of participants spoke of the act of walking (PA05; PA08; PA09; PA10; PA11; PA12), while several mentioned the act of transferring as being of major importance (PA02; PA07; PA13). The act of transferring from one surface to another, related to the idea of gaining freedom for one participant. She stated:

> I'm quite realistic, so I did not expect to walk at any point. I really wanted to gain as much independence as I could, okay? Make the most of what ability I had left and I've got a head and two arms, so you can still do something with that. And it's the transferring, that's really important to me. Really important (pause) the transferring, because that represents freedom. So that's really it. If you can transfer to a car, another vehicle, another chair, anything like that, that's all I need. I can't put on my shoes; that isn't that important to me. It's the transferring. (PA13)

Independence, self-sufficiency and physical actions that would allow independence or greater freedom were the overarching priority goals articulated by participants when asked what they had hoped to achieve during their admission to rehabilitation. Many of the thoughts expressed about independence and self-sufficiency related to physical actions and the ability to care for themselves. Rehabilitation offered an opportunity to attain the goals articulated. As such, it was viewed by participants with varying levels of hope.

Levels of hope. The vision for recovery was often accompanied with expressions of hope, and for some participants, anticipation, at the prospect of going to rehabilitation. Participants expressed this anticipation with such words as "excited" (PA01; PA02; PA08) and "happy" (PA10) when asked how they felt about going to rehabilitation. One participant expressed this in terms of embracing the idea of rehabilitation with enthusiasm stating, "because I thought that I was able to be (pause) able to (pause) to be self-sufficient and ahh, so I embraced the idea of coming here very, very enthusiastically" (PA01). There was a point in time when participants realized they would need assistance to regain a greater level of independence. As one participant pointed out, he realized that only so much could be accomplished in the acute care hospital setting (PA02).

Not all participants embraced the thought of coming to rehabilitation. PA07 stated he did not know what to expect and did not realize it was a good place until after he was admitted. One participant, PA12, acknowledged she had reservations about coming to rehabilitation. She stated that, having had previous experiences with long hospital stays, she usually found that she did better once she returned to her home. She found herself "quite leery" about coming to the inpatient rehabilitation unit (PA12). An opportunity to tour the rehabilitation centre prior to admission gave her a more positive outlook about being admitted, but she continued to express concerns about issues in the physical layout of the rehabilitation facility. Despite this discomfort, she did express satisfaction with meeting her goals.

Disappointments and physical setbacks were experienced by several participants (PA01; PA11; PA08). PA01 described his disappointment with the progress he had made in rehabilitation stating, "I'd have to say that, you know, that rehabilitation as a great tool for me to be self-sufficient; No, not even near". For this participant, the disappointment in rehabilitation resulted in a search for alternative measures to reach his goal. He hired community resources he felt would be more successful in meeting his needs. One participant expressed the hope that he had on starting rehabilitation and the resulting feeling when his physical function began to deteriorate stating:

> It (pause) gave me hope. I could see the light at the end of the tunnel. Until last week; then I started having this set back that I'm having now, but prior to that everything was a step towards the end of the tunnel and that light at the end of the tunnel...So (pause), I could see that light at the end of the tunnel. Now I don't know. (PA11)

Another participant, PA08 relayed the comfort she received from staff when she realized she was not progressing. She expressed this as "a shoulder to cry on". In the field note accompanying this participant's interview, the researcher noted that she appeared very sad and also resigned. Loss of hope was seen to different degrees. Some participants appeared able to refocus and look for other solutions while others appeared to despair and not have the ability to look beyond their loss.

Impact of injury. Most participants were able to clearly describe the event that lead to their SCI. Participants who had a degenerative process which resulted in a SCI had a less detailed description of the moment of injury than those who experienced a traumatic injury. Most, however, were able to clearly identify, in detail, the point of time when they became aware of increased loss of function. In three instances, the awareness of lost function occurred following surgery (PA08; PA11; PA12). Two expressed feeling great sadness at this loss (PA08; PA11). One participant, who had undergone surgery for a degenerative condition and had lost function following surgery, described this sense of increased loss and sadness and the impact it had on him stating the experience was:

> Devastating. Yeah, I'm an active person, I'm a go-getter and it has just (pause). It's devastating to me. I cry a lot now. Every setback I have in rehab is ahh (long pause). It devastates me right to the core. I can't, I can't function like I used to and that really bothers me. (PA11)

A participant who sustained a SCI through degenerative process gave a very clear description of the intense pain she experienced at the point of losing function stating:

> First of all, I take my hands, and I felt the pain in my neck, and then it go in my shoulder down below, down below to fingers. And then I can feel something very wrong (pause) because the pain. It was such a bad pain, so from that pain it stabbed me in my legs, I fell down (pause) I fell down. My legs was completely finished. (PA05)

Those participants who had sustained their injury through trauma described particular details about the event such as the height of the fall, their realization of loss of function, and methods of testing to identify the loss of sensation to parts of the body affected. PA01 described hitting his legs with a stick to see if there was any sensation. Another participant, PA07 stated a friend bent his foot to test for sensation, confirming the initial realization of loss of sensation in his legs. A participant who sustained a spontaneous spinal cord hemorrhage identified that she lost the function of first one leg and then the other. Participants described clear remembrance of details surrounding the events leading up to the loss of function and articulated that the experience was emotionally traumatic.

Loss of control. Loss of control was identified in participants' descriptions of the aftermath following their traumatic SCI, or when those with degenerative injury realized the extent of their loss of function. While one participant was able to clearly describe in detail the traumatic injury which caused the SCI, he articulated that, following his move into Intensive Care Unit (ICU) of the hospital, he lost control of time, stating , "It's fair to say that I woke myself up after maybe a month and a half" (PA01). Another said, "I was in shock then cuz I was in ICU for about a month" (PA03).

Participants described the loss of control that resulted from moving between hospitals during the period of time between the acute and rehabilitation phases of their recovery. They experienced not knowing when or whether they would be going to the rehabilitation centre. One participant, PA05, described how she experienced moves back and forth between home and emergency departments as health professionals sought to diagnosis her neurological loss and find appropriate accommodations for her. Loss of control experienced during this transitional period of time was expressed in terms of fear, sorrow and confusion.

A participant spoke of her tears on hearing she would be sent back to her local area hospital to wait for rehabilitation stating:

> She did say that they will probably send you back to...because that's your address and it's just political, I think. That's why I had to go back there. I remember the day, and she said "It'll be fast". She said, "They'll come in and they'll say you have to go and you have to go within 4 or 5 hours". I remember the day; I cried. I didn't want to go because I wanted to stay here for rehab. (PA10)

Health professionals attempted to inform the participants about diagnostic results, hospital processes and rehabilitation. A participant (PA01) described the event of a physician showing him the x-rays of his injury in chronological sequence. Others identified speaking to health professionals who told them information about rehabilitation, or the possibility of being transferred to their local hospital to wait for admission to rehabilitation (PA02; PA10; PA11). Despite the attempts made by health professionals to inform and prepare the individuals, many participants experienced some level of confusion and loss of control as they moved through the hospital system.

Knowledge about rehabilitation. Many participants had little or very limited knowledge of the work that would be required of them in the rehabilitation program. Participants acknowledged that health professionals spoke to them about rehabilitation while they were in the acute care phase of their treatment (PA01; PA02; PA03; PA07;

PA10; PA11; PA12), yet most had limited understanding of what SCI rehabilitation would involve prior to entering the program. The participants used statements such as, “no idea” (PA01; PA03), “didn’t know what to expect” (PA06), or “didn’t know what I’d be doing” (PA07) when asked about their expectations of rehabilitation. One participant (PA06) said that she did not even know what clothing to bring with her to rehabilitation. Four participants had some experience with outpatient rehabilitation but identified limited knowledge of what to expect in the inpatient program (PA08; PA10; PA11; PA13). One participant had clear knowledge about rehabilitation because a family member had formerly been an inpatient in the facility. He expressed having good understanding of the program and stated, “I was expecting a physically demanding regimen and was determined to work with it” (PA04).

Redefining

Context of Redefining

When patients are admitted to the SCI regional rehabilitation program, they are asked to identify their rehabilitation goals. Some will have identified these goals with the nurse clinician and other health professionals in acute care prior to admission; other patients may not have had that opportunity. Planning goals is considered an important step in the rehabilitation process, as is reducing identified goals into smaller increments or steps towards achievement. Health professionals assist patients with this task, often writing goals on white boards or using a patient goal tracking tool developed by a patient education specialist to allow a visualization of the steps required towards goal attainment. They also give input in the need to modify those goals as necessary throughout the patient's admission. Entering into an interaction with the patient to set defined goals may be correlated to the interactive process defined in King' theory of goal attainment. The theme of Redefining is reflective of the perceptions of the participants as they were asked to define their personal goals in greater detail. Agreement of mutual goals set in this context sets the stage for ongoing transactions to reach goal attainment.

Definition and Factors to Consideration in Redefining

Redefining can be defined as the participants' perceptions of the process of detailed goal setting in which they were required to think about the alternative measures needed for activities of daily living and what those measures would mean to their personal selves and to their lifestyles. It reflected the redefining of self to varying degrees and continued on throughout the rehabilitation process. The factors seen as promoting the participants' roles in Redefining include the possibility for input in goal setting, and the ability to set priorities and acquire a sense of accomplishment. Lack of knowledge about their prognosis, discomfort with goal setting, and the sense of reality given by the process of goal setting were seen as barriers to this facet of their roles.

