THE MEANING, PROCESS, AND CONSEQUENCES OF NURSE CARING
AS PERCEIVED BY SPINAL CORD INJURED INDIVIDUALS
DURING REHABILITATION

by
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ABSTRACT

The Meaning, Process, and Consequences of Nurse Caring as Perceived by Spinal Cord Injured Individuals During Rehabilitation

Kathleen T. Lucke, PhD, 1995

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The purpose of this qualitative study was to describe the meaning, process, and consequences of nurse caring from the perspective of spinal cord injured (SCI) individuals while in rehabilitation. This study addressed the following research questions: 1) What is the meaning of nurse caring to SCI individuals in rehabilitation? 2) How is the process of developing a caring relationship perceived by SCI individuals during rehabilitation? 3) What are the consequences of nurse caring for SCI individuals in rehabilitation? The theoretical foundation of this study was synthesized from philosophical, ethical, feminist, and nursing literature.

A purposive sample of adults with traumatic SCI were interviewed at least once during their initial rehabilitation admission. Only individuals who could speak and understand English were included in the study. Individuals with all levels of injury, both complete and incomplete lesions, were included; individuals with a documented head injury or cognitive deficits were excluded. In-depth, tape recorded interviews with participants were
conducted after receiving informed consent. The constant comparative method of Glaser and Strauss was used for collection and analysis of data; appropriate strategies were used to insure scientific credibility.

Twenty interviews were conducted with fifteen SCI individuals at various times during their rehabilitation stay. Interviews were conducted over a six month period at two free-standing rehabilitation centers in southwestern Pennsylvania. The core category of "getting back together" or reintegration of self, which was the major work of rehabilitation, was accomplished with nurses and therapists who were perceived as caring.

Four dimensions of caring were important to SCI participants in rehabilitation: knowledge, technical skill, interpersonal skill, and competence. The process of a developing caring relationship was conceptualized, from participants' descriptions, in three phases: learning the other, learning what I need to know, and letting me find out. Consequences of nurse caring for SCI individuals were: well-being, self-care, autonomy, independence, and hope.

Nurse caring is perceived by SCI individuals in rehabilitation as central to recovery and to a positive attitude toward disability. Concepts described in this study can be used to develop an instrument to measure nurse caring and to teach nurses and nursing students important aspects of caring in rehabilitation.
DEDICATION

This project is dedicated to my parents and to my family. Without the values instilled in me by my parents this milestone would not be possible. They taught us to be all that we could be and to strive to reach our goals. This instilled in me the confidence and perseverance to achieve this goal.

Also, a tremendous debt of gratitude and love goes to my family, my husband Joe and sons Adrian and Sean. They all made sacrifices to assist me in completing this process and also provided the love and support needed to help me get through this project.
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CHAPTER 1

In the first chapter, a brief introduction to spinal cord injury (SCI) will be provided which will include a description of the injury, the rehabilitation process, and the nurse's role in rehabilitation. Next, an overview of the problem area to be studied, nurse caring, will be discussed. Finally, the study purpose, specific aims, theoretical framework, significance, and assumptions will be outlined.

Introduction

Each year there are approximately ten thousand new spinal cord injuries in the United States (Zejdlik, 1992). The majority of spinal cord injuries occur in young males under age 35 and are alcohol or drug related. SCI from motor vehicle accidents, falls, sports injuries, or violence can cause compression, twisting, stretching or destruction of nerves which leave an individual with paralysis or weakness of the arms and/or legs, loss of sensation, inability to control the bladder and bowel, and impaired sexual functioning (Zejdlik, 1992).

In the past 10 to 15 years, the number of individuals who survive a SCI has increased due to sophisticated emergency and trauma systems in our country. In addition, the lifespan of a spinal cord injured individual is now approaching that of an uninjured person due to advances in knowledge and technology, especially in the areas of
respiratory, urinary, and integumentary management (Eisenberg & Saltz, 1991). The cost of emergency care, hospitalization, rehabilitation, and on-going care over the lifetime of a SCI individual is estimated to exceed 1.5 million dollars (Berkowitz, 1992). Additionally, the economic and social consequences of lost productivity, premature death, environmental modifications, and specialized equipment is staggering (Rice & McKenzie, 1991; Berkowitz, 1992).

Following the initial life-saving and stabilization measures in an acute care setting, the SCI individual is usually transferred to a rehabilitation facility. While in rehabilitation, the individual is assisted in returning to the "fullest physical, mental, social, vocational, and economic capacity of which each is capable" (National Council on Rehabilitation, 1984). The rehabilitation team assists the SCI individual in learning adaptive means of living in a supportive environment, while refining or learning coping and social skills which will enable the return to a productive and satisfying lifestyle.

Over 90% of SCI individuals return home after rehabilitation (Roth, 1992). Rehabilitation in an inpatient setting can last from one month for someone with minor deficits to a year for a person with complete paralysis and ventilatory support (Zejdlik, 1992). Following in-patient rehabilitation, new or modified occupational skills, which
can result in a loss or change in vocational goals, earning capacity, and disrupted family relations, may be required to return to the work force, (Lynch, 1992). The process of adaptation to the devastating effects of a SCI often takes several years (Hammell, 1992; Wortman & Silver, 1989).

Traditional rehabilitation has been viewed as teaching the patient a set of physical skills which would enable the individual to achieve the highest possible level of independence (Marshall, 1984). When more individuals with high level cervical cord injuries began surviving, the traditional approach of rehabilitation viewed these individuals as having little rehabilitation potential, since their ability to live independently was limited. Psychological and sociological theories of adjustment and adaptation to injury began to influence the rehabilitation perspective; to date many of these theories remain untested (Wright, 1983; Trieschmann, 1988; Shontz, 1967). Rehabilitation outcomes continue to be conceptualized and defined predominantly from the perspective of health care professionals (Hammell, 1992).

Although there exists a paucity of systematic rehabilitation research to date, it is recognized that a complex interaction of patient, family, environmental, and economic factors, as well as attitudes of health care workers and society influence the adjustment, community reintegration, and quality of life after SCI (DeVivo &
Richards, 1992; Hammell, 1992; Trieschmann, 1988; Bodnheimer, 1983). The attitudes, reactions, and expectations of rehabilitation staff are found to have an important influence on patient outcomes (Acorn & Brampton, 1992; Mathews, 1976; Aadalen & Stroebel-Kahn, 1981). Rehabilitation patients react significantly to the people they see as important, such as family members and team members (Bodenheimer, 1983; Dewis, 1989; Tucker, 1980; Lawson, 1978). Events personally viewed as positive and negative, opinions of health care team members, and the management of "first time" events in rehabilitation play a significant role in adjustment for SCI individuals (Lawson, 1978). Additionally, hope as been positively related to patient outcomes in rehabilitation (Pizza, et al, 1991).

In most rehabilitation settings, the nurse functions as part of a team which comprises the individual patient, the family, and other health care providers. The SCI individual and family are core members of the rehabilitation team. To participate fully in the rehabilitation plan, the patient and family gain knowledge about their disability and the care required. Ultimately, the patient and family "take charge of their own care and mobility, as well as pursue work and play opportunities and gain expertise in accurately and appropriately directing their own care when unable to perform such care" (Dittmar, 1989, p. 35).

Nurses assist patients in doing things they would
otherwise be unable to do for themselves, while moving the patient toward greater independence (Henderson, 1966; Orem, 1985). Rehabilitation nurses believe that "individuals are complex but unified, whole beings who have the right and responsibility to make informed decisions and choices about their futures; individuals have intrinsic worth that transcends their disability" (Association of Rehabilitation Nurses, 1987). The goal of rehabilitation nursing is the therapeutic use of self in "active partnership with disabled individuals and in collaboration with other healthcare providers to promote health and allow independence" (Mumma, 1987, p. 23). The role of the nurse in SCI rehabilitation is multifaceted. The nurse functions as caregiver, patient advocate, teacher, counselor, partner, supporter, collaborator, facilitator, and coordinator of care (Zejdlik, 1992).

Individuals in rehabilitation have prolonged and intimate contact with a nurse. In the initial days or weeks following a SCI injury, when the paralyzed individual is dependent on the nurse for most or all aspects of self-care, it is only through verbal and nonverbal communication that the patient is able to participate in self-determined choices and self-care.

Because most SCI individuals are not cognitively impaired, the dynamics of the interpersonal relationships between the nurse and the individual are important. How the
nurse acts toward, communicates with, and reacts to the SCI individual can have an impact on whether they want to live or die (Mathews, 1976), how they perceive themselves as a person (Griffin, 1980), their attitude toward their injury, and their attitude toward recovery (Keane, Chastain, & Rudisill, 1987; Dewis, 1989; Zejdlik, 1992). Throughout recovery, the nurse returns responsibility for self-care and decision-making to the individual while maintaining the integrity and self-respect of the person (McFarlane, 1976). It is essential, therefore, to identify those behaviors of the nurse which facilitate the process of achieving these outcomes.

Because SCI individuals are among the most vulnerable, powerless, and dependent patient populations at the outset of rehabilitation, and must acquire a tremendous amount of knowledge and skill prior to discharge, it was imperative to study a theoretical construct which would link the interpersonal aspects of rehabilitation nursing with important rehabilitation outcomes. The construct of nurse caring comprises the values of patient care espoused by rehabilitation nurses: respect, dignity, worth, wholeness, partnership, and therapeutic use of self. Also, patient outcomes included in theoretical descriptions of nurse caring are among the desired patient outcomes in rehabilitation: self care, autonomy, and independence. Because there is little empirical research on nurse caring
in rehabilitation, this study seeks to extend and refine the substantive theory of nurse caring from the perspective of SCI individuals in rehabilitation.

**Problem Overview**

Patients are able to identify caring behaviors of the nurse which they value, but these are not always congruent with caring behaviors valued by nurses. Patients in rehabilitation place great emphasis on having their needs anticipated, while nurses seem to place greater value on patient's achieving independence and self-care (Keane, Chastain & Rudisill, 1987). Also, patients perceive that nurses often have to challenge the institutional norms when choosing to act as patient advocates (Dewis, 1989).

Rehabilitation patients value nurses who take the time to "communicate effectively," largely through the use of empathy, and who are able to discover patient's expectations regarding control of self-care. Patients describe the use of their own unique deliberate strategies, without direction or assistance from members of the health care team, in an effort to manage the rehabilitation regimen, maintain day-to-day routines, create support networks, and generate hope (Dewis, 1989).

In a pilot study, this investigator interviewed four SCI individuals following rehabilitation to explore special relationships they experienced with a health care provider during rehabilitation. All participants described a
particular relationship, usually with a nurse and sometimes with a nurse and a therapist. When describing this relationship and how it differed from their relationships with the other health care providers, three themes emerged: *wholeness*, *individuality*, and *shared responsibility*. These "special" caregivers treated them as a whole person even though the patients felt they had a broken body. Furthermore, these providers individualized care, and let patients share in the responsibility for decision-making, rather than simply telling them what to do. These dimensions of caring, described by SCI individuals in rehabilitation, are not reflected in any of the instruments designed to measure nurse caring by patients.

Nurses, along with other members of the health care team, value self-care, autonomy, and independence as outcomes of rehabilitation (Dunnum, 1990; Lundquist, et al, 1991; DeVivo & Richards, 1992; Yarkony, et al, 1987). How nurses know when patients are ready to begin self-care and how they actually start the process of delegating responsibility for self-care and decision-making to the patient is unknown. Nurses feel they are best able to make decisions about what self-care patients should be completing, but want patients to actually perform their own self-care (Doyle & Stern, 1992). Patients, on the other hand, also want to complete the decision-making phase of self-care, but often want nurses to perform their physical
care in rehabilitation (Dewis, 1989). The process of how a SCI individual moves from dependence to independence in self-care and decision-making, from the patient's perspective, has not been widely studied (Yarkony, 1987; Dewis, 1989).

Autonomy, which has been defined as informed choice and freedom to make informed choices, has been shown to be positively related to self-care ability (Moore, 1987; Ladewig, 1989), and is often equated with control, which has a further positive effect on coping and adjustment to disability (Ferrington, 1986). However, control is only a part of autonomy, (Garbett & Shephard, 1993). It is not known whether caring behaviors of the nurse affect self-care ability and autonomy, as perceived by SCI individuals in rehabilitation.

Given the opportunity, patients will share the meaning of the experiences of SCI and the process of adaptation that begins in rehabilitation (Dewis, 1992). The descriptions of important aspects of nurse caring for SCI individuals in rehabilitation appear incomplete. The meaning of nurse caring to SCI individuals in rehabilitation is unclear. Whether caring actions of the nurse assist patients in rehabilitation identify realistic goals and facilitate the development of self-care abilities and autonomy, rather than merely encouraging compliance with the medical plan of care, is largely unknown. The extent to which patients in
rehabilitation are allowed to choose treatments and goals, whether this is desired by patients, and how it relates to patient's perceptions of the achievement of rehabilitation outcomes is not known.

Statement of the Problem

Although patients and nurses in rehabilitation settings are able to identify caring behaviors they value (Keane, Chastain & Rudisill, 1987), these perceptions are not always congruent. The process of how a caring relationship develops between a patient and a nurse, how roles and responsibilities are negotiated in the relationship, and the consequences of this relationship are unknown. How caring behaviors of the nurse, which are valued by the SCI individual, are related to rehabilitation outcomes of self-care and autonomy is also unknown.

Theoretical Framework

Consistent with the process of verification and extension of theory, current knowledge of the concepts and their relationships must be made explicit. These conceptualizations will either become clearer and richer, be modified, or completely abandoned as the data are compared with existing knowledge.

Caring is relational in that it occurs during the interaction between a nurse and patient (Mayeroff, 1971; Watson, 1979). Each individual brings to the relationship knowledge, values, history, goals, and needs (Mayeroff,
1971). Caring is embedded in the cognitive, affective, and psychomotor skills of the nurse, and is manifested in the interactions with the patient and actions taken by the nurse on behalf of the patient (Benner, 1984; Gadow, 1983; Gaut, 1984). Competence of the nurse is an important element of caring (Fry, 1991; Benner, 1987; Gaut, 1984). As the nurse's knowledge and experience grows, the potential for caring is enhanced (Benner, 1987).

Certain qualities are present in a caring relationship. These are: respect for the dignity of the persons involved (Fry, 1991; Griffin, 1980; Gaut, 1984; Mayeroff, 1971); connectedness (Gilligan, 1982; Benner & Wrubel, 1989); recognition of the uniqueness of the individuals (Heideger, 1964; Gaut, 1984); compassion and truth (Mayeroff, 1971); responsiveness, receptivity, commitment, and reciprocity (Leininger, 1991; Noddings, 1984; Griffin, 1980).

As the caring relationship unfolds, sharing between the individuals occurs, reflecting the uniqueness of the persons involved (Wolf, 1986; Larson, 1987). The nurse explores the patient's values, history, needs, and goals (Cronin & Harrison, 1988; Clayton, 1988; Keane, Chastain, & Rudisill, 1987). The nurse also shares with the patient her knowledge, values, and goals (Valentine, 1989b; Brown, 1986; Wolf, 1986). As the patient gains knowledge and becomes confident in the nurse's competence, the patient becomes more expressive, sharing life history, values, needs, goals,
and participation in decision-making increases (Clayton, 1991; Doyle & Stern, 1992; Blenner, 1990; Gadow, 1989). The patient also begins to feel like an equal in the relationship and truly becomes a partner in his/her health care (Blenner, 1990; Dashiff, 1992; Doyle & Stern, 1992).

A caring relationship then moves into the mutual identification of need for nursing care and desired goals resulting from this care. The nurse, based on knowledge and experience, identifies for the patient possible interventions or actions for which each would be responsible, which would move the patient toward the desired goals (Biley, 1992; Benner, 1987). The patient identifies for the nurse, those goals and actions which would be congruent with his/her values, beliefs, lifestyle, and abilities (Gauthier, 1993; Deci & Ryan, 1992; Ferrington, 1986). Goals and actions would then be mutually agreed upon, with both the nurse and patient accepting responsibility for their respective actions (Gaut, 1984).

Caring is also manifested by the actions taken by the nurse on the patient's behalf. Interpersonal and technical skills are undertaken to: assist the patient to achieve desired goals (Clayton, 1991; Forrest, 1989; Fenton, 1987; Gaut, 1980); enhance patient autonomy in decision-making, self-care ability, well-being and dignity (Mayeroff, 1971; Gadow, 1980; Leininger, 1981; Gaut, 1984; Fry, 1991; Clayton, 1991; Brown, 1986); and assist the patient in
finding meaning in the experience of illness, injury, or dying (Gadow, 1980; Clayton, 1991; Dewis, 1989).

Crucial to a caring encounter is the ability of the nurse to validate her perceptions of the patient's needs and goals with the patient (Orlando, 1961). If the nurse were to simply implement the nursing process by identifying problems, goals, and interventions, without input or agreement of the patient, the ethical ideal of the patient would be diminished. The patient would be reduced to an "object" of nursing care since the uniqueness of this particular patient would not have been considered (Gadow, 1983; Fry, 1991).

The process of a caring relationship or encounter ideally results in positive consequences for both the patient and nurse. Specific outcomes which were established for the relationship will hopefully be met or revised. In addition, as a result of the caring relationship, the patient will ideally experience: increased self-care knowledge and ability (Clayton, 1991; Ailinger, 1993); enhanced autonomy in decision-making (Brown, 1986; Doyle & Stern, 1992; Ladewig, 1990; Cofield, 1990; Moore, 1987); enhanced well-being (Watson, 1979; Mayeroff, 1971; Gaut, 1983; Gadow, 1984; Leininger, 1981); and improved satisfaction (Valentine, 1992; Duffy, 1992; Larsen, 1993). The nurse will experience greater caring competence (Benner, 1991; Clayton, 1991;) and enhanced well-being (Reiman, 1986;

In order for caring to occur, the environment and organizational structure must support this concept. Nurses must have support from each other, their colleagues, and the environment in which they practice in order to have "time to care" (Fry, 1988; Doyle & Stern, 1992). If this does not occur, the moral ideal of both the patient and nurse is diminished, and the well-being of the patient and nurse may be compromised.