Input in goal setting. Most participants stated they had significant input in setting their personal rehabilitation goals. While the opportunity to identify goals was given, several participants stated they relied on assistance and input from health professionals to help them identify those goals and clarify what would be needed to achieve them in their personal situation (PA02; PA03; PA06; PA07). One participant expressed this clearly in saying:

> Ahh, he just kinda said "Well, look at what do you want to accomplish, like getting your bladder under control and your bowel program", which was tough. (PA02)
>
> Had you thought about that at all before he mentioned it? (Researcher)
>
> No, that was the last thing I was thinking of. (PA02)

Other participants acknowledged the assistance of health professionals in helping articulate the goals to greater clarity. A participant used the term "crystallized" (PA06) to describe the assistance given stating, "I came up with three at least on my own and ...or whomever, sort of crystallized my thoughts because I couldn't put them into words per se" (PA06).

Study participant, PA04, who had previous knowledge of the rehabilitation program, stated that he was able to clearly articulate the goals he had already clarified in his mind prior to his admission to rehabilitation. He identified manual dexterity and various detailed activities of daily living as his goals.

Participants had varied perceptions of the assistance given by health professionals in setting rehabilitation goals. While some indicated that health professionals gave much direction in setting the goals (PA02; PA03; PA06; PA07), others felt that the goals were set entirely by them and that the health professional only assisted in the breakdown of the goals into smaller, achievable goals. As one participant stated:

> Oh, I was the one that set them. They didn't set them for me. I set them for myself. They sat down with me and they asked me specifically, "What do you want?" "I wanna walk outta here". "Okay, now that we've got that as part of

> your main goal, we want to break that down for you". At that discussion with the Occupational Therapist, or the therapist, they said to me, "Okay, you're in a wheelchair; you're at that point you're in a wheelchair. Your legs don't work. Your arms don't work. Where would you like to be next week? What would you like to be doing next week? Realistically". (PA11)

Knowledge of prognosis. Several participants identified that goal setting was difficult because of lack of knowledge about their prognosis and what would be required for them personally to achieve the highest possible level of independence. Two participants stated they did not want to set unrealistic goals. There was an indication that they were concerned setting unrealistic goals would result in failure to achieve those goals. One of these individuals said:

> I'm not good at picking them. I don't know what like strive for (pause) cuz obviously you don't want to fail, but you don't wanna pick something too easy and I'm just not good at picking what to do. Cuz I didn't really know what I needed to do. (PA03)

Another offered the explanation that he was not given a clear prognosis, stating:

> Doctors have been unable to tell me basically, "Ok this is the severity of your case. Don't expect anything more". This is a discussion that was never undertaken, and ahh, so how can you set goals if you don't really know where you are at (pause). That's what I'm trying to say. (PA01)

Discomfort with goal setting process. Participants expressed varying reactions to the process of delineating their personal rehabilitation goals. A number of participants stated that they found goal setting difficult because of personal discomfort with the process (PA03; PA07; PA13). They stated that setting goals was not their usual way of thinking or solving problems. One participant stated, "I truly don't think that way. I just don't. I have trouble with that" (PA13). Another said, "Ahm, like it's just me, I'm not a fan of doing goal stuff" (PA03). In contrast, two participants (PA04; PA12), indicated they had begun the process of detailed goal setting prior to admission to rehabilitation. They indicated setting goals had been helpful for them, giving them direction and a sense of accomplishment.

Goal setting gave a reality check. Several participants indicated that goal setting gave them a sense of the amount of work that would be required to regain a level of independence, and consequently, a realization of their current situation (PA03, PA10). A participant acknowledged this as a reason why she found goal setting uncomfortable saying:

> When you think about it, you're scared (Starts to cry). Thinking that I'm not going to be able to drive again is a killer. Cuz I love to drive. I can't even imagine not driving. Well, when you break it down with all your goals, you just, it's just ahh, it's just more of a reality check to what's happened. (PA10)

A second participant echoed this saying, "Personally, Ahm, like it's just me. I'm not a fan of doing goal stuff. It was hard to actually pick them out. It kinda sets in the realization too of your situation" (PA03).

This reality check may have contributed to the emotional reaction that one participant described as she talked about goal setting. She stated that when she was asked to identify her rehabilitation goals, her husband initially became upset and felt the question was unreasonable. She expressed this saying:

> Oh, okay, yeah, you were setting goals yeah. I had to fill out that paper and (pause). It's funny that, you know, because my husband looked at that and he said "What the hell is this (pause)? What do you mean? What is anybody's goal? It's to walk again" or it's to (pause) like everybody's goal is the same. He was kinda taken back by that and he's right. My goal is to be the same way, hopefully same way as I was before. Everybody would like that. (PA10)

Identifying priorities. The participants' involvement in identifying priorities could be noted as they spoke about setting their rehabilitation goals. While some participants felt they were not good at goal setting, they demonstrated insight into prioritizing their goals to suit their current and perceived future needs (PA03; PA13). Some participants identified household chores that they hoped to resume. PA04 and PA05 identified cooking as a priority. Concern for reducing the burden of care for their caregivers played a large role in this prioritization for others. As one participant stated:

> The more important goals are the ones that you use every day, like feeding yourself or just every day movement, because it's one less thing somebody else has to worry about to help you with; so those things that I can do more independently. (PA03)

While reducing the burden of care for their caregivers was of importance to some participants (PA01; PA03), "freedom" was of more importance for one participant (PA13). She articulated that if assistance was needed for intimate personal procedures such as bowel and bladder care, learning less invasive self-care procedures such as putting on her own socks was not a priority for her. She preferred to concentrate on skills that would enhance mobility and personal freedom rather than those that could be performed by caregivers.

Sense of accomplishment. Several participants indicated that goal setting allowed them a sense of accomplishment (PA04; PA07; PA12). They verbalized that setting goals gave them something to strive towards. When smaller steps towards the goals were reached, they identified experiencing a sense of achievement. As one participant stated, goal setting gave him "something to look forward to" (PA07). Several participants indicated that they did not reach their rehabilitation goals (PA01; PA08; PA11). For some, these observations were made with sadness and frustration, while others indicated they were able to modify their goals and re-prioritize them (PA06; PA08; PA09). One participant indicated that he planned to take steps toward achievement of his goals when he was discharged (PA01). It was evident that he had a sense of self efficacy, a confidence that he would reach his goals based on past achievements, and the support of his wife. He explained this, stating:

> Well, I think it's gonna be entirely up to me when I get home. I'm quite creative. My wife is very supportive. Ahh, we will overcome a lot of these problems here. I don't know how, if you ask me now, I have no answer for you, you know, but I know. I know myself, ahh, I'll find a way. (PA01)

Brainstorming

Context of Brainstorming

Patients who are admitted to the SCI regional rehabilitation inpatient program meet with their entire health care team on a bi-weekly schedule in patient conference. These meetings are short, lasting about 15 minutes for each patient. Patients are asked to take an active role in this conference, sharing information about their goals and progress made in achieving those goals. This allows concerns to be addressed in an interprofessional capacity, and keeps the entire team informed of any aspect of the patient's care that may impede rehabilitation or delay discharge. If necessary, goals are modified in collaboration with the team. This interactive process sets a venue for sharing both the health professionals' and the patient's perceptions about the goals, and identifying the meaning of the current situation for the patient. If the interaction is effective, transactions will occur (King, 1981).

Definition and Factors for Consideration in Brainstorming

Brainstorming can be defined as knowledge sharing in bi-weekly patient conferences. It involved the participants' perceptions of discussing and modifying their goals in collaboration with their entire rehabilitation team. Two factors were identified as promoting this facet of the participants' roles. The ability to share and to receive knowledge about their goals with the team was seen as a promoting factor. Familiarity with the team was also seen as beneficial. The initial discomfort experienced by some participants in this venue, the lack of action resulting from shared discussions, and the lack of communication experienced through various situations were seen as barriers to the participants' roles in patient conferences.

Sharing information. Participants viewed their roles in the patient conference as one of sharing information. They articulated awareness that they held the "primary role" (PA01) in the conference and were the center of attention. For some, this was an uncomfortable situation because they did not enjoy being centered out (PA06; PA12). Others seemed very comfortable with that role and expressed awareness that the team was concerned for them (PA01; PA04; PA08; PA11). Participants identified that the rehabilitation health team expected them to speak about their concerns. The conferences were an opportunity to share information about issues such as how successful home passes had been, how renovations to the participants' homes were progressing, and whether pain was impacting on their progress in meeting their rehabilitation goals. The benefit of this opportunity to share information and solutions was expressed by one participant who stated that the conference was an opportunity for "getting everyone in one room and kind of hammering out ideas" (PA03). This concept was shared by another participant who said "Well, they all listened to me. They all had their say in what I said. They kind of built off of it too." (PA07). One participant expressed appreciation for the team's open and honest communication with her during conferences (PA08). PA06, who was reluctant to be the center of attention, stated that she felt the conference was good because it encouraged her to share information about her progress. She stated that her natural reluctance to be the center of attention would have prevented her from speaking out about her concerns if this venue was not available.

Discomfort in first patient conference. Many participants found the first patient conference they attended uncomfortable. One described the atmosphere as "strange" (PA02); others stated it initially made them nervous (PA04; PA10). A participant went so far as to describe the atmosphere as "confrontational" (PA12). A participant related this feeling about the conference to her own personal reluctance to be the center of attention stating, "it was simply not nice for me, because again, I don't like talking about myself, not in front of you know, more than one or two people" (PA06). Initially, participants did not know what to expect and some were uncomfortable with the fact that the team was questioning them rather than simply giving answers to their questions. One participant articulated this perception stating, "I thought they would do more of the talking, not me" (PA13). PA12 indicated that she was familiar with a different model of patient conference and felt that the team should use the conference to give information about tests and treatments that were up-coming. It would appear there was often discomfort in the first, and for some participants, subsequent, patient conferences.

Familiarity with the team and routine. Familiarity with the rehabilitation team and the daily routine helped increase some participants' comfort in their role during patient conferences. While over half of the participants expressed some level of discomfort at the first patient conference, most stated that familiarity with the team resulted in greater comfort in subsequent conferences. Several participants noted that the second conference felt more comfortable because they had become more familiar with the routine and the health professionals involved (PA02; PA03; PA04). One participant stated, “I felt a little nervous appearing before the group, but I was quickly put at ease because of the familiar faces that were there” (PA04).

Lack of action. At least two participants felt there was little value in the patient conference (PA01; PA09). A perception that action was not taken about concerns they expressed resulted in these participants seeing their roles in the conferences as of little value. A participant who had a significant issue that he felt was not addressed described how this affected his appraisal of the value of the conference. He said:

> When I go to these meetings of course I see people that are there. Everybody seems to be concerned. I appreciate that (long pause). The problem still remains. See I was part of the team in terms of participating to the discussion yeah. Sure, (long pause) where is the action; basically where is the piff, you know? (PA01)

This perception was shared by another participant who verbalized that he had shared a concern with the team that he felt was important. In his perception there was no follow-up to the issue and this led him to question the value of patient conferences. In speaking about the patient conference he stated:

> Well (pause) I'm really not sure it did much good. I mean I don't (pause), I went in and expressed my opinion on a couple of things but nothing really transpired you know (pause). Nobody from the conference followed up on it that I know of. (PA09)

Lack of communication. Communication issues were identified in a number of participants' descriptions of the patient conference. One issue was the perception that information was being withheld from a participant. PA09 complained that he felt he was the last to know important details about his care and discharge destination and, as such, felt that there was not enough time to mentally prepare him. The participant used the word 'drifting' to describe the feeling experienced related to the lack of shared information stating, "Times I felt like I was drifting you know… I knew I was here and part of the program but I was drifting, you know (long pause)" (PA09).

One participant experienced a language barrier. This was an obvious barrier to the communication with the team in conference. In speaking about her difficulty in communicating what she hoped to say she stated:

> If I'm not sure what I want to say, then better I'm not say it, because I'm scared if I don't say it (long pause). If you don't understand me what I'm trying to explain to you, then better I don't want to say nothing. (PA05)

Several participants noted that they missed one or more conferences because they were not informed that they were scheduled to attend a conference in a timely fashion (PA06; PA07). Participants articulated that they required some time to adequately prepare for conference either physically or mentally (PA06; PA07).

Rebuilding

Context of Rebuilding

Patients in the rehabilitation program are expected to participate in rehabilitation therapy in collaboration with the rehabilitation team. Goal attainment is facilitated in the day-to-day interactions and transactions with health professionals. Patients are taught skills related to activities of daily living and attend physical and occupational therapy every weekday. They meet with the social worker to address issues related to community reintegration, and with other members of the health care team, such as the respiratory therapist or dietician, as necessary. Most patients have some interaction with every member of the rehabilitation team at some point in their admission. The activities of working on rebuilding skills that are valued by both the patient and the health professional may be correlated to transactions as identified in King's theory of goal attainment.

Definition and Factors for Consideration in Rebuilding

Rebuilding can be defined as the participants' perceptions of their roles in attaining goals through the day-to-day rehabilitation therapy. A number of important considerations were identified in the participants' perceptions of this facet of their roles. Factors that promoted Rebuilding included the personal determination expressed by the participants. Support from the team and other patients within the rehabilitation community also appeared to be of significant benefit to a number of the participants. One barrier to Rebuilding was identified in the lack of personal and community resources available to some as they prepared for community reintegration. Others included factors in the rehabilitation environment which resulted in lack of communication and a sense of vulnerability for some participants.

Personal determination. Participants identified the physical requirements demanded of them in rehabilitation and the effort they put into meeting those requirements. They described the extent of the effort they contributed with such statements as, "I force myself to do it. It's painful sometimes but I grin and bear it like they say, and I just push myself" (PA08), and "Every day I do something a little bit harder" (PA10). Despite indicating that the team "pushed" (PA07) them towards achievement, participants identified that they wanted to cooperate with the team, follow directions the team members gave, and try new skill activities even though those activities were at times "scary" (PA13). They identified that they were happy to do as asked and cooperated to the very best of their ability, realizing the requests made were to promote their personal gains. As one participant stated:

> Yah, I was so happy to do it. What she told me to do it. Because I was thinking my gosh, this is for me, I gotta do it, my best and my heart, my (pause) you know, yah, yah. (PA05)

One participant noted that he quickly realized that rehabilitation required a commitment on his part to fully participate, stating, "The first two days, I had (pause) ahh (pause), I took my meals in my room and I thought, I said to my wife 'you know, I think I have to get with this program and stop holding back' " (PA04).

While participants realized the amount of work and effort that was required of them to achieve their goals, some felt more successful in meeting those goals than others. While one participant stated he was cooperative with all that was asked of him, his perception was that his goal was not achieved (PA01). He articulated that there might be some "fault" (PA01) in his lack of goal attainment. Two others, who also had disappointing outcomes, did not speak of fault in their lack of progress (PA08; PA11). Both of these participants had degenerative processes while the participant who felt there might be some level of responsibility on the part of the team for his lack of progress was a participant who had suffered a traumatic SCI.

Support from rehabilitation team members. Support of the team was identified by participants as helpful in attaining their rehabilitation goals. One participant identified confidence that the team would protect him as he attempted mounting sidewalk curbs, a skill that was frightening to him. He stated:

> I never thought I'd really want to attempt it. It's scary when you're coming at it and hitting it, but they're behind you and they're not gonna let anything happen to you, so you just keep going and eventually you'll get it. (PA07)

Other participants articulated the emotional support offered by the team, indicating that the team gave them "a shoulder to cry on" (PA08), or a sense that they were "number one" (PA10) with the health care team in their personal interactions. PA02 indicated a perception that a physiotherapist shared in his joy at noting increased return of foot movement.

Personal and community resources. Some participants mentioned the value of personal support given by family and friends (PA01; PA04; PA07; PA10). They identified that they expected assistance would be available to facilitate their return to community living. Three participants, who had limited personal resources in finances or family support, identified issues with returning to the community living (PA06; PA08; PA09). Working on rehabilitation goals associated with housing or finances was difficult and produced significant stress for these individuals. They described how these concerns impacted on their ability to concentrate on the work of increasing strength and skill in day to day physical rehabilitation. The difficulty in managing the rehabilitation goals of securing adequate finances or housing to support community reintegration appeared to be overwhelming. As one participant stated:

> Apart from the physical end, but the ah, again, trying to build up strength etc., but apart from that, it's the how to do or how to accomplish various things that you know, need to be done, but I can't do anymore. And then as I say, on top of all that is to find a place to live and worrying about money (teary). (PA06)

Lack of timely communication. Several participants identified lack of timely communication during their rehabilitation stay (PA07; PA09; PA12). One participant, PA09 felt information was not shared about his discharge. He felt this did not allow him the opportunity to prepare. He described this incident stating:

> The only thing that bothered me is to keep them in the loop. People will talk about something and they will say "Oh by the way, you're going next week" and I don't know about it, but they all know about it. You know what I mean? (Pause). Yeah, what the hey (pause). Let me know, so I can, you know, prepare myself. (PA09)

In a second interview he stated:

> I brought up the fact that I found out about a certain program that was going on. I found out that morning by mistake (pause) you know what I mean (pause) and I complained about the fact that I didn't know in advance. Well that never changed! I mean (pause) I brought it up but a couple of days later (pause) you know (pause). There was something that I was really interested in and it was part of my thing because I was going out soon and ahh (pause). I missed it. (PA09)

PA12 identified similar perceptions in stating that she was often given notice about appointments with little time to prepare for them, stating, "You wake up in the morning and they say, 'Oh you're going to Dr. So and So today'. Pardon, now? Who's he and what's he about".

While communication was noted as lacking by some participants, another noted her perception that communication was strong among team members. She stated:

> In fact, I'm in awe of how this place is run. It's (pause); it's magic. You can go to one person and say "Oh, I'm having a problem with swollen legs. The first thing you know thrombo is up with their stockings, or, err (pause). The communication is incredible. I can't express that strongly enough. It's incredible around here. Everyone keeps tabs on everyone else and all these disciplines come in into play constantly. It's wonderful. (PA13)

Sense of vulnerability. Discomfort in the rehabilitation environment, either through physical factors or through a sense of lack of control resulted in a sense of vulnerability for several participants (PA01; PA12). This vulnerability was apparent in a participant's description of an interaction with nursing staff in which he stated, "At 6:00 this morning the nurse comes (pause) whitt (pause). She takes all the sheets off me (pause), leaves me naked." (PA01). Fatigue and pain were experienced by two other participants (PA05; PA07) while another, PA06, verbalized that being moved out of a private room into shared accommodation caused her great distress. She expressed a feeling of embarrassment at the thought of completing her bowel routine while another patient was present in the room. She also anticipated that the other patient might wish to close the door. This was distressful for her as she identified she had claustrophobia.