**Study Purpose and Aims**

Our knowledge of caring is incomplete. Most of the descriptive studies of nurse caring have been conducted with hospitalized patients. Two dimensions of caring seem consistent, however, across patient populations: physical and interpersonal aspects of caring. In the only study of nurse caring conducted with rehabilitation patients, the physical aspects of caring were rated similar to hospitalized patients. The interpersonal aspects of caring, however, were rated differently (Keane, Chastain, & Rudsill, 1987).

Current conceptualizations of nurse caring do not appear to be theoretically complete. Dimensions of nurse caring described, in a pilot study, by SCI individuals during or following rehabilitation are not reflected in the current instruments used to measure nurse caring. These tools were developed primarily from the perspective of
nurses and do not have demonstrated construct validity with patients (Larson, 1984; Fenton, 1987; Valentine, 1991; Duffy, 1992; Wolf, 1994).

There is a proposed association among nurse caring and important rehabilitation outcomes of self-care and autonomy in theoretical discussions and descriptive studies of caring (Gaut, 1983; Bottorff, 1984; Griffin, 1983; Watson, 1979; Brown, 1986; Reimen, 1986; Wolf, 1986; Keane, Chastain, & Rudisill, 1987; Valentine, 1991). Three correlational studies testing the relationship of nurse caring with patient outcomes, however, found only one positive association: patient satisfaction (Valentine, 1991; Duffy, 1992; Larson, 1993). The perceived consequences of nurse caring on self-care ability and autonomy of SCI individuals in rehabilitation have not been studied.

The purpose of this qualitative study is to describe the meaning, process, and consequences of nurse caring as perceived by SCI individuals during rehabilitation.

The specific aims of the study are to:

1) Describe the meaning of nurse caring from the perspective of the SCI individual during rehabilitation.

2) Identify the process of a developing caring relationship as perceived by SCI individuals while in rehabilitation.

3) Identify the consequences of nurse caring from the perspective of SCI individuals in rehabilitation.
4) Refine and extend the substantive theory of nurse caring as it applies to SCI individuals in rehabilitation.

Significance

Often when an individual enters rehabilitation they are expected to conform to the social structure of the setting, and follow the treatment plan and goals established by the rehabilitation team to achieve independence. This model of rehabilitation fosters a role of passive dependence and compliance, which does not recognize the wide variety of individual responses to traumatic SCI, the need to become an active participant in care, and eventually assume responsibility for health (Trieschmann, 1986). Rather, the rehabilitation setting should create an environment where the individual can assess his or her own needs, decide on goals, and implement behaviors to meet these goals (Coles, 1989; Tucker, 1984), in collaboration with the health care team. If all the elements of nurse caring important to SCI individuals in rehabilitation can be identified, a more theoretically complete model of nurse caring would evolve which could guide the development of instruments from the substantive theory of nurse caring for use in rehabilitation research.

It is the role of health care rehabilitation professionals to facilitate the process of adjustment to SCI by recognizing the individual characteristics and life values of the person, and creating an environment where
independence, problem-solving, and coping with disability can be learned (Trieschmann, 1988; Frank, 1987; Tucker, 1980). Patients are often left on their own to develop strategies to cope with the rehabilitation regimen and generate hope (Dewis, 1989; Lawson, 1978). If nurse caring can be shown to enhance patient autonomy and self-care ability, from the patient's perspective, this link between nursing interventions and patient outcomes could be assessed in future studies. The range of treatment options and goals could become more varied, individualized, and realistic which may enhance the SCI individual's sense of well-being and hope. Not only would the quality of patient care be improved, but there may also be a decrease in the length of stay and costs resulting from this individualized, holistic care.

During rehabilitation SCI individuals make significant improvements in self-care, mobility, as well as autonomy and preferred control in decision-making (Glass, 1991; Ferrington, 1986; Yarkony, 1987). Skills and decision-making which patients and families are able to accomplish in rehabilitation, however, are often not able to be translated in the home environment (White & Holloway, 1990). If the process of a caring relationship between a patient and nurse in rehabilitation can be elucidated, and patients feel this enhances self-care and autonomy, perhaps more effective strategies for individualized learning and problem-solving
could be designed and tested which could be better carried over after discharge. SCI individuals and their families would be able to assume more responsibility for their own health care, a goal which is consistent with the plans for health care reform.

Major contributors to health care costs after rehabilitation for SCI individuals are complications and hospital readmissions, primarily from respiratory and urinary tract infections, and skin breakdown (Berkowitz, 1992). Factors which may contribute to these problems are: lack of knowledge, ineffective decision-making regarding self-care, or low self-esteem (Zejdlik, 1992). If the process of caring between a patient and nurse while in rehabilitation can be identified, perhaps more effective nursing interventions could be designed which would include individualized needs, and improved problem-solving, leading to enhanced self-esteem and well-being. These caring strategies could be tested to determine not only their effectiveness, but also the long term impact on complication and hospital readmission rates.

A model of nurse caring which could be related to rehabilitation patient outcomes of increased independence in self-care and autonomy could enhance nursing knowledge development. If key factors were able to be identified, from the patients' perspective, which would assist in the development of independence in self-care and autonomy in
decision-making in SCI individuals, a model of caring could be developed, serve as a guide to nursing interventions, and tested in future research studies. Results from model testing could be used to teach nursing students and beginning nurses ways to develop their caring skills and behaviors to improve patient care. Advanced practice nurses would have additional knowledge to supplement their intuition in order to enhance patient care and teach other nurses (Benner, 1988; Schaefer & Lucke, 1990).

Assumptions

Underlying assumptions of the theoretical perspective presented earlier in this chapter are especially important in a qualitative study, since these assumptions will serve as the set of lenses through which data obtained from SCI individuals in rehabilitation will be interpreted. The study assumes that:

1. The potential for caring is present in all individuals.
2. Caring is learned.
3. Caring ability is enhanced with education, experience, and maturity.
4. Nurse caring can be identified by patients.
5. Caring is valued by SCI individuals in rehabilitation.
6. The process and consequences of a caring relationship can be identified by participants.
7. Self-care, or the ability to direct another in the care of oneself, is a desirable outcome of the
rehabilitation experience for SCI individuals.

8. Autonomy is valued by SCI individuals

rehabilitation settings in the United States.
CHAPTER 2

Review of Related Literature

The construct of nurse caring will be discussed in this section. In addition, current knowledge of self care and autonomy will be explored, since these are two desired outcomes of rehabilitation nursing. The theoretical constructs will be examined from philosophical, rehabilitation, and nursing perspectives. An analysis of research studies will be presented followed by a summary of current knowledge.

Caring

Theoretical Perspective

Caring is a multidimensional construct. Caring is defined as an interpersonal process, a way of relating to another that recognizes the worth, values, needs, and goals of the individuals in the relationship (Mayeroff, 1971; Watson, 1979). Caring actions by the nurse, on behalf of the patient, assist in meeting actual or anticipated needs, alleviate discomfort, and enhance the dignity, well-being, and autonomy of both the patient and health care professional (Leininger, 1981; Gadow, 1983; Gaut, 1984; Fenton, 1987). Theoretical discussions of caring from a philosophical, feminist, and nursing perspective reveal several common areas of thought.

Philosophical. Mayeroff (1971) describes caring as being with another person in their environment which results
in personal growth. His emphasis on "being with" another implies the whole self is involved with the other person, yet they are separate. Mayeroff's notion of caring implies continuity between persons which results in helping the other grow and find meaning in life.

Feminist. Presently, nursing is a female dominated profession. Since most philosophical and psychological theories of morality and relationships were developed from a male perspective, it is also important to consider the unique contribution of the female perspective to these theories (Baier, 1995). Early works on caring appear in feminist writings and research. The early feminist perspective on caring is best reflected in works by Gilligan (1982) and Noddings (1984). Gilligan (1982) describes a "narrative of relationships that extends over time" (p. 28). This different world is "comprised of relationships ... through human connection" (p. 29). Activities of care result in "mutual relationships of human beings...feelings of connection...and a primary bond between other and self" (p. 46-47). Noddings (1984) views caring as the ethical ideal. Caring involves relatedness, responsiveness, and receptivity, and occurs in a reciprocal relationship in which there is self-fulfillment of both individuals involved. There is commitment to the relationship of the individuals involved and a recognition of the special contribution of each to the relationship. The feminist
contribution to the theoretical foundations of caring comprise the uniqueness and equality of human beings in a relationship and the commitment to positive outcomes for those involved in the relationship.

Nursing. Caring is defined several ways in nursing. Gadow (1980) refers to caring as existential advocacy in that it serves to help the patient find meaning in the experience of illness or suffering or death. Leininger (1991) views caring as reciprocal in nature resulting in wellness, growth, or self-actualization. For Benner and Wrubel (1989) caring means being connected and brings together knowing and being. "Care sets up a world and creates meaningful distinctions, and it is these concerns that provide motivation and direction for people" (Benner & Wrubel, 1989, p.1).

Respect for persons is viewed by nurses as the fundamental moral principle which underlies caring (Fry, 1991; Griffin, 1980; Gaut, 1983). This principle enables the nurse to "respect the dignity and autonomy of another human being" (Griffin, 1980, p. 265), ensures that actions taken are directed toward a goal (Gaut, 1980), and helps to maintain independence between the individuals in the caring relationship (Fry, 1991).

Summary. The theoretical components of caring from philosophy, feminism, and nursing have several common elements. Respect for persons is central, which carries
with it respect for the individual's dignity, values, goals, autonomy, decisions, and claims. Also, a process is implied in caring--someone is giving and someone is receiving care. There is a connection and reciprocity between the individuals involved in the caring relationship. Together they find meaning in the experience and work toward an identified goal. Certain attributes or qualities are present in individuals in a caring relationship: these are compassion, truth, respect, knowledge, responsibility, responsiveness, and reciprocity.

Research Perspective

The research on caring has been primarily descriptive. Early qualitative works provided descriptions of patients' and nurses' perceptions of caring behaviors. From these early studies, caring behaviors have been categorized and instruments have been developed, although not validated, which reflect the various dimensions of the construct of caring. More recently, studies have attempted to link nurse caring and patient outcomes with little success; the outcomes studied were not theoretically derived.

Hospitalized patients. Caring behaviors valued most by hospitalized patients include knowledge demonstrated by the nurse, provision of information on which decisions could be made, assistance in feeling secure, and maintenance of confidentiality (Wolf, 1986; Larson, 1987; Cronin & Harrison, 1988; Clayton, 1988; Valentine, 1989b). Reiman
(1986) also described a sense of value that results from a caring relationship which is felt by the patient as well as the nurse.

Rehabilitation. Keane, Chastain, & Rudisill (1987) used a Q-sort to identify the perceptions of rehabilitation patients and nurses of the most and least important nurse caring behaviors. Patients and nurses were in agreement on their ratings on several items related to physical care such as: knows when to call the doctor, puts the patient first, gives good physical care, and gives quick response to patient call. Patients, however, rated two items reflecting interpersonal or expressive caring higher than nurses: 1) "is perceptive of the patient's needs and plans and acts accordingly, and 2) anticipates that the first times' are the hardest and pays special attention to the patient during these times" (p. 187). Nurses' results differed from previous studies in that rehabilitation nurses emphasized self-care practices and active patient participation in decision-making and care.

Process of nurse caring. Brown (1986), in a qualitative critical incident study, asked fifty hospitalized medical-surgical patients to describe an experience in which they felt cared for by a nurse. Eight themes were found through content analysis: recognition of individual qualities and needs, reassuring presence, provision of information, demonstration of professional
knowledge and skill, assistance with pain, amount of time spent, promotion of autonomy, and surveillance. She combined these themes to describe two patterns of caring: one in which the focus was the patient's physical well-being and one in which the focus was primarily the interaction between the patient and nurse. Brown concluded that when the instrumental and expressive caring activities of the nurse were combined in a way that conveyed recognition of the patient's individuality and the nurse's competence, making the patient a decision-making participant, the patient's ability to attend to self, well-being, and autonomy were enhanced. This was the first study which alluded to a process of caring which resulted in consequences for the patient.

Clayton (1991) designed a qualitative study to identify variables that affect caring behaviors and to describe the process of a caring relationship between a cancer patient and nurse. Five categories of behaviors emerged which affect the development of a caring relationship: environmental broker, professional knowing, facilitating factors, personal being, and connecting. A clear process of caring did not emerge from the data, but the author proposed the following stages of "connecting": presencing, attending, affiliating, and empowering. The last stage of the caring experience, empowering, occurred when the patient and family were able to provide more care for themselves.
with less dependence on the nurse, participated more in the decision-making process, and discovered meaning in the illness experience. This process was not able to be validated with patients, since the data were obtained by written accounts.

Swanson (1991), in a series of phenomenological studies with couples who have miscarried, described a caring process: knowing, being with, doing for, enabling, and maintaining belief. This study elucidates a process of increasing independence in a psychologically vulnerable population, facilitated by nurse caring. Findings from the study were validated, however, by having women recall their relationship with the nurse four years after the event.

These studies posit a process and consequences involved in the development of a caring relationship between the patient and nurse. Both the nurse and patient contributed to the relationship; once the patient became confident in the nurse's competence, the patient became more expressive and participated in the decision-making process. For the patient, the caring relationship resulted in increased self-care and less dependence (Clayton, 1991; Swanson, 1991), enhanced feelings of autonomy and self-worth (Brown, 1986; Swanson, 1991), and discovering the meaning of their illness experience (Clayton, 1991). Nurses also benefitted from the caring relationship with the opportunity to "augment the satisfaction of their practice" (Clayton, 1991, p. 167).
Consequences of nurse caring. Recent research studies began to link nurse caring with specific patient outcomes. Patient satisfaction, health status, length of stay, and costs have been studied to date (Larsen, 1993; Duffy, 1992; Valentine, 1992). Of these, only patient satisfaction had a significant positive relationship with nurse caring.

There are several conceptual issues raised by these studies. Establishing an association between caring and patient outcomes is logically the next step for research on nurse caring, providing the theoretical knowledge is complete. However, the outcomes chosen for study must be conceptually linked with the construct of caring or flow logically from the theoretical discussions.

Instruments. Several instruments are available to measure caring. Most were designed to be completed by the nurse (Nkongho, 1992; Servellen, 1992; Fenton, 1987). Three instruments were designed to be completed by patients (Duffy, 1992; Larson, 1984; Wolf, 1994), and two authors designed a pair of instruments to be completed by nurses and patients (McDaniel, 1992; Valentine, 1991). Instruments measure either the technical or interpersonal (Fenton, 1987; Nkongho, 1992; McDaniel, 1992) aspects of nurse caring, or both (Larson, 1984; Duffy, 1991; Servellen, 1992; Valentine, 1991). Even instruments designed to be completed by patients were developed primarily from nurses' descriptions of caring behaviors. None of the available caring
instruments have established construct validity for patients.

Summary. Current knowledge and research on nurse caring has many gaps and therefore systematic study in this area continues to be warranted. Caring behaviors are viewed differently by patients and nurses. Nurses rate the interpersonal aspects of the nurse-patient relationship as most important for nurse caring, whereas patients most often rate knowledge and physical aspects as the important aspects of nurse caring. Most of the studies, however, have been conducted with hospitalized patients. This suggests that perhaps the context within which the nurse-patient relationship occurs, determines in part caring behaviors important to patients.

Rehabilitation patients rate the psychological aspect of anticipating needs as an important part of nurse caring, along with the physical aspects of care. Whether patient perceptions of nurse caring in rehabilitation include other dimensions, is unknown. How the process of a caring nurse patient relationship develops over the course of rehabilitation, and the consequences of this relationship, have not been explored. Whether nurse caring is related to two important rehabilitation outcomes, autonomy and self-care ability, has not been validated with SCI individuals.

For purposes of this study, a caring relationship has been defined as an interpersonal relationship between a
nurse and patient in which the dignity, worth, values, needs, and goals of individuals are recognized and pursued. Nurse caring is defined as the knowledge, actions, and skills of the nurse, applied within the context of a nurse-patient relationship, which recognizes and seeks to enhance the individuality, wholeness, dignity, and well-being of patient.

**Self-Care**

Self-care refers to "those actions in which a person deliberately engages to sustain life and health, to recover from disease or injury, or to cope with their effects" (Orem, 1985). Self-care has been studied primarily from a medical and nursing perspective. Theoretical descriptions of this multidimensional construct will be presented from both disciplines. Definitions and underlying assumptions will be explored. Research studies on self-care will then be reviewed.

**Theoretical Perspective**

Early definitions of self-care in medical sociology referred to a lay phenomenon used largely in preventive health care (Levin, Katz & Holst, 1976). Inherent in this definition is the notion that the lay person is not only the provider of health care, but also the primary resource for self-care decisions.

**Medicine.** The medical definition of self-care is more complex. Viewed from this perspective, self-care includes
not only health maintenance, prevention, symptom evaluation, and self-treatment activities, but in addition, the interaction with the health care professional (Dean, 1981; 1983). Although self-care practices are initiated by the individual and are undertaken as a result of self-determined decision-making, compliance with the medical plan of care is implicit (Barofsky, 1978; Dean, 1986). Compliance itself is viewed as a self-care behavior.

**Nursing.** In nursing, the majority of the work in self-care has been from the theoretical perspective of Dorothea Orem (1980, 1985). Nursing has also viewed self-care as a multidimensional construct. Self-care has been defined as "the activities people initiate and perform on their own behalf in order to maintain life, health, and well-being, conditioned by age, developmental stage, sociocultural orientation, and resource" (Brooke, 1989). Orem described three levels of self-care: universal, developmental, and health deviation (Orem, 1980). This model projected that individuals have the ability to provide and determine their own self-care when they are well, but when illness or injury occurs, a self-care deficit results and nursing care is needed. Under these circumstances the nurse assumes the role of self-care agent, which can be wholly compensatory, partially compensatory, or supportive and educative (Orem, 1985). Also implicit in this model is the notion of compliance: the nurse assists the patient find ways to
implement and cope with the effects of the treatment plan, usually the medical plan of care.

Common underlying assumptions of the medical and nursing conceptualizations of self-care are six: 1) Self-care knowledge and behaviors are acquired; 2) Self-care is valued by individuals; 3) Individuals are capable and willing to perform self-care activities to maintain the desired level of health; 4) A conscious decision is made by the individual to engage in self-care actions; 5) Self-monitoring assists the individual decide whether to continue, modify, or stop self-care behaviors; 6) An environment conducive to the acquisition and maintenance of self-care behaviors is necessary. In addition, both the medical and nursing models of self-care require someone more knowledgeable than the individual (i.e., health care professional) to assist in the acquisition of illness related self-care knowledge and actions. Both models also have in common the concept of compliance.