Physical environmental factors also increased some participants' sense of vulnerability. A participant described the experience of the patient cafeteria as "a nightmare" (PA12). She found the atmosphere rushed and articulated her experience of that saying:

> It takes a lot longer to eat ... so I'm a lot longer, but I don't get to my tea and my dessert until everybody's gone; and people are cleaning up, and I'm thinking oh my god, I better get out of here. (PA12)

Another spoke of concerns he had about infection control, stating:

> Talking about people having infectious disease, I see those people go all over the place. They go in those rooms with gown and gloves. These people touch everything. I cannot go in the dining room because I see them all over the place on the desk, on the table and expect me at the same table. So if you need the gown and gloves when you deal with these people (pause). These people are outside of their room, (pause) so me, I feel unprotected. (PA01)

Concept of rehabilitation community. One factor that supported a number of participants was the sense of community in the rehabilitation centre. Several of the participants indicated a growing connection with the rehabilitation health care team and other patients (PA04; PA06, PA10; PA11; PA13). The connection with other patients was not established by discussing their health issues but in day to day conversations, joking with others in the gym and encouraging each other in their progress. As one participant noted, “It’s been my family for eight weeks. That is what it is, it’s your family and I will miss everyone” (PA13). It is noted that familiarity promoted the participants’ roles in Brainstorming as it increased comfort in the patient conference. It may also have acted as a promoter of the participants’ roles in day-to-day work on rehabilitation goals.

Summary of the Data Analysis

The themes of Visioning, Refining, Brainstorming and Rebuilding can be seen as interconnecting facets of the participants’ perceptions of their roles in setting and enacting rehabilitation goals. The vision of regaining a level of independence that was acceptable to them was the foundational step on which participants built their roles. This vision was initially articulated prior to admission, but remained the foundational goal on which they built their rehabilitation. Participants redefined what was needed to achieve this level of independence through goal setting. They also modified the goals through brainstorming with the rehabilitation team in patient conference, and worked towards goal attainment through rebuilding skills.

As the data were analyzed, it became clear that many participants found goal setting a difficult and, at times, an emotional, task. The first task in their roles, envisioning the overarching priority goal they hoped to achieve, appeared to be far less difficult than redefining the steps that were required to achieve this goal. Participants acknowledged their ability to have input in setting their goals, but often articulated that lack of knowledge or discomfort with goal setting prevented them from engaging in the task.

Redefining what was needed gave an unwelcome reality check for some and created an emotional reaction to goal setting. Several participants, however, articulated that it gave them a chance to set priorities and identify accomplishments.

Sharing knowledge with the team in conference in order to assess progress towards goal attainment or to modify goals could be seen as brainstorming if there was a successful interaction. The patient conference was seen as helpful if the individual participant was able to feel that his or her concerns were heard and acted on. If participants felt no action resulted, or information was withheld, they saw this part of their roles as devalued, and felt there was little purpose in meeting with the team to discuss and modify their goals. Discomfort with their initial conference and expectations that did not match the reality of the experience were also potential barriers to successful Brainstorming.

Working on goal attainment through day-to-day therapy was valued by participants. The role of rebuilding skills was seen as one of personal determination, supported by individual members of the rehabilitation team. Support of family and community was seen as an important factor in this determination. Lack of personal resources and accessible housing was stressful for those who did not have this support and created an added barrier to role achievement. Factors pertaining to the social atmosphere and physical environment also impacted on the participants' ability to achieve their roles.

Interaction with the rehabilitation health care team is an important consideration in each facet of the participants' roles in goal setting and goal attainment. King (1981) speaks about interaction in her theory of goal attainment, outlining steps taken by health professionals and patients to reach a transaction that will result in successful goal attainment and satisfaction. This theory will provide a foundation to discuss the research findings in the following chapter.

Ensuring Trustworthiness

Polit and Beck (2008) pointed out that the terms rigor and validity are often shunned by qualitative researchers because they believe them to be grounded in the positivist paradigm rather than the naturalistic. It was suggested that given the different focus of qualitative research, the term "trustworthiness" (Polit & Beck, 2008, p. 537) is more appropriate. Lincoln and Guba (1985) recommended a framework for establishing trustworthiness which included credibility, dependability, confirmability, and transferability. They later added a fifth component, authenticity (Guba & Lincoln, 1994). This framework provided an opportunity to review the trustworthiness of this research study.

Using qualitative description methodology, with content analysis as the data analysis process, allowed the researcher to address the components of credibility and confirmability. Credibility is a confidence that the data is truthfully interpreted. Confirmability refers to the likelihood that the findings will be unbiased and find congruence among reviewers. Qualitative description methodology requires little interpretation, and lends itself to greater potential that consensus will result among those who review it (Sandelowski, 2000).

Confirmability was also addressed through the involvement of the local research team which included two members of the SCI peer community. This increased the likelihood that personal bias would be checked by the research team. Maintaining field notes and a personal journal provided the researcher an opportunity to reflect on personal bias that might colour the interpretation of the data. The description of involvement with the SCI rehabilitation program provided in the introductory chapter also allows reviewers to identify the personal context from which the researcher conducted the study.

Thorne et al. (1997) suggested that "repeated interviews" (p.175) may add credibility to the initial concepts generated. This was evident in the data collected in second interviews with seven participants. On comparison with their first interview, their perceptions of the experience did not appear to have changed. The participants shared further experiences of setting goals following their discharge and impressions of their community reintegration. This provided a picture of the difference between their perception of goal setting while they were inpatients, and goal setting following their discharge, and reinforced the researcher's interpretation of the perceptions expressed by the participants during the initial interviews.

Using maximum variation as the sample selection procedure, allowed the concept of dependability and transferability to be addressed. Dependability addresses the likelihood that the findings could be replicated if completed with similar participants in a similar context; transferability refers to the ability to transfer the findings to other settings or groups (Polit & Beck, 2008). The use of maximum variation assured a range of SCI etiologies and different levels of injury that are typical of this aggregate. The researcher used description of both the context in time and in the situations identified, to allow others the ability to determine if transferability is possible. Polit and Beck (2008) stated that it is difficult to establish transferability in qualitative data. The researcher can only offer rich description to allow the reviewer an opportunity to establish whether it can be transferred to another sample group.

Authenticity, the fifth criteria for evaluating trustworthiness, reflects the assurance that all voices in the sample are accurately heard and that there is balance in the picture presented (Guba & Lincoln, 1994). This was addressed by using audio taping for the interview process and verbatim transcription which the researcher checked against the audiotapes for accuracy. In data reporting and analysis, the researcher included exceptions and outliers when discussing specific concepts related to the individual themes. The use of the participants' quotes and the description of the context of the rehabilitation setting to which these quotes pertained also added to the provision for authenticity.

Chapter Six

Discussion

The participants' perceptions of their roles in setting and working towards the attainment of their rehabilitation goals as SCI patients was thematically described as Visioning, Refining, Brainstorming and Rebuilding. These themes were interconnected (Figure 5.1). Visioning was the foundational piece in the participants' perceptions of their roles in setting goals to regain an acceptable level of independence. Redefining, Brainstorming, and Rebuilding built on this foundation. This chapter will review the themes identified in the previous chapter using King's theory of goal attainment as a framework for discussion. The participants' perceptions of their roles, and factors to be considered in promoting their roles within the health care team, will also be discussed.

Research Findings

The participants in this study articulated their roles as engaging in rehabilitation with identified overarching priority goals, defining detailed goals for activities of daily living, sharing knowledge with the team, and working to attain goals through their day-to-day rehabilitation. A number of factors influenced the achievement of these roles, acting to either promote or inhibit the participants' involvement in setting and enacting their goals. Each facet of the identified roles was influenced by interactions and resulting transactions with the health care team or the health care organization. King (1981) identified the personal, interpersonal and social interacting systems in health care and suggested the systems influence each other dynamically within the environment. Interactions occur in the interpersonal system as individuals meet to set mutual goals.

Individuals bring their perceived meaning of the situations and their concepts of required action to interactions. Reactions to both the environment and the other individual involved affect the interactions. If the interaction is successful, mutual goals and the means to achieve those goals are agreed upon and transaction occurs (King, 1981). In rehabilitation, the systems can be translated as the individual patients and health professionals, the rehabilitation team, and governing health bodies. The social community system, including personal supports and resources may also be seen as a factor affecting the participants' ability to set goals. The interconnecting influence of each system was evident in the perceptions of the participants as they articulated the interpersonal and organizational factors that influenced their roles.

Visioning

The theme of Visioning became apparent as the participants described their perceptions of regaining what had been lost and the roles they expected to play in rehabilitation. Prior to admission, participants were asked to identify their goals. This was an important component in the process. Identifiable goals are necessary criteria for admission to the program. Visioning the goals they hoped to accomplish in rehabilitation was therefore an important foundational step in role identification for participants. Their roles, at this point, could be seen as those of engagement in order to set goals with the health professional team.

King (1981) identified the need for individuals to engage in interactions with nurses or health professionals to mutually identify and set goals. Individuals and health professionals each bring their knowledge, judgments, past experiences, and perceptions to these interactions. These factors have impact on the meaning that each individual attaches to the situation and the environment. Participants in the study identified traumatic experiences that resulted in a SCI. Some also identified experiencing loss of control either through their experiences in ICU, or in being moved from one hospital to another.

It should be noted that during this acute care phase of health care for SCI, patients are asked to initially identify their rehabilitation goals. The devastating impact of the injury, both physically and emotionally, may result in difficulty absorbing the consequences of the injury and, as a consequence, patients may struggle to identify and direct personal rehabilitation goals (Belciug, 2001; Holliday, Cano, Freeman & Playford, 2007; Struhkamp, 2004). As such, it may be possible that emotional and psychological processes occurring within the patient's own mental framework may create barriers to active participation in goal setting. It may also be suggested that the perceptions generated by these experiences were factors to be considered in their interactions with the rehabilitation health care team. When judging how these perceptions may have affected the participants' roles in transactions with the health care team, we can consider the factors influencing Visioning.

Impact of injury. The impact of their SCI was recognized in the participants' descriptions of the events initiating the need for rehabilitation. These descriptions of the emotions experienced after their injury support the evidence reviewed. Sullivan (2001) described emotions of "shock, disbelief, grief, depression, and uncertainty" (p. 81) as those which accompany a SCI injury. Participants clearly detailed the experiences of losing function and expressed the confusion, shock and emotion involved with these losses. It is evident that the experiences were traumatic and life-changing. It would appear the impact of injury may be an important factor to consider in understanding the patients' perceptions of their roles in setting and attaining their goals.

Loss of control. Loss of control was articulated by several participants in this study. Two individuals described their detachment and disassociation with reality while in ICU. These descriptions reflect findings supported by the evidence reviewed. Research exploring patients' experiences in ICU revealed that loss of sleep, noise, and medications may all contribute to a psychological impact on the patient. Loss of control was identified in both personal body functions and circumstances (Carr, 2007; Elliott, McKinley & Cistulli, 2011; Hewitt, 2002). Patients who experienced trauma were found to have a sense of detachment, unreality, and difficulty with memory while in ICU (Carr, 2007; Hewitt, 2002). In addition, patients often continued to experience "cognitive impairment, depression, anxiety, and post-traumatic stress disorder" following their discharge from the ICU (Carr, 2007, p. 95). The data analysis in this study suggests at least two participants experienced some of these consequences of admission to the ICU.

Loss of control was evident in some participants' descriptions of their move from one hospital to another while waiting for rehabilitation. Moves between the regional trauma centre and local hospitals are often due to the fact that patients may be ready for discharge from the acute care unit, but are not ready for rehabilitation. Consideration of efficiency as an outcome measure monitored by the NRS, dictates that patients are generally not admitted until ready to participate as this would impact the program's length of stay efficiency.

Bed management issues may dictate whether a patient can be admitted directly from the acute care unit. If no beds are available in the rehabilitation unit, the patient may be required to wait in their local hospital for an opening. The organization requires continuous movement of patients to ensure efficient use of hospital facilities. However, loss of control, experienced when individuals are moved from facility to facility, may create a barrier for fulfillment of their roles in the program.

King (1981) theorized the interconnection between the personal system and the social system, and stated that each impact on the other. Relocation between hospitals as the participants waited for rehabilitation was an example of how the hospital system impacted individual participants. Conditions causing psychological consequences for individuals admitted to ICU are another example.

Knowledge about rehabilitation. Lack of knowledge about the rehabilitation program may be interpreted as another barrier to the achievement of participants' perceived roles. Holliday, Ballinger and Playford (2007) suggested that an understanding of rehabilitation is necessary for patients to engage in active goal setting. They indicated that while individuals in their study were able to identify the expected end results of the process, they appeared to have little understanding of how this end result could be obtained. Many participants in the current study identified that they had limited knowledge of what to expect in the program. While rehabilitation was suggested as a means of achieving their goal for recovery, lack of knowledge about the process may well have affected their ability to envision their roles.

Two participants identified setting detailed goals prior to admission. Both felt they benefitted from goal setting. One of these participants had detailed knowledge of rehabilitation, having had a family member in the program. This individual set goals prior to admission and stated he was prepared for the extensive work required to achieve those goals. In relating his experience to King's theory of goal attainment, it can be suggested that his previous knowledge of rehabilitation allowed a perception and resulting judgment about the benefits of rehabilitation. This judgment resulted in formulating his thoughts about the actions required and initiated a strong potential for a positive interactive process with the rehabilitation team.

Levels of hope. Despite limited knowledge of rehabilitation, most participants entered the program with varying degrees of enthusiasm. It could be interpreted that rehabilitation offered hope for regaining an acceptable level of independence. Hope has been identified as an important consideration for recovery in SCI (Dorsett, 2010; Lohne & Severinsson, 2005; Lohne, 2008). Personal meaning of a situation appears to be strongly attached to levels of hope for individuals. Lohne and Severinsson (2005) suggested that patients who had suffered a SCI perceived themselves as caught in a 'vicious circle" (p. 287) of dependency, waiting and loss. This leads to suffering. Hope was seen as a choice to step out of this suffering and to look for comfort within a difficult situation. Hope was connected to longing for the lost lifestyle, and mobility. The authors suggested that any level of progress stimulates hope and that it can be modified throughout rehabilitation to create new hope.

In the data analysis of this study, hope to regain an acceptable level of independence or physical function was noted in varying levels. It was also noted that setbacks in rehabilitation affected the participants in different ways. One participant modified his hope by looking beyond rehabilitation for other means of achieving his goal, while another sought comfort from the team to help her handle the stress from her lack of progress. In both cases, the choice to hope resulted in some action that brought comfort to the individuals. Regardless of whether goals were achieved during the inpatient phase of care or not, hope can be seen as bringing meaning to the situation and as such enhancing the participants' roles of Visioning.

Redefining

The theme of Redefining emerged as the participants described the experience of defining specific rehabilitation goals. This facet of their roles required thinking about alternative measures needed for activities of daily living and what those measures would mean to them and to their lifestyles. It could be interpreted as a redefining of personal strengths, abilities, needs and, as such, of self. King (1981) described self as a person's conception of all that they are "capable of being and doing" (p. 28). She stated that self is subjective and reflects the manner in which individuals define themselves. Situations may create altered meaning to the concept of self in that they may change the individuals' perceptions of who they are and what they are capable of doing. Participants identified several factors to consider in this thematic picture of their roles. Factors that made goal setting difficult were identified as lack of knowledge about their prognosis and personal discomforts with goal setting. Setting goals gave several participants a reality check of their situation, causing distress. Positive outcomes of setting goals were identified as the ability to prioritize their goals and allow a sense of accomplishment as goals were reached.

Input in goal setting. While participants stated that they were given an opportunity to have input in their goal setting, it was evident that this was a difficult task for many of them. The input of health professionals was often mentioned as comprising a significant proportion of goal setting when compared to their own contribution. This observation is in keeping with the evidence identified in the literature review that goal setting tended to be done by health professionals rather than by patients (Bloom et al., 2006; Holliday et al., 2005; Young et al., 2008). Several participants in this study identified that they did not know what was required to gain the level of function and independence they desired, or that goal setting was not a normal thought process for them. These may be factors that contribute to the tendency for health professionals to have strong roles in goal setting.

King (1981) suggested that when mutual goals are set in an interaction between patients and health professionals, and the means of reaching those goals are agreed upon, transaction occurs. When a transaction occurs, stress and tension are reduced. The process of collaborative goal setting in transactions with health professionals may promote patients' roles in this process, and have positive outcomes. In order to promote collaboration in goal setting, health professionals must be cognizant of the need to explore the individuals' perceptions of their personal situations, and their understanding of what will be needed to achieve their overarching priority goals. In doing so, knowledge gaps may be identified and an opportunity for health teaching may become evident. Potential opportunities for emotional support may also be presented.

Knowledge about prognosis. While identifying the overarching priority goal for rehabilitation did not appear to be very difficult for participants, defining detailed goals focusing on activities of daily living was clearly a more difficult, and at times emotional, task. Participants articulated that they did not know what would be required to attain an acceptable level of function, or how much functional gain was possible. One participant articulated that he did not want to set a goal that he could not attain. The fear of failure articulated by this participant may have been an indication that setting a goal that was not achievable would create further loss of hope for the future. Holliday, Ballinger and Playford (2007) reported similar barriers to goal setting in rehabilitation. They found that participants had difficulty setting goals because they did not know what could be achieved. They also indicated that one participant in their study did not want to set goals because of past disappointments with his progress. Similar findings were identified by Young et al. (2008). They stated that participants in their study tended to be passive in the process of goal setting as a result of "lack of expertise in rehabilitation or prognosis" (p. 192). Understanding that lack of knowledge may have an impact on the individual's ability to set goals is an important consideration for health professionals. Exploring individuals' understanding of their prognosis and offering as much information as possible may enhance understanding and promote the patients' roles in goal setting.

Discomfort with goal setting. Several participants identified personal discomfort with the goal setting process for varying reasons. King (1981) identified concepts of the personal system as including perception, self, body image, space, time, and growth and development. In understanding the difficulty in setting defined goals and breaking these goals into incremental steps, the concepts of body image, self, and growth and development may be considered. In SCI, functional tasks that were achieved in infancy, toddler, and preschool development stages, such as gross and fine motor control and control of bowel and bladder are often lost. Body image is changed (Yoshida, Self, Renwick, Forma, King & Fell, 2009; Bassett, Martin Ginis & Buchholz, 2009). Identifying goals that provide alternative means to regularly evacuate the bowel and bladder and simple tasks such as feeding themselves may necessitate a redefining of self, and may have detrimental impact on the individuals' body-images. Not addressing these goals early in the rehabilitation goal setting process may have allowed them the hope that these alternative methods would not be required.