Research Perspective

Medicine. Much of the medical research on self-care reflects the values and norms of the medical profession. Research has focused on actions taken in response to illness (Schiller & Levin, 1983), self-diagnosis (Fleming, 1984), and treatment (Dean, Holst & Wagner, 1983), primarily self-medication (Freer, 1980). Significant correlates of self-care behavior include: age, gender, education, income,
religion, health status, medical knowledge, attitudes about medical care, and health beliefs (Segall & Goldstein, 1989). Being younger, female, having more education, greater income, no religious beliefs, greater medical knowledge, better health, more skepticism about what doctors say and do, and stronger health maintenance beliefs have been associated with greater self-care behaviors (Segall & Goldstein, 1989).

**Nursing.** Most of the nursing research has focused on testing or expanding Orem's Self-Care Model. As with medical research, conceptualizations are primarily from the perspective of the health care professional. Nursing research has demonstrated that successful self-care behaviors are related to knowledge acquisition (Dennis, 1985; 1990; Davidson, 1989), control (Davidson, 1989; Dennis, 1985), and participation in decision-making (Doyle & Stern, 1992; Ladewig, 1990; Neves, 1980; Kim, 1983).

The theoretical construct of self-care was developed primarily from the perspective of the health care professional rather from that of the recipient of health care (Orem, 1985; Dean, 1986). Additionally, instruments designed to measure self-care, derived from the same conceptual perspective, demonstrated adequate reliability and validity when tested in healthy populations of nursing students (Kearney and Fleischer, 1979; McBride, 1987; Geden & Taylor, 1991), adolescents (Denyes, 1980), adults (Reisch...
& Hauch, 1988; Wetstone & Hanson, 1989), and elderly (Hanson & Bickel, 1985). Subsequently, when tested with individuals who were acutely or chronically ill or disabled, adequate reliability and validity were not demonstrated.

**Healthy Subjects**

Correlates of self-care agency (SCA) in healthy adults have been identified as knowledge (Schlatter, 1990; Riesch, 1988), self-esteem (Schlatter, 1990; Vannoy, 1989), self-actualization (Beatty, 1991; Davidson, 1988), self discipline (Vannoy, 1989), perceptions of health (Simmons, 1990; Vannoy, 1989; McDermott, 1988; Davidson, 1988), occupation, marital status, exercise, stress management, nutrition (Davidson, 1988; Simmons, 1990), and gender (McDermott, 1988). Self-care was found to have a significant negative association with learned helplessness in healthy adults (McDermott, 1993; 1988). Locus of control was not related to self-care (Beatty, 1991; Kearney & Fleischer, 1979).

One qualitative study examined the process of attaining self-care in infertility treatment. In this qualitative study, couples described a self-care process that consisted of four sequential phases: 1) perceiving that physicians lack the complete picture; 2) actively acquiring knowledge; 3) "taking control"; and 4) being satisfied with treatment (Blenner, 1990). This study demonstrated that some patients move into an active role, while others remain in a passive
role. For those who assumed an active role, the trigger that most often stimulated pursuit of this role change in self-care was the perception of fragmentation of their care. One important finding of this study was patients' perceptions of a more equal relationship with the health care professional as they acquired medical knowledge about infertility.

Two additional studies found a similar process of knowledge acquisition and taking responsibility for one's attitudes and behaviors (Dickson & Lee-Villasenor, 1982; Caporael-Katz, 1983). Nurses also reported an active process of self-care that requires vigilance, introspection, and a belief in nurturing self (Hutchinson, 1987).

In healthy adolescents, perceived health status, self-efficacy, family satisfaction (James, 1991), risk taking and health risks (Hurse, 1991) were found to correlate with self-care. In a study of healthy Black adolescent girls, family system elements, sociocultural orientation, peers, and developmental state were important in self care agency (SCA) (Dashiff, 1992). The ability to acquire and retain knowledge from an authoritative, personal source was also found to be important for SCA. Two experimental studies with school age children found that self-care was related to autonomy, knowledge, and attention to health status (Cofield, 1990; Moore, 1987).

Illness and Disability
In studies of acutely ill, chronically ill or disabled, the findings on self-care are somewhat different. Perceptions of own health, number of hospitalizations, education (Neves, 1980) and duration of illness were related to self-care agency in hospitalized adults (Ailinger, 1993). In oncology patients four variables accounted for almost half the variance in self-care: lower performance, higher anxiety, less social support, and education (Dodd & Dibble, 1993). In two studies of caregivers of cancer patients, family resources was the best predictor of self-care agency. Subjective burden had a significant inverse association with SCA, as did number of family traditions for wives. Level of dependent care increased the effect on SCA for husbands, while it decreased SCA in wives (Schott-Baer, 1993; 1989).

In the elderly, SCA was significantly lower for those who were dependent on institutionalized nursing (Evers, 1993; Jirovec & Kasno, 1990), had more restrictive environments, were white and had a previous occupation other than self-employed (Jirovec & Kasno, 1990); SCA scores between nurses and elderly individuals were significantly correlated (Lorensen, 1993; Ward-Griffin, 1990). Adolescents with spinal bifida scored significantly lower on autonomy, but there were no differences in SCA and coping compared with healthy subjects matched on age, gender, grade, and socioeconomic status (Monsen, 1992). Mothers of developmentally disabled children had a significant
correlation between SCA and functional social support (Beauchesne, 1989).

SCI individuals in rehabilitation and nurses regarded patient controlled care as an appropriate discharge goal (Doyle & Stern, 1992). There was also an important area of disagreement between participants and nurses. Patients often wanted to complete the decision-making phase of self-care, but wanted nurses to actually perform their care. Nurses, on the other hand, wanted to make decisions about what self-care patients should be performing, but wanted patients to perform the self-care. Successful resolution occurred when "nurses communicated effectively with patients, used empathy, were willing to negotiate, and were able to act as patient advocates by challenging institutional norms" (Doyle & Stern, 1992). A process was also implied in this qualitative study. Nurses had to take the time to explore patient's feelings and be willing to share control with the patient; these are caring behaviors. Patients, on the other hand, had to be willing to listen to the nurse's point of view.

Three studies examined the relationship between SCA and autonomy. In school aged children, autonomy was significantly related to SCA; autonomy was higher with assertiveness training and education, while SCA was higher with education (Moore, 1987). In adolescents with spinal bifida, autonomy scores were significantly lower than in
healthy subjects (Monsen, 1992). In baccalaureate students, occupation and education were strongly related to autonomy in decision-making. Exercise of SCA was weakly but significantly correlated with three subscales of decision-making: authority, social, and additional information (Ladewig, 1989).

Although there has been little systematic research on self-care, the construct poorly conceptualized, and instruments have reliability and validity primarily for healthy populations, some knowledge has been gained. A process of self-care has been identified with the acquisition of knowledge vital to that process. In situations where nursing or medical knowledge is needed, the health care professional is acknowledged by subjects as the source of information. Decision-making is essential to self-care at several points in the process. Responsibility or control for decision-making is eventually assumed by the individual, but how that occurs is largely unknown. Education, perceptions of one's own health, and relationship between patient and health professional perceptions of self-care are all highly related. Less clear is the role of age, gender, developmental state, social support, socioeconomic status, occupation, and marital status in self-care. Rehabilitation patients and nurses describe a process of negotiation about decision-making and performance of self-care activities, when successful self-care occurs. Whether
caring actions of the nurse affect self-care in rehabilitation has not been studied.

In this study, self-care is defined as those actions in which a person deliberately engages, or directs another to perform, to sustain life and health, recover from illness or injury, or to cope with their effects. Inherent in the definition of self-care is the intellectual ability to acquire knowledge and investigate alternatives, make judgments and decisions, perform actions or direct another to perform actions, and monitor the action and its consequences (Geden & Taylor, 1991). This definition differs from Orem's in that the individual does not need to actually perform all the actions to achieve self-care (Orem, 1985).

**Autonomy**

Autonomy involves self-determined choice, uncoerced or uninfluenced by others, given adequate information in an understandable manner, after weighing the alternatives and their consequences (Beauchamp & Childress, 1989). Very little systematic research exists in the area of patient autonomy. Research on related concepts such as choice and control often use terminology of autonomy, self-determination, and independence interchangeably. The philosophical basis of autonomy in health care will be explored, followed by a review of current research on autonomy and related concepts.
Philosophical Perspective

Philosophical foundations for autonomy can be found in the work of Kant and Mill. Kant's (1964) notion of autonomy was based on his principle of humanity, which means that man's rational nature should always be treated as an end in itself. By treating others in such a way, we are respecting that person's dignity and intrinsic value as a rational and autonomous human being (Gauthier, 1993). By encouraging and facilitating others to exercise their own capacity for choice in their goals and actions, a limit is placed on the influence of those goals by another (O'Neill, 1985). In order to accomplish this a relationship is established with the other, thoughts and goals are shared, yet the ends of the other are promoted in a way that fosters the "development, preservation, and exercise of their rational capacities" (Hill, 1989, p. 377).

Another philosophical position on limiting interference with individual independence is that of John Stuart Mill. Mill based his concept of respect for autonomy on the principle of liberty (1977). He felt that society should refrain from power over any individual in a community, except to prevent harm to others. Individuals should be free to pursue a life plan congruent with their "character"; this he believed would promote individual happiness and the good of all society. This consequentialist argument stated that individuals should base their actions on what they
think is right, without interference from others, except when the risk of harm to others is present (Gauthier, 1993). This view recognized that it is the individual who is the most knowledgeable about their own situation, values, and goals.

Only recently in health care, has the paternalistic approach to decision-making been abandoned, and one which values the provision of information and support to patients and their families to facilitate autonomous decision-making been recognized (Davis & Jameton, 1987). Traditionally relationships between the patient and members of the health care team have been viewed as unequal. Health care professionals held all the knowledge, therefore all the power, including that of decision-making. Information was actually withheld from patients in the belief that health care professionals knew best (Okem, 1961). Today, it is widely recognized that patients have the best knowledge of their life history, values, needs, and goals (Beiseker, 1988; Gadow, 1989; Sutherland, 1989).

**Research Perspective**

Little research has been conducted in the area of patient autonomy. Most of the research has been conducted in hospitalized surgical and oncology patients, and elderly nursing home patients. A paucity of nursing research in the area of patient autonomy yields numerous areas for further work.
Hospitalized patients. In a series of studies designed to examine values in the treatment choices of cardiac surgical patients, Gortner and Zyzanski developed and validated an instrument to measure autonomy, beneficence/nonmaleficence, and justice (Gortner, 1988). An initial study supported a relationship between patient and family values that was consistent over time; autonomy was valued by medical and surgical patients alike (Gortner, 1984). In subsequent studies reliability and validity of the refined instrument was established and the original findings were supported. However, in later studies it was found that patients over the age of 70 valued autonomy significantly more than younger patients (Gortner, 1988). A limitation of these studies is the measurement of the variable of interest after the decision for surgery and the actual surgery were performed.

In an exploratory descriptive study also of surgical patients after discharge, determinants affecting patient decision-making about nursing care were explored (Biley, 1992). Analysis of the qualitative data collected from interviews with eight patients revealed three categories that effected patient choice and participation in decision-making; these were: 'If I am well enough', 'If I know enough', and 'If I can'. Each of the categories were described on a continuum of greater patient involvement. Being too ill, not having enough technical knowledge, and
organizational constraints restricted patient choice, whereas improved physical well-being, having enough 
information to make a choice, and perceived situational 
control enhanced decision-making regarding nursing care.

**Nursing home patients.** A study of nursing home 
patients examined the relationship among perceived choice, 
desired choice, and functional ability, after pilot work 
revealed that nursing home induced dependence was negatively related to morale and perceptions of self-care ability 
(Jirovec & Kasno, 1990). Perceived choice available and amount of desired choice were significantly different, but not related to functional abilities (Jirovec & Maxwell, 1993). Perceptions of actual choice, however, were weakly and inversely related to perceived self-care ability. As functional dependence decreased, perception of choice increased. The instrument developed and used to measure perceived and desired choice in this study had only face validity and test-retest reliability.

**Rehabilitation patients.** Only two studies of the related concept of control were found in the rehabilitation literature. A serendipitous finding in a study of job satisfaction and nurse turnover in which patients and nursing staff used a standardized measure to rate the ward environment, revealed that patient and staff perceptions of autonomy and control were vastly different. Using the Ward Atmosphere Scale (Moos, 1974), an instrument with well
established reliability and validity, staff control was
rated significantly higher by SCI patients admitted for the
first time to a rehabilitation unit than by staff or
readmitted patients (Glass, 1991). Autonomy was rated lower
by patients new to the rehabilitation setting than new staff
or readmitted patients, however, these were not significant.
Findings were explained by the researchers on the basis of
patients not having enough information or ineffective
communication between patients and staff in order for
patients to fully participate in the rehabilitation
experience. An important implication of this study is that
patient's perception of autonomy may differ at various times
during the rehabilitation process.

In a nursing study, the relationship between personal
control and coping effectiveness in SCI persons was
investigated (Ferrington, 1986). Control was conceptualized
in three dimensions: preference to control, expectation for
control, and perception of options for control; depression
was used as the indicator of coping effectiveness.
Participants were hospitalized individuals who had
experienced a SCI at least five months prior to the study.
Two significant associations were found: 1) decreased
perceived control was associated with increased depression,
and 2) for respondents with a high preference for control,
depression was negatively related to perceived control. In
other words, lower levels of depression were associated not
only with increased levels of perceived control, but also
with the congruence between high-perceived and high-
preferred control.

This study provided limited support for involving
patients in decisions regarding their care, if only to
determine the extent to which individuals want to be
involved. Different forms of control were not measured in
this study; investigators did not differentiate between
behavioral, decisional, or cognitive control. Scope of
control was also not designated in this study.

How is autonomy related to control? Deci and Ryan
(1987) hypothesized that behaviors which support autonomy
would maintain or enhance intrinsic motivation. They found
that positive feedback enhanced intrinsic motivation when it
affirmed competence, but only when accompanied by the
experience of self-determination. An implication from this
study is "when contextual factors function to support
autonomy rather than control, people tend to be more
intrinsically motivated, more creative, more cognitively
flexible, more trusting, and more positive in emotional
tone" (p. 1030). A relationship which facilitates the
experience of self-determination or autonomy, may enhance
the rehabilitation experience for SCI individuals.

Instruments. There are several concepts implicit in
the construct of autonomy. These include freedom to chose,
freedom from coercion, access to information and resources,
knowledge of self and one's needs and goals, an understanding of the consequences of various choices, and finally self-determined choices. Hertz (1991) developed and tested an instrument to measure perceived enactment of autonomy (PEA) in the institutionalized elderly. Three dimensions were reflected in this concept: voluntariness, individuality, and self-direction. Significant relationships were found between PEA and perceived control and between PEA and morale in this population.

What form and under what conditions SCI individuals desire autonomy, and how it relates to the overall rehabilitation experience is unknown. The process of how nurses discover and enable patient's desire for self-determination is also unknown. Whether enhanced autonomy is a consequence of caring actions of the nurse, as perceived by SCI individuals in rehabilitation has not been studied.

In this study, autonomy is defined as "a state of sensing and recognizing the ability to freely choose behaviors and courses of action on one's own behalf and in accordance with one's own needs and goals" (Hertz, 1991, p.31). These actions are chosen to meet needs for either independence or dependence or both.

Definition of Terms

Spinal cord injured (SCI) individual: a person who has suffered an injury to the spinal cord resulting in motor and/or sensory deficits.
Rehabilitation: the process by which individuals who have suffered an injury or illness are assisted to return to the "fullest physical, mental, social, vocational, and economic capacity of which each is capable" (National Council on Rehabilitation, 1984)

Nurse caring: the knowledge, actions, and skills of the nurse, applied within the context of the nurse-patient relationship, which recognize and seek to enhance the individuality, wholeness, dignity, and well-being of the patient (Gadow, 1980; Gaut, 1980; Benner & Wrubel, 1989; Leininger, 1991).

Self-care ability: those actions in which a person deliberately engages, or directs another to perform, to sustain life and health, recover from illness or injury, or to cope with their effects (Orem, 1985).

Self-care agency: "the complex acquired ability to meet one's continuing requirements for care that regulates life processes, maintains or promotes integrity of the human structure and functioning and human development, and promotes well-being" (Orem, 1985).

Autonomy: a state of sensing and recognizing the ability to freely choose behaviors and courses of action on one's own behalf and in accordance with one's own needs and goals. This means choosing to act to meet needs for both dependence and independence either separately or simultaneously (Hertz, 1991).
CHAPTER 3

Method

In an effort to understand the meaning, process and consequences of nurse caring important to SCI individuals in rehabilitation, a qualitative approach was used for this study. The constant comparative method of Glaser and Strauss is a methodology used for the discovery and development of theory, incorporating extant theory into a new theory of greater scope, or uncovering how an existing theory applies to a new situation (Glaser, 1978; Strauss & Corbin, 1990; Strauss, 1993; Hutchinson, 1993; Denzin & Lincoln, 1994; Strauss & Corbin, 1994). Grounded theory is particularly suited to substantive theories where the task is to discover and conceptualize a complex process, the relationships between concepts and their consequences from interviews or field observations (Glaser, 1978; Glaser, 1992; Strauss & Corbin, 1994). Data collection, coding of data, integrating categories, generating memos, constructing theory, and generating propositions are all guided and integrated by the emerging conceptualization (Glaser, 1978).

In this chapter, a preliminary study used to clarify the construct under study is described. Next, the sampling technique, setting, data collection and analysis are described. Finally, the methods used to insure the completeness, consistency, and confirmability of findings are detailed.
Preliminary Study

Once the construct for the study was identified, a small pilot study was undertaken to determine if the theoretical descriptions and instruments used to measure nurse caring reflected the elements which were important to SCI individuals, since none of the instruments had demonstrated construct validity with this population. The purpose of this preliminary study was to have SCI individuals provide exhaustive descriptions of a special relationship they experienced with a nurse while in rehabilitation. Content analysis was used to identify key elements of the construct important to SCI individuals in rehabilitation.