Goal setting gave a reality check. The sense of self was evident in the personal pleasures participants took for granted before their SCI such as driving, involvement in community, and sports activities. While Young et al. (2008) found goal setting to be beneficial in establishing realistic expectations, in the current study the need to comprehend the reality of the implications of SCI could be seen as a barrier to goal setting. When participants defined these activities as future goals, it brought the realization of their loss into sharp focus and caused distress. One participant stated this distress was felt not only by her but also by her husband. The distress caused by articulating tasks that the participants had taken for granted for most of their life may have been a factor in considering their roles in goal setting. In a study conducted with patients in SCI rehabilitation, Belciug (2001) found they used the “Cognitive Avoidance” and “Emotional Discharge”(p. 158), categories of coping identified by Moos in the *Coping Responses Inventory-Adult* assessment tool to assist in coping with their emotions. Responses indicated a tendency for patients with SCI to avoid thinking about the injury or to react to stress with anger. From this perspective it can be suggested that the reluctance to set defined goals reported in the current study may be related to an avoidance mechanism and may provide an opportunity for further research.

Allowing a sense of Accomplishment. While goal setting was seen as difficult by many participants, most acknowledged them as beneficial once set. Participants identified that meeting small increments toward the larger goals felt satisfying, and that goal setting provided a focus. Young et al. (2008) concluded that goal setting provided psychological benefits to both patients and their care givers. They stated that goal setting increased motivation as patients were able to see accomplishments. Lohne and Severinsson, (2005) identified that any step in progress of regaining lost function for SCI patients stimulated hope. This may explain why goal setting was seen as a benefit to some participants in the current study. The ability to see progressive steps in goal attainment may have stimulated hope for recovery. Several participants were not able to achieve their goals while in rehabilitation. One participant stated that he had sought alternative means to reach his goals. He said that he knew he would be able to achieve his goals following discharge, with support from his wife. It could be suggested that although his goals were not perceived as fully attained, the ability to identify them may have allowed him to plan for their future attainment.

Prioritizing goals. Prioritizing goals may have provided an opportunity for some participants to regain a sense of self as they identified priorities they saw as important for their emotional wellbeing and that of their loved ones. Yoshida (1993) suggested that the "reshaping of self" (p. 217) includes various aspects of life, including vocation and interaction with family and others. She stated this process is dynamic and that the perception of self may fluctuate as individuals "interpret and take action" (p. 241) in a situation. Identifying personal priorities that related to their individual lives allowed participants to take action towards attaining goals that they interpreted as valuable to them. This may have assisted in redefining their concept of self and promoted their roles in goal setting.

Brainstorming

Participants articulated their roles in bi-weekly patient conferences as one of sharing knowledge. They stated that the team sought input about their progress in meeting their rehabilitation goals. Participants saw merit in the conferences if they perceived their input as valued, and they received necessary information in return. When this perception existed, sharing knowledge resulted in the ability to "hammer out ideas" (PA03). In those cases, brainstorming was an appropriate description of the interaction. When participants felt they were not heard or agreed upon actions did not take place the experience was perceived negatively. Factors that were perceived as promoting successful interactions in this venue included participants' perceptions of effective communication in the conference, and participants' familiarity with the team.

Discomfort in conference. Many participants identified discomfort with the first patient conference they attended. Most had met individual members of the team by this time, however, meeting the entire team at one sitting created negative experiences for some. It was apparent that some participants did not understand what was expected of them at this first conference. Several participants articulated that their expectations of the patient conference were not congruent with the actual experience.

Past experience, culture, personal beliefs, and values determine perceptions individuals bring to interactions (King, 1981). The descriptions of two participants' expectations may have been informed by past experiences with a medical hierarchy model rather than a collaborative team model. They expected to receive information from the team, but did not expect to engage in a collaborative knowledge sharing process. King (1981) stated that roles are "learned from functioning in a variety of social systems within society" (p. 92). Past experience with a medical hierarchy model of care may have influenced expectations of these participants and resulted in barriers for their roles in sharing knowledge with the team. It would appear that understanding patients' expectations of the conference is an important consideration for promoting their roles in this venue.

Familiarity with team. Discomfort, identified by many as being experienced mainly during the first conference, may have been created by the timing of the venue. The first conference for most patients occurs within the first few weeks of admission.

Participants articulated increased comfort in the conferences as they grew more familiar with the team and the routine. Several mentioned that by the second conference they felt more at ease.

It could be suggested that as participants worked with the individual team members in day-to-day rehabilitation, they grew more familiar with them and found them supportive. That judgment may have been brought to interactions with the team in later conferences. It could also be suggested that by the second and subsequent conferences, participants came to better understand both their roles and the roles of the health professionals. Therefore, placing a priority on building familiarity between the SCI patient and the team could promote the patient's role in Brainstorming.

Lack of action. It was apparent that the value of meeting with the team to share knowledge was compromised in the perceptions of at least two participants. They indicated that the input they gave did not result in action on the part of the team. King (1981) stated that the "concept of role requires individuals to communicate with one other and to interact in purposeful ways to achieve goals" (p. 91). If interaction with the team did not result in action, the role of the participant was devalued. In addition, it is possible that the role of the health professional was also devalued in the participant's perception. This perception may have translated to a judgment of the value of interaction with the health professional and resulted in decreased potential for successful transactions and goal attainment. Mutual respect is a requirement for effective communication (Sieloff, 1991). The perceptions that their input was not acted on may have devalued the roles of the participants in these interactions, and impacted negatively on their roles of sharing knowledge about their goals.

Lack of communication. Issues surrounding communication also impacted the effectiveness of the participants' roles in sharing knowledge. Some of those issues included a language barrier, lack of timely notification of conferences and lack of adequate information given about discharge issues. This lack of communication led one participant to vocalize the resulting perception as "drifting" (PA09). He articulated that because he felt information was withheld he was unable to mentally prepare himself for discharge. His description of being in the program yet "drifting" (PA09) suggested a disengagement from the process of rehabilitation and, as such, a disengagement from his role. It would appear that he may have felt powerless to direct his goals.

A language barrier led one participant to refrain from speaking in patient conferences. She indicated that it would be better not to speak than to chance that her communication would be misunderstood. Culture and language differences are important considerations for interaction. This participant indicated that, when enacting her goals, she simply did as she was told. It may be possible that the inability to share her thoughts in patient conferences had a detrimental effect on her ability to modify and direct her personal rehabilitation goals. It may be of benefit to offer an opportunity to have a family member or translator present at conferences in these situations. Doing so would enhance communication and allow the patient to feel his or her input was valued.

Some participants stated they were not informed in a timely fashion of their conference times. Communication is both verbal and nonverbal in nature (King, 1981).

Lack of timely communication may have sent a nonverbal message suggesting the interaction was unimportant. This would have devalued the contribution of the individual participant and implied that his or her role of sharing knowledge with the team was of no importance. It may be suggested that their personal conference dates be given to patients on admission with an explanation of the role expectations of both the patient and the health professional in these conferences. Doing so may offer the patient greater ease in the situation and permit them to adequately prepare for the interaction with the rehabilitation team.

Rebuilding

Working to attain goals through their day-to-day rehabilitation was a vital component in the participants' perceptions of their roles. They described learning new skills and attempts to relearn skills long taken for granted before their SCI. They attempted activities that were frightening to them, yet seen as promoting independence and a sense of freedom. This facet of their roles appeared to be the one most clearly perceived and articulated in the interviews. Rebuilding can be clearly correlated to steps in the transaction process described in King's theory of goal attainment. King (1981) theorized that if interaction between the health professional and patient is successful, mutual goals will be set, and transactions will occur. Transactions are seen in observed behaviours as "human beings communicate with the environment to achieve goals that are valued" (King, 1981, p. 82). It was clear that rebuilding skills was a highly valued goal for the participants.

Barriers to the participants' achievements of this facet of their roles included both physical and psychological environmental factors. A sense of vulnerability was also noted in the perceptions of some individuals. Lack of timely communication and lack of personal and community resources also impacted on their roles. Factors that promoted the participants' roles included their personal determination to succeed, the perceived support and caring from the rehabilitation team and, for some, a sense of community.

Personal determination. King (1981) suggested that transactions are valued "because the goal is meaningful and worth achieving" (p. 82). Participants indicated that they felt their day-to-day achievements, particularly in addressing the physical aspects of rehabilitation, were very important to them. They described interactions with team members in addressing their goals and stated that while they were pushed to achieve by these individuals, they also pushed themselves. While participants stated that they cooperated with the team to the fullest extent possible in addressing their mutually set goals, not all attained their initial overarching priority goals. Some modified their goals and continued to find satisfaction with rehabilitation. One participant felt dissatisfaction when his goal was not met and articulated that there might be some "fault" (PA01) on the part of the team in this failure. He perceived the concerns he had presented in conference were not addressed, and this resulted in failure to meet his goals. It could be hypothesized that this perception was the result of failed transaction in another facet of his role, that of Brainstorming. This finding highlights the need to recognize the interconnection of each identified facet of the participants' roles, and the impact that failure in one may have on another.

Support of the team. Support from the rehabilitation team was perceived as an important factor in goal attainment. Most participants identified the perception that the team supported them in their efforts to rebuild functional skills. The perception that the individual health professionals involved gave them their full attention was perceived as of great benefit to goal attainment. One participant described gaining returned function in his foot and verbalized his impression that his physiotherapist shared in his joy at this discovery. Yoshida et al. (2009) suggested that a supportive team offers hope for recovery to individuals, and that this hope is beneficial. Lohne and Severinsson (2005) indicated that hope can be given even if goals are not achieved by SCI patients, and that hope will translate to comfort. This was evident in the descriptions given by two participants who did not achieve their rehabilitation goals. These individuals continued to express satisfaction with the team. It was apparent that the support of the health care team was of benefit in the participants' roles of rebuilding their skills.