In-depth interviews were conducted with four SCI individuals during or following rehabilitation by this investigator. They all described a special relationship they experienced during rehabilitation, usually with a particular nurse, sometimes with a nurse and a therapist. When describing this relationship and how it differed from the relationship with other caregivers, three themes emerged: wholeness, individuality, and shared responsibility. This particular caregiver treated them as a whole person, even though they felt they had a broken body, or as one person described, "I felt like just a head lying in the bed".

A second way in which individuals in this special
relationship felt different was the caregiver also treated
them as an individual and tried to individualize their care
as much as possible. For example, one patient described how
one nurse individualized her care. "This nurse knew I
washed my hair everyday at home and that I hated to be seen
in public with my glasses, so she told me that until I could
do it myself, she would see that my hair was washed and my
contacts were in everyday before I went down for therapy."

The last way these particular caregivers demonstrated
caring was to let the individual share in the responsibility
for decision-making. One patient described how a particular
therapist demonstrated caring. "Instead of saying, like
everybody else, the team has decided this week we will work
on 'x', she would say, we could do this or that, what do you
feel ready for, or I think you are ready for 'x', what do
you think?". Although SCI patients in rehabilitation
described wholeness, individuality, and shared
responsibility as important aspects of caring, there are
currently no instruments designed to measure nurse caring by
patients which include these dimensions.

Sample

A purposive sample of adult patients admitted to a SCI
rehabilitation unit was obtained. Data were collected from
individuals age eighteen or older, during their initial
rehabilitation admission due to a traumatic spinal cord
injury, after receiving informed consent to participate in
the study. Only individuals who could understand and speak English were included in the study. Individuals with all levels of injury, both complete and incomplete lesions, were included in the study. Individuals with a documented head injury or cognitive deficits were excluded from the study, since higher level thought processes may be impaired.

Informed consent was obtained from all participants prior to beginning data collection. Participants were asked to sign an informed consent after having read it or having it read to them, and all questions were answered to their satisfaction. For individuals who were unable to sign their name, a witness was present during discussions to request consent to participate in the study. If the participant indicated agreement to be included in the study, the witness signed the consent form, along with the researcher. If the participant desired, a family member or significant other signed the consent for them, with a witness also signing to indicate agreement of the participant.

Purposive sampling was used to select potential participants, that is, maximize variation in cases and access to data that were representative and contributed to knowledge and insight (Taylor & Bogdan, 1984). New cases were selected to study, based on background information, according to their potential to help expand or refine the concepts and theory as they were emerging. Potential participants who would add unique variations to the sampling
parameters were approached to participate in the study
(Miles & Huberman, 1994; Lincoln & Guba, 1985).

Sampling parameters from the literature which were
collected as background information included: level of
injury, age, gender, mechanism of injury, cultural
background, previous employment and educational level, and
previous living arrangements. When new themes or patterns
about the major constructs under study no longer emerged
from the data, and when concepts and relationships were
validated with a variety of participants, selection of new
participants for the study ceased. Although sample size
could not be determined a priori in the constant comparative
method, it was estimated that approximately 15 to 20
participants would be included. The number of participants
interviewed continued until theoretical saturation occurred,
that is, no new ideas or themes about the construct under
study emerged from the data (Strauss, 1978). All interviews
were conducted by the researcher.

Description of Settings

Data were collected from two free-standing
rehabilitation centers in southwestern Pennsylvania after
obtaining approval from the respective Institutional Review
Boards (see Appendix D). Both centers provided specialized
rehabilitation for SCI individuals, having a combined
average annual census of 160 SCI persons. Primary nursing
was the model of care delivery on the SCI units of these
rehabilitation centers.

Data Collection

Background information collected from participants and/or medical records included: age, gender, educational level, cultural background, mechanism of injury, circumstances surrounding injury, previous employment, support system, previous living arrangements (see Appendix B).

In-depth semi-structured interviews were conducted with participants, who agreed to participate, to study the meaning, process and consequences of a caring nurse-patient relationship in the rehabilitation setting, from the patient's perspective. The methodology of in-depth interviews, which is most like a conversation between equals, is consistent with the framework of caring (Taylor & Bogdan, 1984).

An explanation was provided to all participants about the purpose of the interviews and the background of the researcher as an introduction, using a standardized script (see Appendix C) (Kaufman, 1986). This included information that the researcher is a nurse who was interested in learning what they thought was important about how nurses care for persons who have experienced an injury similar to theirs, what it means to them, the results of the important aspects of how the nurse cares for them, and whether it has an effect on how they learn to care for themselves and make
decisions about their care.

Data were collected during the patient's initial rehabilitation experience using tape recorded semi-structured in-depth interviews. An interview guide was used to insure all areas were explored with each participant (see Appendix B), but questions were not necessarily asked in the order presented (Kaufman, 1986). The principle guiding the interviews was to have SCI individuals talk about aspects of nurse caring that were meaningful to them then in rehabilitation, and to describe the process and consequences of a caring relationship.

Interviews were tape recorded. A general question was used to set the tone of the interview by getting subjects to start to talk about their experience and situation, and trying to place participants in the role of teacher (Kaufman, 1986). The interviewer followed up with questions that probed and clarified the experiences and meaning participants attached to the events to obtain thick descriptions of the experiences (Taylor & Bogdan, 1984). Thick descriptions contextualize the experience for the participants; they provide detail, evoke self-feeling, and establish the significance and meaning of an experience (Denzin, 1989). Brief notes were taken during the interviews in an effort to obtain complete information which would assist in data analysis, such as tone of voice, facial expression, or other non verbal behaviors. Field notes were
used together with transcripts of the interviews for data analysis.

Questions in the interview guide were evaluated with the initial participants. The researcher determined whether the questions were eliciting the types of responses for which they were designed. In addition, clarification of wording or changing a question was required if feedback from participants indicated that a question was unclear or participants did not understand what it meant. After the questions were refined, the researcher asked the same questions of all participants, but not necessarily in the same order.

Interviews were conducted only after participants had been in rehabilitation at least 2 weeks, and throughout the rehabilitation stay. The initial weeks in rehabilitation were not an ideal time to conduct in-depth interviews about caring, when individuals were dealing with fears, anxieties, and possibly anger about a new setting and it's routine. This timeframe gave the SCI individual an opportunity to become acclimated to the rehabilitation setting and the goals of their rehabilitation program, and to develop a relationship with a nurse.

Data Analysis

A data management program designed for qualitative research, NUDIST, was used to assist the investigator with the organization, retrieval, and interpretation of data.
Descriptive characteristics of the participants were provided from the background information. In addition, as patterns and themes were generated from the data, the investigator explored their relevance with participants having different backgrounds to maximize similarities and differences (Glaser, 1978; Glaser, 1992). During data analysis the researcher also explored patterns from the background data as they might relate to the meaning, process, and consequences of caring. For example, patterns were examined by age, gender, ethnic affiliation, and level of injury, to determine if there were differences in perceptions based on background characteristics.

Following each interview, a summary was completed by the interviewer (Miles & Huberman, 1994). This summary identified the main themes, issues, problems, and questions arising during the contact, in addition to any reflective remarks, and unanswered questions that needed to be explored during the next contact with the participant. Up to three interviews were conducted with participants to clarify ideas and verify their intended meaning. The summaries were numbered sequentially to correspond with the transcripts of the interviews, and background information sheets to maintain anonymity of the participants.

Tapes of the interviews were transcribed. The transcription was reviewed with the tape for accuracy, as soon after the interview as possible. Comments from field
notes about tone, gestures, etc., were added to the
transcripts in the appropriate places, to make the
transcript more complete.

Coding. Coding of data then took place, using the
transcripts, summary sheets, and field notes. Phrases or
sentences were identified with a short descriptive label
reflecting the understood meaning of the participant or
themes that emerged from the data (Glaser, 1978). Labels
referred to words used frequently by the participant which
captured the meaning of phrases or sentences. Or the labels
referred to concepts or relationships that emerged as the
researcher read and reread the transcripts (Miles &
Huberman, 1994; Kaufman, 1986). Whenever possible, coding
of an interview took place before the next interview
occurred.

Categorization. Codes were then grouped into
meaningful categories. An index of codes was developed by
the researcher, with a reference to the transcript and page
where it could be found. Codes were compared and similar
codes were clustered and given an initial label. As data
collection and analysis continued, the researcher looked for
similar patterns in the data to validate or rename the
categories and to look for relationships between the
categories. Each category was given a name, reflecting the
theme, pattern, or explanation provided by the category
(Chenitz & Swanson, 1986).
**Memoing.** During the coding and clustering of codes, as well as when tentative relationships or explanation of codes and categories were being proposed, memoing or reflective theorizing was recorded by the researcher. Memoing is the process whereby ideas about concepts, their possible relationships, and theorizing occurs during the analysis of data. These theoretical notes are dated, and reflect the investigators thinking about key concepts, their properties, dimensions, relationships, processes, variations, and consequences. In addition, memos were anchored to references in field notes, transcripts, or summary sheets (Miles & Huberman, 1994).

**Conceptualization.** Conceptual labelling, identification of paradigm features, conceptual relationships, indications of processes and consequences occurred as the theory emerged from the data (Glaser, 1978; Glaser, 1992; Strauss, 1993). Meaningful clusters of data were initially labeled and defined as concepts. The researcher then returned to the literature and to participants to compare and verify the identification and meaning of the concepts as they emerged.

Paradigm features of each concept were then identified. These key features were then compared in descriptions between participants to determine consistency. The conditions under which these key features occurred or did not occur were then explicated.
Finally, the relationships between concepts were explored. During this period of refinement in the data analysis, the investigator went back and forth between the data and the emerging conceptualizations to determine prerequisite or antecedent behaviors or concepts, processes, and consequences. The researcher also returned to participants during this phase of the study to verify the accuracy of the conceptualizations.

Methods to Insure Completeness and Accuracy of Findings

Data analysis occurred concurrently with data collection to insure the credibility and confirmability of the analysis. The researcher explored emerging themes with participants, to determine whether in fact the interpretation of the data was accurate. The investigator was also able to go back to participants in order to validate relationships and consequences that were proposed (Kirk & Miller, 1986; Lincoln & Guba, 1985).

Auditability. Documentation occurred at each decisional point throughout the study beginning with determining the unit of analysis, preliminary schedule of questions, including sampling decisions, and continuing through the explication of analytic strategies. This audit trail helps to insure the trustworthiness of the findings and provides a mechanism to go back and reproduce the results. The method of constantly comparing new data, themes, and patterns with those that were previously
analyzed enabled the researcher to determine if the early
data analysis was accurate and being repeated in subsequent
data and analysis (Glaser, 1978; Glaser, 1992). Revisions
in labels, naming of concepts, and proposed patterns of
relationships was an ongoing process, as new insights from
the data emerged and interpretations were either validated
or refuted by future participants (Miles & Huberman, 1994).

Comprehensiveness. All materials were indexed and
cross-referenced using a computerized data management
system. Heterogeneous purposive sampling helped to provide
access to a wide variation of participants. With each level
of theorizing alternative or competing explanations were
explored. Support for the adequacy of linkages between
concepts were confirmed by referring back to the examples
from the data. Interviews with participants continued until
themes, patterns, and relationships were repeated by
participants with varied backgrounds, according to study
parameters. When no new information about the major
constructs under study was being obtained, and when the
concepts and relationships proposed by the researcher from
the data, were verified by the participants, data collection
was discontinued.

Consistency. Dependability or consistency of the
conceptualizations was insured by encouraging responsive
flexibility by participants, thereby reducing researcher
bias. Responses from participants about the meaning,
process, and consequences of nurse caring were followed up with further questions and probes until exhaustive descriptions of the major concepts under study were obtained. In addition, the fit between categories and their definitions was determined by going back and comparing with examples from the data. Finally, the explanatory power of the conceptualizations was established. By returning to the transcripts to determine how much of the data was explained by the emerging substantive theory, and how much data was not accounted for by the conceptualizations.

**Confirmability.** Confirmability of the findings were determined in four ways: 1) reducing researcher bias; 2) reducing premature closure; 3) exploring alternative inferences and gaps in the substantive theory; and 4) identifying unexplained phenomena. Researcher bias was controlled in two ways. Approximately one month after the beginning of data collection and analysis, when the computer software was obtained, the initial four interviews were recoded using the computer. The initial coding was compared with the subsequent coding and found to be very consistent. Secondly, the researcher returned to five participants for a second interview to confirm the labelling of concepts, their meaning and relationship with other concepts. Participants provided further support for the emerging conceptualizations.

Premature closure was avoided by continuing data
collection and analysis until redundancy of information began to occur about the major concepts under study. A tentative structure for the coding and analysis of data was provided by the investigator's theoretical and empirical knowledge of caring and the proposed relationships of the theoretical constructs as depicted in figure 1 (Miles & Huberman, 1994). Data were coded initially into three dimensions: meaning, process, and consequences. Within the construct of caring, data was coded initially in two dimensions: physical care or technical aspects of caring, and interpersonal or expressive dimensions of caring. However, because this structure did not match the data after analysis of the first three or four interviews, it was refined to include additional dimensions based on descriptions provided by participants. There were two areas of unexplained phenomenon, learning the system and pain, which were outside the purview of the construct under study, nurse caring.

Throughout the process of data collection, analysis, and theorizing, the researcher moved back and forth between the processes of induction and deduction. Using induction, the concepts, patterns, and relationships were allowed to emerge from the data. The accuracy with which this is done, of course, depended on the quality of the data collected (the skills of the interviewer) and the quality of the analysis. Using the process of deduction, the concepts,
relationships, propositions, and hypotheses which were interpreted from the data, were compared with what is known about the meaning, process, and consequences of caring from theory and previous studies. In this way, the conceptualization of caring, the process of how a caring nurse-patient relationship develops, and the relationship(s) among nurse caring and the perceived consequences of nurse caring for SCI individuals in rehabilitation were refined.

<table>
<thead>
<tr>
<th>Nurse Caring</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dimensions</strong></td>
</tr>
<tr>
<td>Patient knowledge goals</td>
</tr>
<tr>
<td>Nurse technical skill interpersonal skill</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

*Figure 1. Initial Conceptual Schema of Nurse Caring.*
CHAPTER 4

Findings

This study describes the meaning, process, and consequences of nurse caring from the perspective of SCI individuals during rehabilitation. Twenty in-depth interviews were conducted with fifteen participants over a six month period to answer the research questions. The constant comparative method of Glaser and Strauss (1978) was used for data collection and analysis to refine and expand knowledge of the theory of nurse caring. Following a brief overview of the meaning, process, and consequences of nurse caring which emerged, this chapter provides a description of the sample and the settings in which data collection occurred. Then, an in-depth analysis of the meaning, process, and consequences of nurse caring are provided using illustrative examples from participant interviews. Pseudonyms will be used for participant names to provide anonymity.

Overview

During rehabilitation, a process that lasts from several weeks to several months, the SCI individual moves from feeling helpless, powerless, having a body that is foreign to them, and not knowing how to take care of their body, to taking charge, taking care of their body, independence, feelings of well-being, and hope. The main work of rehabilitation, "getting back together," that is the

64
reintegration of self in preparation for returning to the family and community, is accomplished with nurses and therapists perceived as caring. This caring connection brings feelings of humanness, dignity, trust, wholeness, and uniqueness to situations that are often viewed as discouraging, disgusting, embarrassing, or degrading to the SCI individual in rehabilitation. A caring relationship allows the SCI individual the freedom to ask questions, experiment, and make mistakes while learning to make decisions and take care of their body. Four dimensions of nurse caring were important to SCI individuals during rehabilitation: knowledge, technical skill, interpersonal skill, and competence.

A caring relationship in rehabilitation proceeded through three phases, with each phase having intermediate consequences for the SCI individual: "learning the other," "learning what I need to know," and "letting me find out". In each of these phases there are reciprocal behaviors or tasks for the nurse and the SCI individual. The nurse initiates the first two phases while participants described themselves initiating the third phase. If the nurse did not initiate the first phase or the patient did not perceive the nurse as caring during the initial phase, the work of rehabilitation did not occur with that nurse, and the patient's progress does not move forward as easily or as efficiently.
Positive consequences resulted from a caring relationship for the SCI individual. These were: "lifting my spirits" (well-being), "taking care of my body" (self-care), "taking charge" (autonomy), independence, and hope ("there can be a meaningful life after SCI"). It became obvious to the investigator that caring relationships with both nurses and therapists are important to SCI individuals during rehabilitation to accomplish the work of "getting back together". It is with nurses perceived as caring, however, that participants described "getting through" the difficult times, such as the first night in rehabilitation, after family members leave, upon returning from a pass, or when having a difficult or emotional day. Nurse caring is perceived by SCI individuals as important to the emotional and physical work of recovery during rehabilitation.

Description of the Sample

Understanding perceptions of nurse caring during rehabilitation after spinal cord injury occurs within the context of the distinguishing characteristics of the participants in the study. Background information of participants as well as details of their personal lives provide the social context with which to appreciate the rehabilitation experiences of these particular SCI individuals. First, the demographic characteristics of the study participants are described. Then, the social context is addressed which includes living arrangements, employment
prior to the injury, and sources of support for the participant. Third, the type and mechanism of injury and resulting physical injuries are discussed. Lastly, the timing of the interview in relation to the injury and the time in rehabilitation is examined.

**Demographics of the Sample**

Fifteen SCI participants were interviewed at least once during their initial rehabilitation stay; four were female (27%) and eleven were male (73%). Ages of participants ranged from twenty-three to eighty-nine years, with a mean age of 48 years. Nearly half of the SCI participants (47%) were young men under the age of fifty-five. Three of the participants were African-American (20%) and the remaining twelve were Caucasian (80%). Table 1 displays the breakdown of the sample by age, gender, and race. Due to the small sample size, ages were grouped consistent with the reporting of trauma statistics: age 34 and under, 35-55 years of age, and age 56 and over (Rice & MacKenzie, 1989).

**Social Context**

In this study, social context encompassed living arrangements, employment prior to admission to rehabilitation, and sources of support identified as important by participants. Three of the participants lived alone (20%), a young man and two elderly woman. All three lived close to their family prior to their injury and were now planning to return to live with family, at least for a
period of time. The remaining twelve (80%) lived with either parents, a spouse, or a girlfriend as depicted in Table 2.

Table 1

**Frequency Distribution of Age Categories by Gender and Race**

(N=15)

<table>
<thead>
<tr>
<th>Age</th>
<th>Caucasian</th>
<th>African American</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Men</td>
<td>Women</td>
<td>Men</td>
<td>Women</td>
</tr>
<tr>
<td>18 - 34</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>35 - 55</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Over 55</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 2

**Living Arrangement Prior to SCI by Age Category**  (N=15)

*Note.* SO = Significant Other.

<table>
<thead>
<tr>
<th>Age</th>
<th>Alone</th>
<th>Parents</th>
<th>Spouse or SO</th>
</tr>
</thead>
<tbody>
<tr>
<td>18 - 34</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>35 - 55</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>56 and over</td>
<td>2</td>
<td>0</td>
<td>4</td>
</tr>
</tbody>
</table>
Seven (47%) of the participants were employed outside the home, two (13%) were unemployed, while the remaining six (40%) were either retired or a homemaker prior to their injury as described in Table 3. Two of the participants were self-employed. One would be able to continue in some aspect of his previous work as a health care professional, although confined to a wheelchair. The other self-employed participant was nearing retirement and had already begun training his son to take over his business when his accident occurred.

Table 3

**Employment Status Prior to SCI by Age Category**  
(N=15)

<table>
<thead>
<tr>
<th>Age</th>
<th>Full-time</th>
<th>Part-time</th>
<th>Unemployed</th>
<th>Retired/Homemaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>18 - 34</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>35 - 55</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>56 and over</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
</tbody>
</table>

All participants described a stable and nurturing system of support consisting of family and friends, which were very important to them during their recovery as displayed in Table 4. Family members consisted of children and siblings. Family and friends visited almost nightly for
those who lived close by. Having family and friends visit on the weekends made the time pass more quickly, since the weekends were relatively quiet compared to the hectic pace of therapy during the week. The time immediately after family members left from visiting was often very emotional for participants. They were saddened about being away from their loved ones, but also began to realize the enormity of the change in their lives as a result of their SCI.

For the young adults, parents were an important source of support, but friends were identified as important more often than family. For the middle aged and older group of participants, spouse and family were more often identified as the sources of support rather than friends.

Table 4

Sources of Support by Age (N=15) *

* Note. The totals are greater than the number of participants since more than one category could be identified.

<table>
<thead>
<tr>
<th>Age</th>
<th>Parents</th>
<th>Spouse/SO</th>
<th>Family</th>
<th>Friends</th>
</tr>
</thead>
<tbody>
<tr>
<td>18 - 34</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>35 - 55</td>
<td>0</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>over 55</td>
<td>0</td>
<td>4</td>
<td>6</td>
<td>1</td>
</tr>
</tbody>
</table>
Description of Injury

Eight (53%) individuals suffered SCI at the cervical level and the remaining seven (47%) experienced thoracic injuries. All participants used a wheelchair as their means of mobility; although two individuals were able to stand for short periods of time using braces.

Motor vehicle accidents (MVAs) and falls caused of the majority of injuries (n=12; 80%). One individual (7%) was injured as the result of a gun shot wound (GSW). Two (33%) of the six participants involved in MVA experienced cervical injuries, while four (67%) individuals who fell experienced thoracic injuries. The majority of participants under age thirty-five (83%) experienced MVAs, while most of the individuals over age fifty (67%) experienced falls. Most participants under age 35 experienced thoracic injuries (67%), whereas most of the participants over 55 experienced cervical injuries (83%). Table 5 describes the types of injury by age.

Some individuals viewed the cause of their accident as "purely accidental", that is, simply "being in the wrong place at the wrong time." Others viewed the accident which caused their injury somehow as their fault, the result of "doing something stupid" or "not paying attention." There did not seem to be a difference in perceptions of nurse caring or the rehabilitation experience based on
attribution of injury.

Table 5

**Level and Cause of Injury by Age** (N = 15)

*Note.* MVA = Motor Vehicle Accident; GSW = Gun Shot Wound; C = Cervical level injury; T = Thoracic level injury.

<table>
<thead>
<tr>
<th>Age</th>
<th>MVA</th>
<th>Fall/Trauma</th>
<th>GSW</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>C¹</td>
<td>T²</td>
<td>C</td>
</tr>
<tr>
<td>18 - 34</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>35 - 55</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>over 55</td>
<td>0</td>
<td>0</td>
<td>4</td>
</tr>
</tbody>
</table>

*Timing of Interview*

Participants were interviewed from two weeks to six months following their injury. At the beginning of the study, the initial four participants were interviewed toward the completion of their rehabilitation stay. The next four participants were interviewed initially two to four weeks after admission and then again two weeks prior to discharge to their home. The remaining seven participants were interviewed once toward the end of their rehabilitation stay.

After data collection and analysis with the first group
of participants, the dimensions of caring and the perceived consequences of nurse caring began to emerge. What was less clear was the process of how a caring relationship developed over time. The second group of participants was able to articulate what caring behaviors were important early in their rehabilitation stay. Also, by comparing with them what was important during the early phase of rehabilitation, to what was important as they prepared to return home, the process of how caring relationships develop became clearer. It also became clear that important caring relationships developed not only with certain nurses, but also with certain therapists during rehabilitation. Interviews with the last group of participants were used to confirm the dimensions, process, and consequences of nurse caring as they emerged from the data, as well as elucidate the conditions under which each of the facets did and did not occur.

By interviewing participants at different times during rehabilitation, phases of a caring relationship began to emerge. Participants described consequences resulting from each phase, for themselves and for the nurse. In addition, different caring behaviors were perceived as important during different periods in the rehabilitation process. For example, "getting me through" a difficult night or a rough day was often important early in rehabilitation, while "telling me consequences" or "telling me straight" when
something might be harmful or impede progress were important later in the rehabilitation process.

Summary

Fifteen participants, four females and eleven males, were interviewed at least once during rehabilitation. Five participants were interviewed twice during their rehabilitation stay. Participants ranged in age from twenty-three to eighty-nine, with a mean age of 48 years. Three participants were African-American and twelve were Caucasian. Eight participants sustained injuries to their cervical spinal cord which resulted in the loss of most use of their arms and all the fine motor movement of their hands. The remaining seven participants suffered thoracic injuries which resulted in the loss of the ability to walk as well as bladder and bowel control. All participants used a wheelchair for mobility. The majority of injuries were from MVAs or falls.

Prior to their injuries, seven of the participants were employed at least part-time, six were retired or a homemaker; two were unemployed at the time of their accident. Twelve individuals lived with family or a significant other at the time of their injury. Of the three participants who lived alone prior to their SCI, all were planning to return to live with family, at least for awhile following discharge from rehabilitation. All participants described family and friends as sources of support during
the rehabilitation process, many having visitors daily. Religion was not explicitly identified by participants as important during rehabilitation from SCI, however, this topic was not specifically explored as part of the interview.

Dimensions of Caring

Research Question one: What is the meaning of nurse caring for SCI individuals in rehabilitation? By asking participants what was important to them about how nurses cared for them in rehabilitation, exploring each of the areas in-depth, as well as asking participants to give examples of each of the important elements they identified, the dimensions of nurse caring important to SCI individuals in rehabilitation emerged.

Caring is perceived as multidimensional by SCI individuals in rehabilitation (Figure 2). Four dimensions of nurse caring are described as important: knowledge, technical skill, interpersonal skill, and competence. Each dimension is comprised of different facets which may be important at different times during rehabilitation. For example, early in a relationship, "attending", and "getting me through" were important aspects of interpersonal skill of nurse caring. Later, "sensing", and "using humor" were important aspects of interpersonal skill after the SCI individual and nurse had gotten to know one another, as illustrated in this example.
Although the elements of each dimension of nurse caring are unique, a nurse perceived as caring possesses a repertoire of skills and behaviors from each dimension. **Knowledge** is a prerequisite for the other dimensions of caring. Initially, the knowledge described as "knowing what they're doing," is comprised of formal knowledge: what the nurse learned in school and classes about the care of SCI individuals. Also evident to participants was the nurse's experience; what the nurse learned from other SCI individuals, or practical knowledge, became important when the nurse needed to individualize the patient's care. As the nurse and patient were getting to know one another in the early weeks of rehabilitation, sharing personal knowledge was important. The nurse began by sharing information about family, hobbies, preferences, and values. This created an atmosphere which invited the patient to also share personal knowledge. Later, knowledge of the individual patient became important and was evident in the way the nurse provided physical care, demonstrated competence, and interacted on an interpersonal level with the SCI individual.

During the early weeks in rehabilitation, several aspects of **technical skill** were important to participants, primarily because they were now in a new and foreign environment and felt very helpless. Responding in a timely manner to the call light and requests for help, the skill
with which the nurse performed physical care, efforts to provide comfort and relieve pain, and anticipating the patient's needs based on the degree of physical disability were important to the establishment of a caring relationship. Later, following through with other members of the rehabilitation team and surveillance to pick up potential problems early were perceived as important aspects of nurse caring.

### Dimensions of Nurse Caring and their Components

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Having knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sharing knowledge</td>
</tr>
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**Figure 2.** Dimensions of Nurse Caring and Their Corresponding Components.
Interpersonal skills were used almost intuitively by nurses perceived as caring. Attending, or being truly present to the patient during interactions and "getting me through" the difficult times were important throughout rehabilitation, but especially in the first few weeks when the patients were feeling extremely vulnerable. Later, after the nurse and patient had established a relationship, "sensing" something was wrong and "using humor" to get through difficult or degrading situations were possible, since the nurse and patient had learned the particular nuances about each other. Nurses perceived as caring were able to draw from a repertoire of interpersonal skills, based on the situation and knowledge of the particular other, the patient.

Patrick: "the nurse who stayed with me that first night when I was in so much pain, and I was upset about being away from my family for so long, and didn't know what to expect from rehab; well, she stayed with me and got me through that first night. Do you know, she's turned out to be the wicked witch of the west (grinning); that's what I call her. Not really, what I mean is she doesn't miss a thing and she doesn't let me get away with a thing. She tells me exactly how something is going to help me, or if doing it the way that I'm doing it will keep me here longer. She tells me exactly the way it is. I have a tremendous amount of respect for her."
Competence encompassed the ethical comportment of nurse caring for SCI individuals. How well nurses were able to individualize care, treat the participant as a whole person with dignity, respect the uniqueness of the individual, and break the rules to insure the individual's needs were met, communicated competent caring to the SCI individual. Competence was the culmination of the knowledge and experience of the nurse, interwoven with the nuances of learning the patient, manifested in technical and interpersonal behaviors. A beginning practitioner or a student nurse were not perceived as demonstrating competence because they had not learned to individualize care, treat the whole person, or break the rules. They were perceived as "going by the book."

Ned: "the student nurse asked me what time I wanted my shower. I told her around 8. I was in the TV room at the time. In the meantime, I got some visitors and we went into my room. Well, at 8 o'clock the student nurse came into my room, walked over to my bed where I was sitting talking with my visitors, and proceeded to start to unbuckle my pants. She said, "It's time for your shower." I was so mad I asked her to leave."

Knowledge: First Dimension of Nurse Caring

"Knowing what they're doing" was consistently described as the most important dimension of nurse caring early in the
rehabilitation phase. A knowledgeable nurse was the first prerequisite for nurse caring; the knowledge dimension was foundational for the other three dimensions of nurse caring. Without knowledge, the technical, interpersonal, and competence dimensions of nurse caring would not be possible. "Knowing what they're doing" was comprised of having knowledge, sharing knowledge, and knowing what to assess. Initially, the nurse's knowledge about SCI was important, but as time in rehabilitation progressed, knowledge of the individual participant and their particular nuances became just as important. It was only by incorporating the knowledge of the individual with their knowledge of SCI, that participants' perceived nurse caring as facilitating their recovery.

**Having knowledge.** Specialized knowledge about SCI, including practical knowledge, was an important aspect of "knowing what they're doing." An expectation of participants was that nurses would have specialized knowledge of their needs and what it took to aid their progress through rehabilitation. In addition to specialized knowledge of a SCI individual's needs, participants expected nurses to have practical knowledge which they could share and which would assist in moving them forward toward their discharge. Participants often stated that they felt nurses gained their practical knowledge from working with other patients or perhaps from having a family member or friend
who had a SCI.

John: "I sort of pick up on who knows what, and you know, a couple of nurses here their husbands or somebody that they know is handicapped. They got experience after experience being around somebody that's handicapped. And you got a professional worker who tells you to do it this way and that way, and when you get home it might be easier for you to do it different. So I usually ask those nurses if I have a question or want to know something. They're going to tell me if it's easier or quicker in one way or another."

Sharing knowledge. Sharing knowledge about SCI, about the system and how to get things done, and about resources were important aspects of the knowledge dimension of nurse caring. Nurses shared knowledge in a variety of ways: showing, telling, breaking it down (into smaller units of information), and answering questions. From the very first day of rehabilitation, nurses perceived as caring, shared their knowledge with participants whenever they performed a procedure, gave a medication, or told them about a new order. Not only did they share with participants what they were doing, but they also told them why it was important. Nurses would tell them why they were doing it this way, what the consequences were, other ways of doing it, and what those consequences were. By simply sharing information with participants and being open to questions from the beginning,
caring nurses invited patients into a relationship as a partner in their rehabilitation.

Daryl: "...showing you things. Showing you so you won't be doing it forever. Like these caths. He said if I do my cathing right I would be off it eventually. That is really what the object is, to be off them. I took heed to that, the way he told me to do it. He came in the other day and said, 'Hey man, you're off those caths.' So telling you why, explaining why cathing is done, why am I doing this. He broke it all down for me, telling me why am I doing this and how to get off of it."

In this study, only "learning the system" was perceived to be achieved independently of health care professionals. SCI individuals in this study learned about the system primarily by watching, observing, and asking questions. In this way they learned the rules and who to go to for what to get things done most efficiently. This did not necessarily occur as part of nurse caring as perceived by SCI individuals, but was something they learned on their own. Developing support networks and generating hope was described within the context of previously existing support systems and in caring relationships with nurses and therapists in rehabilitation. Participants occasionally described learning helpful information from other patients and sharing information with other SCI individuals.

Knowing what to assess. Knowing what to assess about
each participant was an important aspect of the knowledge dimension of nurse caring. Most participants felt there were particular features of the physical manifestations of their injury which only caring nurses picked up on or monitored. Even though it might seem like a trivial detail to someone not involved in their care, to participants the implications were immense. The fact that only certain nurses paid attention to these particular nuances and felt they were important, communicated caring to participants:

Patrick: "I had a couple of pills that kept getting stuck in my throat when I swallowed them. It would take forever to pop them out or I'd have to wait for the darn thing to melt. A couple of times I felt like I was choking to death. This same nurse would always stay until the pills were down. Everyone else would just hand them to me and just leave. After a couple times when she saw I was having trouble she said you know these come in a liquid form. Maybe that would be better for you."

Another participant described the difficulties he was having with transfers to and from bed. Only one nurse identified the problem of fluid retention in his legs as an obstacle to his independent transfers:

Ralph: "For some reason I was having trouble getting my legs up on the bed to do my transfers. We tried several different ways of getting my legs onto the bed, but none of them seemed to work. One day this nurse I was telling you
about was in here when I was trying to get into bed and she saw how swollen my legs were. Right away she knew that's why I was having problems. So she took care of it. The next day the doctor started me on a water pill and I have these things on my legs. It still isn't easy, but at least I can transfer myself into bed now. But she was the only one who figured out why I was having problems."

**Summary.** A knowledgeable nurse is a requirement for a nurse to be perceived as caring. The knowledge dimension of nurse caring is comprised of having knowledge, sharing knowledge, and knowing what to assess. Nurses who demonstrated caring began sharing their knowledge with participants immediately upon admission to rehabilitation. This communicated to SCI individuals an invitation to become a partner in their rehabilitation which eventually enabled them to "take charge" of their rehabilitation and become independent. Knowing what to assess often prevented complications or delays in the rehabilitation process.

**Technical Skill: The Second Dimension of Nurse Caring.**

The technical dimension of nursing caring included physical care, comfort, anticipating needs, follow-through, surveillance, and responding. This dimension of caring, along with knowledge and the interpersonal dimension, was important early in rehabilitation. Participants began to identify nurses who were perceived as caring early in their course of rehabilitation, based on a
cluster of behaviors from these three dimensions.

**Physical.** Included in the physical aspects of the technical dimension of nurse caring are activities which are basic to daily living: bathing and hygiene, getting in and out of bed, positioning, and managing skin integrity and elimination needs. The skill with which the nurse was able to perform these activities, together with the knowledge the nurse shared about how and why activities were performed, and the interpersonal finesse of the nurse communicated caring. Two examples illustrate these behaviors. One participant relates how a couple of nurses perceived as caring approached intermittent catheterization:

*John:* "Well, they talk to me first; when they're doing things with me they explain what they're doing. They don't just come in and throw stuff at me and say it's time to do your cath now like some of the nurses. They come in and talk to me and then they say, we should do this now, what do you think?"

Another participant described how nurses perceived as caring positioned him:

*Daryl:* "There was this one night I just couldn't get comfortable. I needed to be turned about six times. Those two, they just came in when I rang the buzzer and asked me which way did I want to be turned this time. They weren't nasty or anything. They just turned me. They knew not to grab my one leg that hurts and they were careful not to hurt
me. The others will just come in and grab you and flip you, and they're hurting you."

**Comfort.** Providing comfort was another important aspect of the technical dimension of nurse caring. Many of the participants experienced physical pain as the result of their injury or the surgery on their back or neck required to stabilize their vertebral column. Providing comfort included knowing my pain, decreasing my pain, rubbing my back or legs, and handling me gently. Providing comfort was something routinely offered by nurses perceived as caring, but never offered by nurses perceived as noncaring. Caring nurses seemed to know when and how to provide comfort; as a result of "learning the other" these nurses seemed to know what would make the patient feel better at that time.

**Daryl:** "Those same couple of nurses, when I get out of the shower, they rub my back. You know they ask me, do you want your back rubbed? Do you want me to rub your back for you today? I said, well, are you supposed to do that? This one nurse says, It's nothing. I'll do it for you. She rubbed my back and when she got done I was feeling pretty good. When she got done it was like...she knew my pain, she knew the pain I was having."