Concept of rehabilitation community. A sense of community in rehabilitation was noted by a number of participants. They described growing connections with both the team and other patients within the SCI rehabilitation program. Interactions with other patients were not based on discussing health concerns but rather on communication that was supportive and encouraging. Participants indicated that the environment was made more enjoyable through these interactions. It can be suggested that transaction occurs in interactions with other patients as individuals form judgments and react to each other. In sharing mutual goals of encouragement, they are able to achieve greater potential for goal attainment. Yoshida et al. (2009) stated that the importance of peers should not be undervalued. The authors suggested that communication with peers offered an opportunity for learning that may have been overlooked by health professionals. This may be an important factor in understanding the complexity of interactions in the inpatient rehabilitation environment. SCI patients' roles in setting and attaining goals may be enhanced by encouraging greater interaction and involvement with peers.

Vulnerability. Aspects of the rehabilitation environment that were perceived as inconsistent or rushed appeared to create a sense of vulnerability for several participants. Awareness of issues such as infection control procedures, and perceived insensitive nursing practices in his personal care created stress for at least one participant. Moves between rooms created tension for another. One participant noted concerns about the physical environment that made her feel rushed, and upset her. King (1981) addressed concepts of space and time in the personal system. Nurses' roles often require a need to have very intimate contact with patients in the SCI program. These actions may invade individuals' perceptions of their personal space. Understanding the perceived meaning of nursing actions to the individual patient is an important consideration. Actions that are unfamiliar and invasive to the patient must be carried out with explanation and with respect. Providing flexibility to meet time requirements may also alleviate anxiety. It is important to understand the impact of room moves and other organizational routines on patients. Patients, who feel vulnerable, may not understand specific organizational routines that health professionals take for granted. This may contribute to difficulty in fulfilling their roles in rehabilitation.

Communication. Communication in day-to-day rehabilitation activities was mentioned by several participants. Some identified it as lacking, while others found it very effective. When lacking, it resulted in participants articulating a sense of disengagement and lack of satisfaction with the program. If participants found it effective, they felt valued and confident that the team addressed their needs in a timely fashion. There is a wealth of literature exploring the impact of communication between health professionals and patients. The reviewed evidence indicated that good communication empowered patients and improved outcomes (Holmström & Röing, 2010; Trummer, Mueller, Nowak, Stidl & Pelikan, 2006). King (1981) stressed the importance of communication as the "vehicle by which human relationships are developed and maintained" (p.79). She noted that communication is complex and the meaning of the message sent may be different for those sending and those receiving it. As such, seeking to promote the patients' roles in setting and attaining goals as active members of the team requires careful attention to clarifying perceptions and providing timely and effective communication.

Lack of personal or community resources. While some participants spoke of the importance of personal support in assisting the return to community living, others were not as fortunate. Those who identified a lack of personal or community resources described this as an additional stressor to their roles of Rebuilding. The impact of financial concerns and finding appropriate housing in the community appeared to eclipse the ability to focus on their rehabilitation in some instances. Affordable, accessible housing is lacking in our communities. In 1991, the Canadian Mortgage and Housing

Corporation (CMHC) issued a report that outlined the housing conditions for persons with disabilities. This report indicated that one in seven people with a disability have problems with affordable and accessible housing. It does not appear that improvements in this situation have been significant in the last decade. A 2011 report of the Ontario Non-Profit Housing Association (ONPHA) noted an increase of 7.4% in households waiting for affordable housing (ONPHA, 2011). Finding both affordable and accessible housing will continue to be extremely difficult. This issue had significant impact on the individuals involved and can be seen as an example of organizational or social system issues outside of the health care system which have an impact on patients. These situations address the need for nurses to become involved in areas of community health. Social action should be considered as an important aspect of nursing. When advocating for more resources in the community for those who require assistance, nurses address the social systems that affect the health of many individuals.

Conclusions

Four themes were identified in the participants' perceptions of their roles in setting and enacting their personal rehabilitation goals: Visioning, Redefining, Brainstorming, and Rebuilding. Each theme reflected a facet of the participants' roles. Participants were able to clearly identify their roles of engaging in rehabilitation, sharing knowledge, and rebuilding skills for community reintegration. However, it was apparent that defining specific rehabilitation goals to address activities of daily living was much more difficult. Factors that impacted on the participants' roles involved interactions with both the rehabilitation team and the health care system. Effective interactions led to transactions, goal attainment and satisfaction. When interactions were not effective, transactions did not successfully occur and the roles of the participants were negatively impacted. Important considerations emerging from these findings include the need to a) understand the patients' perceptions and past experiences, b) provide knowledge, and c) support effective communication.

Chapter Seven

Future Directions

This chapter will discuss the implications for nursing practice resulting from this study, the limitations of the study, and suggestions for future research. Implications for nursing practice, based on King's theory of goal attainment, focus on the need for health professionals to be conscious of the fluid nature of the interactive process. Recommendations for research will be offered to suggest areas that may provide opportunity for greater insight into this phenomenon.

Implications for Nursing Practice

Implications for nursing practice, resulting from this study, focus on the need to generate effective interactions for the purpose of promoting patients' roles in goal setting. Results of this study suggest the need to understand the patient's past experiences and perceptions, the importance of sharing knowledge, and the impact of both verbal and non verbal communication. Sharing knowledge to provide deeper understanding of rehabilitation may allow greater opportunity for patients to actively engage in collaborative goal setting. Opportunities for obtaining knowledge are important, not only for patients but for health professionals as well.

Rehabilitation Practice

Understanding meaning for patients. Evidence in the study suggested that some patients may perceive goal setting to be a difficult task for a variety of reasons. These reasons include lack of knowledge about their prognosis and the emotional impact of absorbing the reality of their current situations. In understanding the implications of the patient's lack of knowledge about SCI prognosis and the impact on his or her role in goal setting, it is crucial that the patient's meaning of the situation be explored. Lack of knowledge about prognosis may make goal setting difficult (Holliday, Ballinger & Playford, 2007; Young et al. 2008). Discomfort in goal setting may be related to the patients' avoidance of the reality of the situation (Belciug, 2001). Exploring the individual's perceptions of reality will prepare the health professional for effective communication about the interventions required. This will provide understanding of the patient's perception and judgment of his or her current situation and allow mutual exploration of options for goal attainment in a collaborative interaction.

It may be suggested that the importance of emotional support for the patient in the early phase of SCI care requires the intervention of a health professional with expertise in addressing psychological issues. Given the impact of SCI and the resulting emotional adjustments required, it may be of importance to initiate intervention with a social worker or neuropsychologist prior to admission to the rehabilitation program. This will allow for a continuum of emotional support as the patient transitions from the acute care setting to rehabilitation. The importance of offering hope, while articulating realistic expectations, is also a crucial requirement for health professionals to consider when providing care to patients with SCI (Dorsett, 2010; Lohne, 2008). Health professionals should be aware that offering hope for continued life satisfaction may help the patient avert despair.

Providing knowledge. The study offered an indication that knowledge regarding the rehabilitation process prior to admission was of benefit to promoting SCI patients' roles in goal setting. Implications for practice may include a number of opportunities for knowledge transfer. It was noted that a tour of the facility assisted one individual in familiarizing herself with the program. Offering individualized tours of the rehabilitation facility to SCI patients who will soon be admitted to the inpatient program may be of benefit. The continued use of the CPA peer support program to coordinate meetings between SCI patients in the acute care setting and peer support volunteers will allow early communication with individuals who may have attended rehabilitation in the recent past (CPA, 2011b). This will allow patients to receive information from a peer who has experienced similar situations.

Multimedia educational options to assist patients in learning about the inpatient rehabilitation program are also opportunities for knowledge sharing. Developing teaching videos and providing them to patients and families prior to their admission to rehabilitation may be of benefit in familiarizing them with the rehabilitation process. Written patient education material that has been developed specifically for the SCI population should also be used to offer information. This will provide general SCI information as well as information specifically about rehabilitation that may be helpful to patients and their families. Reviewing the information with a rehabilitation health professional prior to admission will allow an opportunity for questions, and provide a venue for initiating a relationship with the patient.

Familiarity with the team was seen as reducing stress. A clear understanding of expectations of both the rehabilitation routine and the role expectations in the program will be beneficial to patients. Communication of expectations and interventions in a timely fashion may relieve anxiety and promote the roles of patients in setting and attaining goals. Health professionals are familiar with the routines within the health care system and may overlook the need to communicate the reasons for those routines to patients. Education to address concerns that may be troubling to patients in the environment, such as methods to address infection control issues while allowing full participation in rehabilitation, will provide necessary knowledge and decrease patients' anxiety. Providing a venue where an infection control nurse offers education to the patients can be one method of sharing knowledge. Addressing environmental issues that cause distress for patients ensures them of nurses' respect and concern for them.

Ensuring timely information is also an important factor in demonstrating respect for the patients' roles. Nurses may also feel frustrated by the lack of time given to prepare patients for interventions. Creating a process that ensures this information is passed to both staff and patients in a timely process will empower both the patients and rehabilitation health care staff.

The concept of the rehabilitation community became apparent in the descriptions given by some participants. The value of peers was seen as enhancing the environment by creating an atmosphere of camaraderie and support. Capitalizing on the benefit of peer support may offer an opportunity for increased engagement in the program. Peer led learning opportunities, supported by the rehabilitation team, will allow patients to speak about the challenges of community reintegration with those who have met those challenges and found successful means for overcoming them. It may also be an opportunity to promote peer connections for emotional support both during and after rehabilitation (CPA, 2011b).