Often times just the mere fact that a particular nurse was on duty for a shift would provide comfort and the participant might forego taking pain medication for that shift. So sometimes just the presence of a nurse perceived
as caring would have a comforting effect for the patient:

Walter: "You know I was trying to get off those Percocett. They made me sweat, and they messed up my bowel and bladder training program. I was trying to switch to something over-the-counter for when I went home. This one night I was having pain in my back and shoulders; maybe I overdid it in therapy or something. And I was trying to decide whether I needed a pain pill. Well, when I saw that this nurse was on for the night I knew it was going to be a good night, so I decided I would try it without the pain pill. And it was okay. I was able to get through the night because I knew she was there and if I really needed something she would be there."

Rehabilitation patients in this study related that relieving pain was important, but in addition knowing the patient's pain was crucial. This connotes a compassionate recognition of the patient's pain as well as a compassionate manner in moving and handling the patient consistent with this acknowledgement. As rehabilitation progressed and acute pain became less of an issue, comfort and recognition of the participant's emotional pain became important.

Responding. Responding to the participant or responding in a timely manner was another important aspect of the technical dimension of nurse caring. Answering the call light promptly or face-to-face, not having to wait, getting medications or treatments on time, coming to see
what I needed, and telling me when they would be there (giving an accurate time estimate of when they would be in the room) were perceived as important features of responding. These behaviors of the nurse communicated several things to participants: their needs were believed by the nurse, activities involved in their recovery were important to the nurse, and the patients themselves were viewed as important. The following example illustrates what a nurse communicated to a patient in the way the call light was answered:

Carl: "...when you ask for things, not having to wait one or two hours to get it done. There are a few nurses who will come in and see what you want pretty quickly, like within a half hour. When I need something and push the button, they'll come to see what I need, rather than just asking me over the speaker. And that's important; that's a long time especially if you're hurting."

Anticipating needs. Anticipating needs incorporates the nurse's general knowledge of SCI patients and their needs, as well as the particular needs of this SCI individual, and manifests itself primarily in the technical dimension of caring. Paying attention to details which may have implications for the patient, trying to understand what they would do if they were in the same position, letting the patient know what might lie ahead, and planning ahead for what the patient might need were perceived by SCI
individuals as caring behaviors which comprised anticipating needs. One participant described this aspect of technical care as "micromanagement" in that the tiniest detail which might be overlooked by the nurse before s/he leaves the patient's room can have tremendous consequences for the patient. This particular participant was wearing a Halo brace, to provide stability for the neck and cervical spine, which limited his mobility even further than his SCI. Normally a patient would have some mobility while in bed, but the Halo restricted what little movement there was because of its weight and awkwardness.

**Patrick:** "When I get in bed I can barely roll, so I have very little self-control of my environment. If the phone or the call bell are a half inch out of my reach it becomes a very frustrating thing. One day I was going to read the mail after physical therapy and the call bell was too far out of my reach on the bed. So the thought is there, but they need to follow-through a little bit and really determine, can he get a hold of it, can he get out of trouble if he gets into trouble?"

Early in the rehabilitation stay anticipating needs was very important to participants since a sense of trust had not yet developed and they did not know which nurses would routinely be checking on them at fairly regular intervals. Once it became obvious who the nurses were who were perceived as caring, anticipating needs was less of a
concern when these nurses were on duty. If a caring nurse was finishing a shift and a nurse perceived as non-caring was coming on for the next shift, the nurse who was leaving would try to anticipate as many needs as possible for the entire upcoming shift.

*Walter:* "This other nurse was coming on, not the one I was telling you about, so I knew it was going to be a long night. The nurse who was working with me all day said she would give me my pain medicine and make sure I was turned before she left. She even let me do my cath early 'cuz I told her I didn't know when the other nurse might get around to it."

*Surrveillance.* Another aspect of the technical dimension of nurse caring was surveillance. Participants described surveillance as "checking on me," "knowing something isn't right," and "picking up on things." Surveillance included the nurse's knowledge of SCI in addition to their knowledge of the nuances of the particular patient and manifested itself in the nurse's ability to monitor the patient's progress and detect anything early which might have deleterious consequences for the patient.

*Ralph:* "I got this little red spot on my bottom. This nurse picked up on it right away because she checked my skin every day or had me check it. The other nurses and the doctor only looked at it about once a week even though they saw me every day. She made sure it didn't get any worse and
she told me to sit in the chair less until it healed. She
told me that if it got worse I would only be able to be up
for 2 hours and I might be here for an extra week or two.
And when it started to go away she told me so I could be up
like I normally am."

Participants in this study also emphasized that
"knowing when something was wrong" and "picking up on it"
were important aspects of surveillance. Perhaps because of
the length of time with a nurse in rehabilitation, SCI
individuals expected nurses who demonstrated caring to "pick
up on things" that were outside their individual variations
in emotional as well as physical manifestations of injury.

Following through. In the technical dimension of nurse
caring, following-through incorporates getting back to the
patient about things and also getting things done that the
patient needs. Participants included the nurses knowing
their limits and knowing when to call the doctor as part of
following-through. Participants often perceived that nurses
"had to go out on a limb" to follow-through and get things
done for them. But nurses who did not follow-through were
perceived as noncaring and "not doing their job." For
example, one participant developed a pressure sore after
being admitted to rehabilitation. The one nurse he
perceived as caring and really looking out for him had to
follow-through several times until the correct treatment was
initiated.
Walter: "I got this sore on my butt after I got here. She was really mad 'cuz she said it meant the other nurses weren't doing their job. So she told the doctor about it. The next day he ordered this one kind of dressing. The next time she worked she told me it wasn't the right thing because the sore wasn't healing. So she told the doctor again and he changed the order again. The next time she came on she said it still wasn't the right dressing. So she talked to the doctor again and this time he got it right. And now this sore is finally healing. But I lost about a week because they wouldn't listen to her when she was the one who saw the sore. But she kept after them until they got it right. I'm glad she did because I might even be here longer."

Summary. The technical dimension of nurse caring was comprised of physical care, comforting, anticipating needs, responding, surveillance, and following-through. Each of these aspects of technical caring required a knowledgeable nurse who had learned the nuances of the individual patient. Early in the rehabilitation stay, the technical dimension of nurse caring was important since participants had not learned yet who was caring and who they could trust. Once a caring relationship was established, and the patient became more of a partner in the rehabilitation process, the competence of the nurse became more important.

Interpersonal: The Third Dimension of Nurse Caring.
The interpersonal dimension of nurse caring encompassed "attending," "sensing," "getting me through," "and using humor." For several participants the first night in rehabilitation was a crisis. The nurse who stayed with them and got them through that first night was usually one of the nurses with whom a caring relationship developed. For two aspects of the interpersonal dimension, attending and "getting me through," time was a key factor. The nurse was willing to spend time with the patient. Participants also perceived that a caring nurse wanted to spend time with them. Sensing and using humor required "learning the other." After the nurse and patient had established a relationship perceived as caring, both individuals knew the other well enough to pick up when something was not right or to discern when and how to use humor.

**Attending.** When a nurse took time with participants, sat down, listened, and looked in their face, the nurse was perceived as caring. This communicated to patients that they were an individual, the nurse respected them as a person, and eventually a sense of trust developed. Participants also described a sense of closeness they felt with nurses with whom they developed a caring relationship. This trust and closeness was important as participants moved through the work of rehabilitation. They felt they could ask questions and talk about things with this nurse that they could not discuss with anyone else. Often this
included issues of sexuality and sexual relationships or other things they felt were too personal or embarrassing to discuss with anyone else.

Daryl: "They don't be rushing and acting like they have to do something else. When they're with you, you know they're there for you and not thinking about something else. They talk to you and look at you and they're not rushing. And they answer my questions. They take their time with you."

Sensing. Sensing what the patient needed was the result of "learning the other" and the nurse's competent caring. Unless the nurse knew the patient as a person and their particular nuances, this sense of what the patient needed did not occur. Often a nurse perceived as caring could tell what a participant needed after being in the room only a few seconds or by simply looking at their face. This sense of the patient as a person included "knowing when I needed to be alone," "knowing something was wrong," or "knowing what to do." The nurse who was perceived as competent would either proceed with "knowing what to do" which often included "using humor," or would ask if there was a problem or if there was anything they could do. Nurses perceived as noncaring would not pick up on the patient's cues.

John: "Sometimes when I'm in alot of pain or if I'm quiet, they know something is wrong. They'll ask me, "what
do you want to do?" Or they will ask if something is wrong, or if they can help."

Another participant explains a similar experience:

Daryl: "They can tell your moods. If you're down, they cheer you up. They look at your face and they can tell if they think you're down or having a bad day. They'll ask if there's a problem, or if there is anything they can do. The others will just ignore you."

Or one participant described how nurses who sense something is not quite right helped him "sort it out:"

Patrick: "Even when you're not in trouble or you're not emotionally overwrought, there are a couple (of nurses) that seem to be sensitive to your needs. That you might have pain or that things aren't quite right and they spend a little extra time trying to sort it out and pick up on what you need."

Getting me through. "Getting me through" described how participants perceived caring nurses helped them through the difficult times. Nurses used a variety of strategies which included listening, telling a story, giving encouragement or reassurance, being there, hugging me, and talking me through it.

Mary: "Sometimes I get real teary and depressed about what's happened. Sometimes the nurses would be here. They would listen. They would tell me it would get better. Sometimes they hug me. Sometimes they tell me a story about
another patient they knew that had something similar happen and they would tell me how that person handled it. They tell me they understand. They give me encouragement. Sometimes they talk me through it."

Another participant had nightmares for a few weeks in rehabilitation and a couple nurses helped her through that:

**Maureen:** "Sometimes I have nightmares and they comfort me. I guess they would hear me screaming. And they would come to find out if I was alright. They would talk me through it, or listen to me tell about it. Then they would remind me it was just a dream."

One young man had been in rehabilitation for over three months and had just returned from his first pass for the weekend:

**Carl:** "I came back and I bawled when I got back. I just was real mental that day, and a couple of the nurses, the ones that know me, asked if I was all right and stuff and came in to make sure I was okay. They said it was going to be all right, and that it happens to everyone, and that you'll be getting out of here soon. They just talked to me. They tried to talk the truth until I was alright again, you know."

"Getting me through" was referred to by participants for those times that were emotionally charged or were difficult from a physical standpoint, such as their first transfer or cath. Nurses perceived as caring by
participants, sensed that these times were particularly difficult and initiated a response or gave participants an opening for how they wanted to deal with the situation.

"Getting me through" was perceived differently by males over 50 years of age. After "getting me through" difficult times was identified consistently by the initial participants, the researcher explored this area with subsequent participants. It continued to be an important aspect of the interpersonal skill of nurse caring for participants, except for the above group. They stated that it had not happened to them or they dealt with it—Lloyd, "I just dealt with it;" Ralph, "I haven't had any bad days;" and Walter, "That has not been my experience." Additional male participants over age 50 were sought by the researcher to further explore this aspect.

Having to be strong and to always be there for their family was part of the religious value and work ethic instilled in male participants over age 50 while they were growing up. So now in this time of personal crisis, they felt the expectation was the same. Since they perceived family members took cues from them, they had to continue to "be strong." One participant describes what it is like for him.

Ray: "I can't let myself get down. You can't even let that first thought it. You don't let them in. I mean you don't even let that first cry come in. When I came to
my senses and realized what the situation was, why you know you do a lot of thinking. You push the negative stuff out of the way. You think positive and go. Cause when you're down, I could see easily in a situation like that, that things could fall apart real quick. That's the way I was raised. We were always determined to take the situation by the horns and run with it. We were looked up at to do that. Well, not looked up at, we were expected and we knew we were expected to do these kind of things, you know, without even a question. You know, care for and do as much for yourself and do it rightfully and put your whole heart into it. If it's worth doing, it's worth doing it with your whole heart. I have to be strong for my family and for my own self. It's always my own feeling that if you keep yourself up your body works better."

Using humor. The use of humor by nurses perceived as caring had a positive effect on mood, motivation, self-esteem, and the spirits of participants. Using humor helped to dissipate some of the tension in an embarrassing situation or it helped participants to get through times when they weren't successful in accomplishing a task. Humor was also used when participants and nurses were interacting on a personal level rather than on a professional level. This helped communicate to participants that caring nurses enjoyed interacting with them as a person and it also communicated wholeness— that is, the nurse was interacting

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with them as a whole person, not a SCI individual. Joking, teasing, "calling me affectionate names" were all viewed by participants as using humor to communicate caring. Using humor was viewed as appropriate only when the nurse and patient had developed the relationship and learned how the other would respond.

Mary: "Sometimes they tease me, now. They didn't at first and I wouldn't expect them to; they didn't know me. But now that they know me and I know them, they tease me. Or they call me affectionate names. I like that because it let's me know they care about me."

Some nurses used humor to push participants a little harder:

Daryl: "They know when they can joke with me or pick on me or goad me on a little bit, you know. Like one nurse says, "You're real independent now, here's your shorts. Do it yourself." And she's laughing at me on the way out."

Summary. Nurses perceived as caring interacted with the SCI individual differently than other nurses. They spent time with participants and took the time to get to know them as a person. Interpersonal interactions were often therapeutic for participants with caring nurses "attending," "sensing," and getting them through difficult times. Because nurses perceived as caring interacted with participants as whole persons, not just SCI patients in rehabilitation, interactions were also many times of a personal nature. Nurses shared nonprofessional aspects of
their lives with participants in a manner that conveyed their dignity and importance as a person. Nurses often used humor once they got to know participants, and this helped them get through embarrassing or difficult situations. Based on their knowledge of SCI nursing and their knowledge of the participant, nurses perceived as caring intuitively seemed to know what was needed interpersonally in each encounter.

**Competence: The Fourth Dimension of Nurse Caring.**

The fourth dimension of nurse caring, competence, is comprised of four aspects: individualizing care, treating the whole person, respecting the uniqueness of the individual, and breaking the rules. Competence was important to participants after they learned which nurses were caring; competence became an expectation of nurses perceived as caring. Competence was manifested in the interpersonal interactions with participants and in the technical dimension of caring, by the nurse's combined knowledge of SCI and knowledge of the individual participant.

Competence was the manifestation of the ethical dimension of caring. A nurse who demonstrated competent caring, communicated to participants their dignity as an individual, which contributed to their sense of well-being and "getting back together." Competence resulted from the nurse's knowledge, experience, and intuition, and empowered
the nurse to creatively meet the individual participant's needs. It was through their creativity and willingness "to break the rules" to meet the individual's needs that nurses communicated caring through competence.

**Recognizing the Uniqueness of the Individual.**
Recognizing and respecting the uniqueness of the individual resulted from the nurse taking the time to get to know the participant and also from the nurse's knowledge and experience of working with other SCI individuals. Consequently, nurses perceived as caring recognized that each person has a unique life history, has unique goals, and that each individual responds differently to SCI. By taking the time to "learn the other," nurses perceived as caring incorporated the particular nuances of each person into the plan of care.

By including the participant in decision-making and negotiating a plan of care, nurses conveyed a recognition of the uniqueness of the individual and also their respect of that person.

**John:** "I'm not like anyone else. I know what I want to do and what I've got to do whenever I get out of here. But they give me choices. There's things I'd rather do than what they're telling me to do. They explain to me why it should be done like this or why it shouldn't. And let me make my own choices to see if that way is gonna be harder or easier on me."
One participant described how the nurses' and therapists' knowledge of him being an instigator and being competitive was incorporated into his rehabilitation plan.

Ralph: "I'm the guinea pig. I do everything first. One of the nurses said that in their staff meeting, they say I'm the instigator. They say you do it first. So if they tell me I need to lift 30 pounds this week, you know I'll lift 35 or maybe even 50. Then these other two guys, who are a lot younger than me, will try to keep up. And they told me I needed to learn to put my jacket on myself. So I figure I can do this, so one day I worked at it until I got it. Of course it took me about 30 minutes and I was exhausted when I got done, but I did it."

Delicacy was required to handle very emotional situations. Nurses who were able to deal with the emotional as well as the physical aspects of the SCI individual's needs, the whole person, were viewed as competent.

Patrick: "The interpersonal time is limited. Although this weekend or Memorial Day weekend I was having a real down day. I think it was Sunday. I had physical aches and pains, but I think I was exhausted and I was just down and I started to cry. You know and I was out in the patient area here, and she just whisked me right back in the room and sat and we talked for a good half hour. You know she kind of picked right up on that real quick and got me out of the mainstream. But she was willing to just sit down and
let me have it out."

**Individualizing Nursing Care.** Participants stressed the importance of the nurses knowing that what worked for one person might not work for everyone. Being willing to listen to what was important to participants, incorporating individual nuances into the routine, "breaking the rules," and allowing participants to experiment and make mistakes, nurses perceived as caring communicated competence. Inexperienced nurses or nursing students were not perceived as able to individualize their plan; individualizing the plan required a certain confidence and comfort level with the knowledge of SCI nursing. Only seasoned nurses perceived as caring were described as individualizing the plan of care.

**Mary:** "They let me go at my own pace, you know, when I'm ready. And them being there that's important. That let's me know they care. And I like things to be challenging, so when I learn something new, I try to understand it and they explain it and show me and I try to do it. Right now I'm learning to dress myself. I can put on my shirt, and pull my pants up to my thighs, and put on my left shoe. That might not seem like a lot, but it's important to me. It takes a long time for me to do it. I'm sure it would be easier for them if they would just do it, but they know it is important to me, so they are very patient and let me do it."
Continuity of assignments was also a prerequisite to individualizing care for participants in this study. Once a nurse learned what worked best for this patient, which sometimes takes a few days or weeks, it is important for that nurse to continue to work with that patient and remain current with where they are in their rehabilitation plan.

Carl: "...instead of different ones every night because a lot of them don't know your care or how you like this or that, and the other one knows and there's never no problem. This one night I have to go to the bathroom and I have to do it myself. I have to use the bedside chair. Well, she had the bright idea we were going to go to the commode in the bathroom. I can't get in and off the commode hardly at all yet because I don't have enough strength built up to throw myself on and off. It took her a damn hour to get me on there and she had to go get help to get me off. Where if I could have just did it the way I usually do it, I would have had it done, and she wouldn't have hurt her back none. I tried to tell her but we had to do it her way anyway. I told her there would be a big problem. Well, she found out the hard way."