Enhancing communication. Results of the study identified that detailed goal setting is a difficult and, at times, an emotional process for many SCI patients. While patients should be encouraged to set personal rehabilitation goals, health professionals must individualize their support for them in this endeavour. Collaborative goal setting based on individual patient needs will allow the benefits of goal setting to be realized while providing opportunity for the patient to articulate their personal priorities for interventions. The use of a decision-making tool outlining the goal setting process may provide opportunity to allow patients to digest the meaning of the situation and the process required to regain a level of function that will be acceptable to them. Patient education material suggesting potential rehabilitation goals should be offered prior to admission, allowing the patient opportunity to prepare for goal setting.

King (1981) stated that there may be incongruence between the goals of the health professional and the goals of the patient. Recognizing this is important to promote effective interactions. The College of Nurses of Ontario (2009) emphasizes the responsibility of nurses to provide knowledge that will allow informed and autonomous patient decision-making. Accepting that the values attached to certain rehabilitation activities may differ in the health professionals' and patients' perceptions is a crucial element in effective interactions. Health professionals must be aware that they bring their own meanings, based on personal perceptions, judgment, and convictions about required actions, to interactions with patients (King, 1981). Acknowledging these, while supporting the patient's right to autonomy, will lead to more effective communication and will promote the role of the patient in mutual goal setting.

One area that was identified as a barrier to the patients' roles in goal setting was the first attended, and at times, subsequent patient conferences. Participants in the study identified initial discomfort in this setting and the need to have an opportunity to prepare for attending conferences. Providing information about conferences, identifying the roles that health professionals and the patient are expected to take, and providing dates when the patient is scheduled to attend, well in advance, may reduce the associated discomfort. It may be suggested that the first conference with the team be delayed to allow the patient to become familiar with the rehabilitation routine, or that this conference be dedicated to helping the patient understand the goal setting process. It is important to realize that some individuals with SCI may find attending a conference with many health professionals uncomfortable. Steps should be taken to reduce the number of staff attending the conference to only those who are necessary. Support from an accompanying CPA peer or family member may also reduce stress.

While patient conferences with the team may be seen as a valuable venue for sharing knowledge, it is crucial that the team act on the mutually agreed upon goals. Patients must perceive interactions in mutual goal setting as having been followed through by the team to bring about agreed upon transactions (King, 1981). It is noted that if patients believe their priority goals are not being addressed they may not be successful in their roles of sharing knowledge and rebuilding skills. It is also imperative to realize that if patients perceive their input as not valued, they may become disengaged and feel disempowered in the rehabilitation process (Holmström, & Röing, 2010).

Implications for Supporting Rehabilitation Staff

Education for rehabilitation staff. Education is important for front line health professionals. The dissemination of evidence defining coping mechanisms seen in SCI patients will benefit those who are caring for them. Knowledge of behaviours that may be commonly exhibited while patients are dealing with the emotional aspects of SCI will allow health professionals to address the psychological needs of their patients. A strong understanding of SCI etiology, levels of injury, and accompanying health issues is important for all staff to acquire. Encouraging attendance at SCI conferences, and providing both multimedia and hard copy educational materials to new staff will help promote knowledge and prepare staff for effective communications with SCI patients.

Promoting interprofessional education will build team collaboration and allow understanding of the value of each individual health professional's role (Laurenson & Brocklehurst, 2011; Thibault, 2011). Thibault (2011) suggested that it promotes nursing leadership and breaks down barriers between professionals. It can also be used as an opportunity to develop team skills that will enhance interactions with patients. The focus on self-management for individuals with chronic care has resulted in a range of educational opportunities for preparing health professionals to teach patients to direct their own care (Lorig et al., 2001; McWilliam et al., 1997; Miller & Rollnick, 2002). Offering workshops that focus on the promotion of self-management skills and decision-making for patients will prepare staff to meet challenges in mutual goal setting with patients. It may be useful in promoting the patients' roles in rehabilitation, and supporting self-efficacy for patients returning to the community.

Connecting teams. Interfacing connections between the acute care team and the rehabilitation team should be strengthened to ensure the patient is given consistent information. It may be of benefit to encourage meetings between the SCI health care team and the rehabilitation team prior to the patient's admission to rehabilitation. This would ensure that the rehabilitation team is aware of issues arising in the acute setting, that they would be prepared to address ongoing concerns, and that the acute care team would be aware of the options available to assist the patient in rehabilitation. It would also allow some leeway to begin preparations for community reintegration while the patient is still in the acute care setting, providing an opportunity to streamline the rehabilitation process.

Implications for Research

Supporting current research. The study findings supported current research. The psychological impact of SCI on patients suggested by Belciug (2001), Holliday, Cano, Freeman and Playford (2007), and Struhkamp, (2004) was evident and seen to have significant impact on the participants' roles in rehabilitation. The research findings of Holliday, Ballinger and Playford (2007) and Young et al. (2008) were also supported in this study. While goal setting could be seen as beneficial in all three studies, it is evident that more research in understanding the challenges and barriers to patients' roles in goal setting will be beneficial.

Supporting King's theory. The findings of this study support evidence of the importance of effective interactions to promote successful transactions and goal attainment as suggested by King (1981) in her theory of goal attainment. They also confirm the individual's basic need for health care information (King, 1971), and the importance of effective communication. The impact of social systems was evidenced in the findings of the study, and confirms the need for health care professionals to be aware of all levels of the interconnecting systems. This study is evidence that King's theory of goal attainment continues to be of value for all health professionals.

Implications for Policy

Advocating for social change. Advocacy to change areas of social systems that negatively impact on both patients and health professionals will require nurses to pursue political power. Nurses have long understood that they stand as the strongest patient advocates in the health care system. They represent a large and respected group of health care professionals (Canadian Nurses Association [CNA], 2009; Registered Nurses of Ontario [RNAO], 2010). There is power to change the system when nurses understand the personal impact social systems can have on patients' lives and share that knowledge with governing bodies. The need to act within the public, as well as the health domain, is an imperative action to promote nursing autonomy and act as strong advocates for patients (CNA, 2009; RNAO, 2010). Taking an active role in disseminating information regarding social determinants of health and informing both politicians and the public about the concerns of inadequate housing and finances for those with disability will result in empowerment for both nursing and individuals in the community.

Advocating for changes in health care. Addressing the impact the health care system may have on patients' sense of personal control is another area of action for health professionals. It may be suggested that greater emphasis should be put on promoting a continuum of care between the acute care setting and rehabilitation. A strong interfacing connection between SCI acute care and rehabilitation health professionals would allow rehabilitation care to be initiated prior to admission, and allow acute care follow up to continue after admission to rehabilitation. Advocating for a health care process that allows the smooth transition directly from an acute care setting to rehabilitation for patients with SCI will reduce the sense of loss of control and will promote patient autonomy. This, in turn, will enhance the patients' role in goal setting both in rehabilitation and as they progress to community reintegration.

Limitations of the Study

There are a number of limitations in this study. The research was completed on only one rehabilitation site in one city. This reduces the potential for transferability of the findings as other rehabilitation facilities may have alternative practices that affect goal setting. The small sample pool available at the facility, the familiarity of the team with the participants' life stories, and the connection of the researcher with the facility required extreme diligence to protect the privacy of participants. This reduced the ability to provide individualized detail of the participants which may have enhanced ability for those reviewing these findings to judge their transferability to other populations. Age groups were not as well represented as could be hoped. Only two participants were under the age of 25 while nine were over the age of 55. Marital status was included in the demographics to allow an understanding of the personal support available to the individuals. However, this did not adequately reflect other personal resources such as parents and family members. Despite limitations, this study revealed concepts that allowed a picture of the participants' perceptions of their roles in setting and enacting rehabilitation goals. Findings in this study were consistent with those found in the reviewed literature. Similar findings were identified in the research conducted by Holliday, Ballinger and Playford (2007) and Young et al. (2008). This research will add to current knowledge in that it supported current evidence and identified factors that promoted or hindered the fulfillment of those roles in a specific SCI population. It also revealed factors that would worthy of further exploration of patients' perceptions of goal setting.

Suggestions for Future Research

Future research to explore the possible connection between increased knowledge of SCI rehabilitation at specific time points prior to admission, and the promotion of successful goal setting, would be of benefit. Lack of understanding of the rehabilitation process, found to be a barrier for patients with SCI in this research, was also identified as a hindering factor in the study conducted by Holliday, Ballinger and Playford (2007). The unique example offered through a participant who had detailed knowledge of the program prior to admission, provides limited evidence that knowledge may be a factor in promoting the patient's role in goal setting. This concept would be worthy of future investigation.

Research to expand on the understanding of the possible connection between the process of goal setting and the perception of self would also be of interest. The participants' observations about the emotional and difficult task of defining specific goals and its connection to the realization of their situation offer some foundational insight into this phenomenon. Further research has potential to enhance that knowledge.

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Appendix A

Sample Interview Questions

1. What brought you here to rehabilitation?
2. How did you hear about rehabilitation?
3. What did you hope to accomplish in rehabilitation?
4. What has been your experience in rehabilitation?
5. Can you tell me about patient conference?
6. How do you see your role in these conferences?
7. What does goal setting mean to you?
8. What input did you have in setting your goals?
9. Is there anything you would like to add about your experience in rehabilitation?