Treating the Whole Person. Being treated as a whole person was an important aspect of nurse caring for SCI individuals during rehabilitation. Nurses perceived as caring did this in a number of ways. By sharing with participants about themselves as people, nurses invited the
SCI individual to share more personal aspects of their lives, which communicated that the nurse was interested in them as a whole person. Using humor was also perceived as a means of communicating wholeness, because often the joke was about something personal or some individual predilection which had been shared between the two. In addition, activities viewed as normal outside the rehabilitation setting, such as sharing musical tapes or CDs, inviting them to have lunch, or stopping by to have a conversation about world events or mutual interests, communicated concern or respect for them as whole persons.

Patrick: "...a couple of them have come in and made it a point after their shift to come in and chat a little bit and it might be about my family and what we've done or something totally irrelevant, or it may be something directed specifically at what I'm going through and getting this better. They love the role reversal--a male physician helpless, and I tease them about it: here we have a great stereotype going, and they've been able to reverse the roles."

Another participant described:

John: "They treat me like a person; they talk to me like a person; they get to know me as a person. They joke around with me, they explain things to me, and they answer questions that I have. Nothing is too personal, at least not that I've found yet."
Breaking the rules. Participants perceived that nurses often had to "break the rules" to meet their individual needs. Often nurses had to be very creative in how they accomplished this task. Participants also felt that nurses "went out on a limb" or put their jobs on the line when they broke the rules to individualize their plan. Oncology patients also described caring nurses who manipulated the environment and went beyond the call of duty (Clayton, et al, 1991).

"Breaking the rules" required knowledge and experience for the nurse to discern what was safe for the patient. Inexperienced nurses or student nurses were not perceived as feeling comfortable making waves or hiding things from other members of the health care team in order to meet the individual patient needs.

Ralph: "Every night when I am back in bed I get this shaking chill. I understand from the other nurses and patients it is not unusual with this type of injury, especially with the air conditioning. This nurse, she pulls the covers up to my chin and puts the heating pad underneath so I am nice and warm. And the last thing she does before she leaves the room is give me my clandestine orange under the covers."

Another participant described how a nurse perceived as caring helped him hide his occasional voluminous urine outputs from overindulgence.
Patrick: "I've been doing my own caths now for a few weeks and they've been going pretty good. I haven't had any problems. I know the volumes are supposed to be under 500 so I don't get an infection—and they are most of the time. Last week I overdid it when my family brought me Chinese. I love Chinese and they brought my favorite soup and cashew chicken. I couldn't eat the chicken because I couldn't swallow the cashews, but I drank all the soup and there was a lot of it. Well, with my next cath there was so much urine. I knew I was going to get yelled at by the doctor, but it was the first time in a long time that I went over. So the nurse writes down 499+. She said that would be our secret, but she made sure I knew this was a special occasion."

Nurses perceived as caring communicated their competence to participants by their willingness to recognize the unique needs of each person, individualize the plan of care, and break the rules to accomplish a goal. Competence required knowledge and experience with SCI patients, as well as knowledge of the individual participant. Continuity in assignments was also required, so nurses who knew the SCI individual and their current rehabilitation plan could demonstrate their competence in their technical and interpersonal skill. Competence contributed to feelings of hope and well-being in participants, in addition to the resolution to begin to take charge and become as independent
as possible.

**Summary.** The first research questions addressed the meaning of nurse caring for SCI individuals in rehabilitation. Four dimensions of nurse caring were conceptualized from SCI individuals' descriptions of the meaning of nurse caring. For rehabilitation patients in this study, a knowledgeable nurse was the first prerequisite for nurse caring. SCI individuals in this study described technical and interpersonal skill as important aspects of nurse caring early in the rehabilitation experience. Once a caring relationship was established, the competence of the nurse became most important, since this communicated wholeness, dignity, and uniqueness to the SCI individual, and enabled the nurse to individualize the rehabilitation plan.
The Process of a Developing Caring Relationship Between a SCI Individual in Rehabilitation and a Nurse

Research question two was: How does a caring nurse-patient relationship develop during the rehabilitation experience, as perceived by SCI individuals? Detailed descriptions of how SCI individuals got to know the nurse and how they thought the nurse got to know them were elicited from participants. By interviewing participants at different times during the period of rehabilitation, the phases of a caring relationship emerged. By returning to participants and asking them to detail what was important to them during the various phases of a relationship, distinguishing features for each phase became apparent.

The three phases of a caring relationship in rehabilitation were: "learning the other," "learning to take care of my body," and "letting me find out." Each of the three phases of a caring relationship had intermediate consequences for the nurse and the SCI individual. As the consequences or results were felt to be reached, the relationship moved into the next phase (see Figure 3). In the first phase "learning the other," the nurse invites the patient into the relationship and a connection is established. In the second phase, as the nurse shares knowledge with the SCI individual, participants viewed themselves as becoming partners in "learning to take care of my body." In the last phase, which participants described
as initiating, SCI individuals began to make changes in their activities, trying to find a way for it to work better or feel better. As SCI individuals became more independent and took charge of their care, the role of the nurse became one of consultant to participants.

The Process of a Developing Caring Relationship

Phase I:
Learning the Other → Mutual Trust & Respect

Phase II:
Learning What I Need to Know → Knowing When I'm Ready

Phase III:
Letting Me Find Out → Finding Out What Works Best

Figure 3. The Process of an Developing Caring Relationship between a SCI Individual and a Nurse in Rehabilitation.
Learning the other

The first phase in the development of a caring relationship, learning the other, began with the nurse asking the participant what they wanted to accomplish in rehabilitation (see Figure 4). Since participants did not even know what a SCI involved or what was entailed in the rehabilitation process, the goal identified was often very broad. But this broad goal communicated to the nurse and the health care team what was important for this individual. One participant described his goal: John, "I want to be able to take care of myself. I don't want to rely on anyone else." Another participant related what he told the nurse that first week: Ralph, "I want to go out of here upright. I don't want to go out on a stretcher or in an ambulance."

Next, the nurse invited the SCI individual to become a participant in the relationship. By sharing with the individual their knowledge of SCI and also about themselves personally, the nurse initiated the relationship by extending to participants an invitation to become a partner in their rehabilitation plan. Sharing by the nurse occurred on two levels, a professional level and a personal level. This communicated to participants that the nurse was interested in them as a whole person, not just as a SCI patient going through rehabilitation.

Carl: "There is this one nurse, she'll talk about her family and some of her personal things, you know,
certainly not tragedies or problems, but some of the things that she likes to do and what you like to do with your family and that kind of stuff. It's a little more personal interaction, not like I'm here for eight hours and you're a piece of lead we gotta move around and do these various things to. The longer they're with you as an individual, the more that seems to come out."

Nurses perceived as caring share their knowledge with the SCI individual every time they go in the room or do a treatment or give a medication. The underlying message to participants is they must become a partner in their care and eventually assume responsibility for it.

If participants accepted the invitation into the relationship, they began to share with the nurse what was important to them. This sharing also occurred on two levels; participants shared what was important to them as a person and also what was important to them about their rehabilitation plan.

John: "They talk to you and you talk to them about mutual interests. Sometimes not things you have in common. You joke around like, "You're listening to that hillbilly music again." Or "there's that ole long hair music person again." You learn things about them as a person and they get to know you. They learn how to read me and I get to know them--like if they're having a bad day. You know we're here a long time. They get to go home at night."
We're here 24 hours a day. It would be awfully boring if all we did was talk about what went on here. So we get to know each other as people."

**Learning the Other**

<table>
<thead>
<tr>
<th>Nurse:</th>
<th>Asking what I want to accomplish</th>
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<tr>
<td>Patient:</td>
<td>Identifying a goal</td>
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<td>Nurse:</td>
<td>Sharing knowledge of SCI and self</td>
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<td>Patient:</td>
<td>Sharing knowledge of self and values</td>
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<td>Mutual Trust and Respect</td>
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**Figure 4.** Phase 1 of a Developing Caring Relationship: Learning the Other

As the result of "learning the other," mutual trust and respect developed between the participant and the nurses perceived as caring. Participants knew which nurses would believe them, who they could trust, who they could ask
questions, and in whom they could confide. These were the nurses with whom the work of rehabilitation occurred. Participants also believed that the nurse trusted and respected them.

**Carl:** "the ones I get along with better I am able to trust better and listen to, at least I listen to them a little more if I trust them. If I don't really trust them I might think they're saying the first thing off the top of their head and not really caring about the consequences. Where if I trust them on things it probably justifies doing what they say. And they probably believe me a little more, if I say this is really hurting me today, you know, whereas another one might think he's trying to get babied a little bit or something."

**Trust.** Trust meant feeling safe to try things the first time and taking a risk even if you might make a mistake. Participants knew that nurses perceived as caring would stand by them through those first times which were frightening, and if they made a mistake the nurse would simply tell them and they would continue to work on it. Sometimes the nurse and the SCI individual would decide together to wait for awhile before the task was attempted again to prevent discouragement.

**John:** "I knew it would be okay to do it with her if I made a mistake. She would tell me I did okay, and even if I made a mistake it would be okay. That makes you feel like
you've accomplished something....If I have a problem, I just say I have a little problem and we talk about it. I know they won't use it against me later. Some of the other nurses might. The trust and respect goes both ways I think. They know if they make a mistake I won't tell on them either."

Nurses perceived as caring also demonstrated their trust by giving the SCI individual choices. When trust had been established, the nurse knew as the result of learning the other that participants would try to make the best choices based on the knowledge they had. The nurse also seemed to know that participants would do their best to follow through with what they planned. Similarly, once trust was established between the nurse and participant, then the phase of "learning what I need to know" proceeded.

_Ned:_ "When I first came here I had a feeding tube. I kept telling them, if you take this out I will eat. They wouldn't take it out. I told this one nurse if she took it out I would eat. So after a day or two, she took it out and I started to eat. That was it. I haven't had anymore tubes and I've been eating fine ever since."

_Respect._ Mutual respect was the other intermediate outcome of learning the other. By respect participants felt that nurses perceived as caring included them in decision-making about the rehabilitation plan and treated them as partners in their rehabilitation.
Alan: "She knows I've got a heart problem and she'll say, "Are you tired?" If I say I am she asks me if I want to do 1 or 2 transfers. And I said we'll do two. But if I said I wasn't up to it, one would be all we'd do. Or none if I was, if I didn't really feel up to it. She's real thoughtful about that. I think that comes from earlier experiences. If you have always been on time and done what they said, they're gonna believe you. But if you're always late and don't care what you do, they're gonna say you do it now and that's the way it will be."

Two participants described their expectation that nurses would recognize and respect the fact that they had been making decisions for a long time and would naturally include them. This in fact only happened with nurses perceived as caring.

Daryl: "I'm not no kid. I might act like a baby sometimes; we all act like babies sometimes 'cuz we're injured. But I'm a grown man. I really want them to acknowledge that."

John: "I'm a grown man. I've been making my own decisions for a long time; I don't need to be told what to do. They (particular nurses) treat me like a person."

When participants acquired knowledge about their injury and the changes required in their life, they felt confident participating in decisions regarding their plan of care. When nurses recognized this and included the SCI individual
in developing the plan, they felt like a partner in their rehabilitation plan.

Patrick: "They ran out of these scope patches. They're not manufacturing them until September or something like that. The company got in trouble with the FDA because it had inaccurate dosages in the patches. They weren't uniform, so they had to revise their process. So there just aren't any more scope patches. There are none around. Well, I found out this is an illegitimate use of the patch anyway. They found out that paraplegics sweat heavily and if you use the patch it reduces some of the excessive sweating. I don't know that I had that much; I normally sweat alot when I work out anyway. There's no longer any supply left so they wanted to start me on another medication, an oral thing. I said let's try nothing first, rather than add another medication; let's see how bad it is. And she agreed with that and that was fine and we didn't get it added. That made me feel good; like a contributor."

Summary. For both the nurse and SCI individual, learning the other involves learning the strengths, needs, limitations, and goals of the other, which results from the honest sharing that occurs in a caring relationship. As a result of learning the other, the nurse learns how the respond to the individual needs of this particular other and what limitations must be overcome with the assistance of other team members. The work of rehabilitation, getting
back together, proceeds with nurses and therapists perceived as caring. It is with these member of the health care team that sharing of successes and sharing of difficult moments occurs. This sharing is possible because trust and respect has developed between the SCI individual and the nurse as the result of learning the other. Learning to take care of their body and learning to make decisions, the next two phases in a caring relationship, transpired between the SCI individual and a health care professional perceived as caring.

**Learning what I need to know**

The second phase in the development of a caring relationship, "learning what I need to know," occurred with nurses and therapists perceived as caring. It is with these health care professionals who are perceived as caring that the work of rehabilitation proceeds. The SCI individual now knows as the result of learning the other, who they can trust and with whom they feel safe trying things and making mistakes if necessary. It is not perceived by SCI individuals that the work of rehabilitation occurs with health care professionals viewed as noncaring.

Learning what I need to know ensues through a series of reciprocal behaviors between the SCI individual and the nurse (see Figure 5). This process is repeated a number of times with all the various activities the participants learned prior to discharge from rehabilitation. The
intermediate consequence for each of these activities is "knowing when I'm ready" to begin taking over the tasks themselves.

Learning What I Need to Know

<table>
<thead>
<tr>
<th>Nurse</th>
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<td>Showing</td>
<td>Watching</td>
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<td>Telling</td>
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<td>Breaking it Down</td>
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<td>Answering Questions</td>
<td>Asking Questions</td>
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<tr>
<td>Waiting until I'm Ready</td>
<td>Knowing when I'm ready</td>
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Figure 5. Phase II of the Process of an Developing Caring Relationship between a SCI Individual and a Nurse: Learning What I Need to Know.

Ralph: "I've been working on dressing; learning how to put my pants and shirt on by rolling back and forth in
the bed. I watch how they do it and they give me little pointers. Well, as soon as I mastered that she told me the next thing she was going to make me do is put my jacket on myself. And I just couldn't visualize me getting this thing on by myself. So when there was nobody around, I thought now's a good time to try it. I'm as ready as I'm gonna be. And I did get it on. So by the time she came in the room I was dressed. Then she told me I was going to have to learn how to get dressed in the chair."

There are times when the SCI individual felt ready to begin taking over some aspect of the activity, and when they began, it did not work out. It may be that they did not have enough strength yet or did not yet have a prerequisite skill. When that happened, the nurse continued performing the activity to avoid frustration, based on mutual agreement, until the participant felt ready to try again. For example, one individual, who was a quadriplegic, wanted to begin performing intermittent catheterizations. After the first couple of attempts it became obvious there was not enough strength and control in his hands yet. So the nurse continued doing the caths for another couple of weeks while he worked on strengthening his hands in therapy. Then, when they both felt he was ready, he tried it again and this time was successful.

Ned: "A few days after I got here they took the catheter out and they taught me how to do these caths. I
did them for awhile but it didn't really go very well. My hands didn't work very well and many times I couldn't get it in, so I decided to stop. I didn't do them for about a month, and that was ok with her. I couldn't do the caths for awhile because I couldn't move my fingers and put my thumb and finger together. But when I finally could do that after therapy, then I was ready to do the caths. So I'm doing them again now. Once my hands got stronger and I can move my fingers better now, I can do them better."

Another example is when one individual wanted to begin performing his own bowel program, but could not role over in bed and position himself yet. So he waited for a short period until he could position himself in bed to perform the task.

**Carl:** "I always asked alot of questions from the time I got here, like what are you doing this for, what's that for, you know I ask them alot. Finally I get tired of them doing this and I say how about showing me or they ask me do you want to try it. I tried it for a couple of times and it didn't work out. I couldn't roll on my side right and hold myself over at the same time. They waited awhile and then they asked me if I wanted to try it again. They try to get you independent on your own is what they do."

There is one aspect of this process that needs to be explored further. Some individuals always took the
initiative to let the nurse know they were ready to begin performing an activity themselves, while others waited until the nurse asked them if they were ready. When examining who took the initiative and who let the nurse ask them when they were ready, with the background variables it was not obvious what factors played a part in this particular aspect of "knowing when I'm ready." Once participants began successfully performing the activity themselves, the relationship moved into the next phase, "letting me find out."

Letting me find out

In this last phase of a caring relationship, participants began to experiment with the activities in their plan of care and discover, mainly through the process of trial and error and consultation, what worked best for them in how they performed the task or how they would fit the activity into their routine, either in rehabilitation or after they returned home (see Figure 6). During this particular facet of the process, participants often hid what they were doing from the nurse until they found what would work. When that occurred, they would "let" the nurse find out what they were doing or would show the nurse what they were doing in an effort to learn if what they were doing was harmful in any way or would delay their rehabilitation. During this phase, the nurse served more as a consultant to participants; once the nurse found out the modifications
made by participants, they were expected to "tell me the consequences" or "tell me straight" if this was harmful or not or would result in potentially deleterious consequences in the future.

Letting Me Find Out

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<thead>
<tr>
<th>Nurse</th>
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<tr>
<td>Giving me choices</td>
<td>Going at my own pace</td>
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<tr>
<td>Letting me try</td>
<td>Making changes</td>
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<tr>
<td>Helping me through it</td>
<td>Making mistakes</td>
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<tr>
<td>Giving me permission</td>
<td>Getting permission</td>
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<td>Letting me decide</td>
<td>Hiding it</td>
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<td>Calling me on things</td>
<td>Working at it</td>
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<tr>
<td>Telling me consequences</td>
<td>Finding Out What Works Best</td>
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Figure 6. Phase III of the Process of a Developing Caring Relationship between a SCI Individual and a Nurse: Letting Me Find Out.

This example by a participant illustrates the process of "letting me find out."
John: "I started making little changes, but I didn't tell them. I wouldn't let them know. And then if one of them would say something I would say I've been doing it that way. They switch around so often they don't notice. Until I found out if it was going to work. Sometimes it wouldn't always work. Or sometimes I would start something and they would see that it was going okay and then they would say I could go ahead and do that. That happened with my arm. They know that I have to do it at home and I can't do it just like I do it here in the hospital, so they say it's okay. They let me know it's okay. Now if it was something that was doing to hurt me or something they would tell me."

If the modifications would not result in any potentially harmful consequences, the nurse would tell them it was okay and they would continue; if their modification might be harmful, participants would continue to experiment until they found a way to perform the activity in a way that "worked better" or "felt better."

Carl: "...explain to me why it should be done like this or why it shouldn't. Let me make my own choice to see if that way is gonna be harder on me or easier. Cause maybe it may seem like it's easier to them to do something a certain way, but I tried it that way and my own way, or another way until I find a way I like it."

Nurses perceived as caring gave SCI individuals the freedom,
as a result of the trust developed between them, to experiment and discover what worked best for them. Participants shared with the nurse what they discovered works best because of the trust they developed; they knew the nurse would "be straight" with them about whether this particular way was a good idea. Creative problem-solving in rehabilitation was fostered by a caring relationship.

Rehabilitation patients in this study perceived that they participated in decision-making with caring nurses from the outset. However, in this phase of a caring relationship, "learning what I need to know," responsibility for decision-making was actually relinquished by the nurse to the SCI individual. In rehabilitation, nurse caring began with the nurse initially performing the actions but eventually turning over responsibility for the actions and problem-solving to the SCI individual. Perhaps this is due to a more long term relationship between the patient and nurse, and lifelong changes which will be required by the SCI individual as the result of injury.

**Summary.** The process of a developing caring relationship between a SCI individual in rehabilitation and a nurse progressed through three phases: learning the other, learning to take care of my body, and letting me decide. In the first phase, learning the other, nurses began sharing information with SCI participants to facilitate their assuming a partnership role and eventually
a decision-making role in the plan of care. The second and third phase of this caring relationship, "learning what I need to know" and "letting me find out" were repeated for each of the tasks or skills the SCI individual acquired before discharge from rehabilitation. During each of these phases, reciprocal behaviors occurred between participants and a nurse perceived as caring.

Each of these phases resulted in intermediate consequences for participants, which resulted in them moving into the subsequent phase. Mutual trust and respect, which resulted from learning the other, contributed to the motivation and willingness to want to learn to take care of their body. "Knowing when I'm ready," which was a result of the second phase, gave participants the courage to begin to try different approaches to a task or skill until they found what would work best for them under their particular circumstances. "Finding out what works best," which resulted from the third phase, "letting me find out," was accomplished in an environment which reinforced safe, creative problem-solving in preparation for discharge. The last two phases facilitated SCI individuals achieving a sense of self-care, autonomy, and independence prior to re-entry into their family and community from rehabilitation.

**Consequences**

Research question three: What are the perceived consequences of nurse caring for SCI individuals in
rehabilitation? After particular relationships with nurses perceived as caring were explored in-depth, participants were then asked to identify the result for them of these special relationships. Early in the rehabilitation experience, participants described the consequences of "lifting my spirits," which resulted from interactions with nurses perceived as caring; nurses invited participants into the relationship and treated them as partners in their rehabilitation plan. A sense of wholeness, value, and uniqueness began to return to the SCI individual within these special relationships. Toward the end of the rehabilitation experience, "taking care of my body," "taking charge," "knowing there's life after SCI," and independence were described by participants as important consequences of a caring relationship. Nurses became consultants to participants as they began to take charge of their plan and the decisions required for discharge.

Getting Back Together

"Getting back together," the core category or variable, was the endeavor toward which SCI individuals aspired during rehabilitation. Nurse caring, which was comprised of the dimensions of knowledge, interpersonal skill, technical skill, and competence, enabled SCI individuals in rehabilitation to accomplish this aim. The process of an unfolding caring relationship, expedited "getting back together," or reintegration of the self in
preparation for the participants' reintegration into their family and community. As SCI individuals returned to feeling a whole person, hope emerged that life beyond SCI was again possible and could be meaningful.

Through learning the other, the participant and nurse uncovered the best means to accomplish "learning to take care of my body" and "letting me decide." As they discovered when they were ready to take over their plan and what worked best for them, participants began to take charge, take care of their body, feel independent, have hope, and experience well-being. Each of these consequences will be described in detail along with illustrative comments by participants (see Figure 6).

Lifting my Spirits

During the rehabilitation experience participants described many encounters with nurses perceived as caring which resulted in "lifting my spirits." These encounters might involve an interpersonal interaction with a nurse in which a personal anecdote or a story about another SCI individual was shared with a participant. Or the interaction might involve positive feedback about some progress the participant made or it might include a joke or humorous story shared between the nurse and participant. Occasionally, during a time when a participant might be feeling particularly down or sad, or having an emotional day, the nurse stayed with them and got them through the
difficult experience. These interactions all resulted in "lifting my spirits."

Patrick: "They point out your improvements too, you know, which is the key. Some of the improvements are just so minute. They point them out and show what you're doing right and how you're making progress. That's uplifting to me. Part of the problem with the injuries that I have, it's very hard for me to tell how much I'm doing. When I do transfers into a chair, they have their hands on me so that I'm not going to fall all over the place. And it's very difficult, at least at first, to tell how much I physically did and how much they were scooting me over. That was really a very hard perception for me to catch and they've been very good at saying, "Look, I'm not holding you at all. You did it all yourself." They show it to you and it's minute increments. But they point it out repeatedly that there are certain things that you do that are just a little bit better than they were last week. I think that's very important."
Figure 7. Consequences of Nurse Caring for SCI Individuals in Rehabilitation.

Another participant described what it meant to him when, as the result of an interaction with a nurse, it "lifted his spirits."

Ralph: "It makes me feel good to know that I might be able to handle that all without somebody there all the time. It wants me to get as much stuff, as much as I can get to do. If I quit and say no and I don't know by now, I'm going to have to get it later on and it may be harder on
my own. It feels better. You know they say laughter is the best medicine, but just feeling good helps you out too. Feeling positive, in a good mood, if you get, when you feel bad you just don't want to put forth the effort to do stuff. No, you just kind of screw it, you know, and I don't want to do that, but like when you're in a good mood, well good, let's try it, you know. And it might not bother me so much if I fail. If I'm not getting something, I think well maybe I'll get it next time."

Lifting my spirits helped participants get through the rough times, helped with motivation, and helped them move forward. Lifting my spirits also helped participants feel good about themselves and about their accomplishments.

Walter: "...they try to give me some "atta boy" and give me some encouragement to boost it up. All in all I think the girls here have done an incredible job in terms of trying to bolster morale. And morale is a significant portion of what helps us get through here."

When participants were asked to explain "lifting my spirits" a number of explanations resulted. The most common was feeling better or feeling more positive. Another common explication was enhanced motivation, having more strength and courage to push forward, and wanting to learn as much and do as much as possible. Lastly, "lifting my spirits" meant enhanced self-esteem. Participants described feeling positive about what they had accomplished, wanting to share
their accomplishments with important others, including family and caring individuals in the health care team. "Lifting my spirits" was similar to well-being in that personal growth ensued and a positive sense of self resulted from the caring relationship.

Daryl: "Your self-esteem start to build. You strive off that. When they come, you want to show them what you've learned. Like, look what I learned today. I can move my leg more. Almost like a family member, not really a family member, but like one. They're close, not just acting like they're close, but they're close."

Taking Care of my Body

Another consequence which resulted from a caring relationship with a nurse and contributed to "getting back together" for SCI individuals, was taking care of my body or self-care. By sharing knowledge with the SCI individual, the nurse communicated to participants their desire for them to become partners in their rehabilitation plan. Once participants acquired knowledge and learned which nurses they could trust, SCI individuals wanted to begin performing some of the skills required in their plan. Then, when they felt comfortable with the knowledge and the skill, participants began to experiment with how the task worked better or felt better, in an effort to refine their skills in preparation for discharge.

Ned: "I usually get to do whatever I want. It's my
body and they know that. And they know that I have to be the one to eventually take care of my body."

Another participant described what was important to her:

**Mary:** "The thing that is real important to me is what they have taught me about my body and how it is different now. You know you learn things in high school and during your life about your body, but it's not like I need to know now. I really need to know how my body works now that it has changed. And they teach me that. I know so much more than when I came here. They take the time to explain things to me and teach me. That's what is important."

And yet another participant described what was important to him:

**Lloyd:** "They talk to you and try to explain things the best they can. They talk about spinal cord injury and about getting well. I generally ask questions and they explain the best they can. They wait until I ask questions so I can learn as much as I can about spinal cord injury. 'Cuz I don't know about this and the different levels and what I'll be able to do. I need to learn as much as I can because I'm going home and then me and my girlfriend will have to do everything. So I need to know what to do."

One thing which concerned participants was their ability to explain about their injury, spinal cord injury, and what their plan entailed if they ever had to go to
another hospital, if they ever needed an ambulance, or just to their family, friends, or the public. Nurses perceived as caring shared with participants not only how to take care of their body, but also why their body responded the way it did, why they needed to do certain things, and what to anticipate in the future. As a result of being able to take care of their body, participants also had the confidence to explain to others what taking care of their body meant. Four participants were readmitted to hospitals from rehabilitation for additional surgery or complications experienced. They experienced first hand why it was important to know how to take care of their body.

Carl: "When I was in the hospital, they didn't know anything about taking care of spinal cord injury. I had to tell them everything I learned here. So the nurses have to be professional, you know what I mean? And teaching me what I need to learn is part of that; I've got to know it sooner or later."

As participants learned an aspect of taking care of their body, nurses perceived as caring, turned that portion of their plan over to them. Participants were responsible for performing that portion of their plan. Caring nurses held participants accountable for those aspects of their plan, but continued to demonstrate interest and concern for how things were going. That communicated to participants they could always ask questions or discuss problems with the
nurse if they arose. In this way nurses perceived as caring assumed the role of consultant in the care of their bodies and continued to communicate a respect for participants as individuals. Nurses perceived as noncaring would "nag" participants about whether they had done the task, but that was the extent of their involvement. They did not convey an interest in how it was going.

Nursing care initially began as doing thing for patients that they were unable to do for themselves because of illness or injury. As patients became less ill, stronger emotionally, and more knowledgeable, nurses eventually turned responsibility over to the patient for their own plan of care. The process of how this actually occurred has not been clearly elucidated for rehabilitation patients prior to this study.

Taking Charge

When participants learned to take care of their body and what worked best, they began to take charge of their plan of care. They did this in a number of ways: they were determined, they began to take over, they began to speak up more, and they began to insist on doing things their own way. Nurses perceived as caring recognized what participants were doing and supported them in this endeavor, assuming their new role as consultant. Nurses perceived as noncaring often became angry and demanded that participants do what they were told.
Daryl: "I'm a good problem-solver. I mostly figure it out by watching and I observe how they do it. Like before I was wondering how I was going to get in bed. They've been using the sliding board. And pretty soon I'm thinking I can do that. I learned; I learned to do things my way. I learned to do things so I won't have to wait on nobody. I was determined to get in my bed that night. From then on I got so good at it I didn't need the board no more. They were surprised. There's a lot of patients around here, so that's why I was determined to do it on my own. I don't got to worry about them doing it. I just jump in bed."

Another participant described:

Mary: "I am able to take charge when I feel good. When I'm not in pain or not too tired I am more confident in my ability to do the things I am able and that makes me try harder."

One participant described how he began to take charge when he felt he learned enough about how to take care of his body.

Carl: "If I feel up to it I can try where I think it ain't going to hurt me, I'll do it. But if I don't feel right and I'm hurting that day I'll tell them; I'll just refuse it. And a lot of them will make you go through it anyway. Though the other ones will respect your wishes and wait another day if you're feeling better then do it with them. There's a lot of negotiating room here. Lately I've
learned enough of my care for myself to know what I need and what I need to do. So now I speak up; I didn't used to."

Taking charge involved having the knowledge and determination for participants to do what they thought was right for them at the time. Taking charge required knowledge of SCI, self-knowledge, self-confidence, and permission from nurses perceived as caring that they were ready to assume the role. Most participants knew when they were ready to take charge. Occasionally the nurse would tell participants when they were ready to take charge. It is unclear whether these participants did not feel they had enough knowledge, lacked the confidence to take charge, or did not feel they had permission to take charge. Achieving the desired degree of self-care, along with participation in decision-making, contributed to feelings of autonomy, or "taking charge."

**Independence**

Being independent was a goal that became more important as participants progressed through rehabilitation. SCI individuals felt very dependent, alone, and powerless when they first arrived in rehabilitation. Gradually these feelings began to dissipate as participants began to learn the other (nurse) and learn to take care of their body. As they began to do more activities on their own, including taking care of their body and being more mobile, feelings of independence began to emerge. Also, as participants began
to participate more in decision-making and take charge, feelings of independence became greater.

**Lloyd:** "They try to get you independent on your own is what they do. Which is nothing wrong with that at all. Mostly since they try to get you independent so you can do it yourself. And if it's up to where they can allow you to try it, they'll let you, you know, or go with you step by step, to try to explain it to you how to do it. So maybe in a couple of weeks you can be doing it and they don't have to."

Another participant described less reliance on adaptive devices and on the nurse.

**Daryl:** "Like today when I got out of the pool. She asked me; she gave me that choice. She knew I was independent. She asked me do you want to put your clothes on or would you like me to do it? If that was another nurse they wouldn't even ask you. They would put your stuff right there and they would be gone. ...There's tools that they give you, like grabbers, and there's things they give you. I don't use none of them; I'm independent."

One participant described why feeling more independent was important to him:

**Alan:** "There's a lot of different levels to go through, I guess. Like when I first got here I couldn't even use this arm hardly, to lift myself up. Working with it now, and now I'm up to doing independent transfers and..."
stuff; that's something there you know. It helps me get more independent when I do get out of here. It does make you feel better when you can do stuff by yourself without having to have someone else's assistance. It makes me feel good to know that I might be able to handle that all without having somebody there all the time."

Being independent and being able to take care of their body contributed to feelings of well-being, hope, and autonomy for participants. The consequences of nurse caring on "getting back together" were not linear. Often participants described a sort of snowball or cumulative effect, as well as going through these feelings repeatedly as the period of rehabilitation progressed.

Independence has been one of the primary goals of rehabilitation since its inception. It is clear from participants in this study that independence is a desired goal almost from admission to rehabilitation. It is not something instilled in SCI individuals from the rehabilitation team.

**Hope**

The consequence participants began to feel during the last couple of weeks prior to discharge from rehabilitation was hope. This was described as feeling like there was "life after spinal cord injury." Participants described feeling that they could still have meaningful relationships and resume meaningful activities. For individuals with
children, this was especially important. There were many milestones in their children's lives in which they wanted to participate. Participants also wanted to feel that they could still be a partner and not a burden to their significant other.

Nurses who were perceived as caring contributed to feelings of hope in several ways. First, they took the time to listen to participants' concerns, raised these issues for discussion, or created an atmosphere where participants felt comfortable bringing these concerns up for discussion. Second, nurses genuinely listened and communicated to participants the importance of these concerns. This contributed to feelings of wholeness and dignity. Lastly, nurses perceived as caring helped participants explore possible ways of handling situations, shared with them what they learned from other SCI individuals, or referred them to another SCI individual with an injury similar to theirs with whom they could talk.

Patrick: "I've noticed that relationships have been maturing somewhat. You know they are willing to talk about it, you know. They'll tell you, "you can ask my anything you want." They haven't refused any question that I've asked. It's kind of an ongoing dialogue that they talk about things. I don't know if education is the right word, but it's certainly reinforcement that you're at a bad point now, but it is going to get better and there is life
after paraplegia. It's different, but it's there's still something there. I really noticed you know, it's some of these nurses that I've talked with all night long, why I'd have probably got them fired!"

Another participant described how a nurse put him in touch with someone who had a injury similar to his.

Ray: "For example, there's a guy up in, uh, that works here that's a paraplegic. He has basically the same injuries I have had. He's had it for 24 years; he's had it since he was 17. And they made it a point of getting a hold of him and saying, come on down and just talk to this guy. So there's a very definite effort to continue the interaction."

Hope often began to appear in the last couple of weeks prior to discharge. Participants described getting their cues from the nurse, and subsequently their family getting cues from them. Often, as SCI individuals prepared to return to their environment, participants and their families were unsure about which of their previous activities and roles they would be able to continue. As these thought or concerns became known, the nurse would often give helpful hints on how participants could handle these situations, or give them permission to be as creative as possible in dealing with the concern. This creative problem-solving communicated caring and also gave participants hope that nothing was impossible or off-limits. Occasionally it
communicated to family members or significant others to be positive and creative in their approach to issues that might arise. Participants in this study suggested that nurse caring contributes to feelings of hope toward the end of the rehabilitation stay.

**Ralph:** "I was telling my wife we were out there doing car transfers today and she says to the nurse, "he can't do that." And she said something about farming and well, he can't do that. And the nurse said to her, "I don't want to hear you say that again." She says, "he can do that." Somewhere in a couple of days she'll (his wife) think about it and she'll say something about it."

**Summary.** The third research question addressed the consequences of nurse caring from the perspective of SCI individuals in rehabilitation. Consequences of nurse caring were perceived as important throughout the rehabilitation program. Initially, "lifting my spirits" resulted from positive interactions with nurses perceived as caring. This feeling of well-being contributed to mood, motivation, and self-esteem, empowering participants to move forward. As participants began to learn to take care of their body, they began to experiment and take charge of their plan of care and the decisions it entailed, empowered from this caring relationship. Self-care and autonomy fostered feelings of independence. As participants learned creative problem-solving strategies, nurtured by caring nurses who fostered
their self-care, autonomy, and independence, feelings of hope began to emerge. The reintegration of self or "getting back together" which resulted from the work of rehabilitation, advanced by nurse caring, restored a sense of wholeness, humanness, and dignity to SCI individuals. Participants perceived that nurse caring facilitated the rehabilitation experience and contributed to their physical and emotional recovery from SCI.
CHAPTER 5

Summary of Findings, Discussion and Limitations

This study addressed the meaning, process, and consequences of nurse caring from the perspective of the spinal cord injured individual in rehabilitation. The constant comparative method of in-depth interviews and data analysis was used by the researcher to conceptualize the dimensions, process, and outcomes of a caring relationship between a SCI individual and nurse in rehabilitation. Nurse caring contributed to the SCI individual "getting back together" or reintegration of the self into a whole person in preparation for return to family and community after rehabilitation. Dimensions of nurse caring perceived by SCI individuals as important to the work of rehabilitation included knowledge, technical skill, interpersonal skill, and competence. The process of a developing caring relationship with a nurse which facilitated the work of rehabilitation occurred in three phases: "learning the other," "learning what I need to know," and "letting me find out."

"Learning the other," initiated by the nurse, was the process of mutual sharing which occurred during the initial weeks in rehabilitation between the SCI individual and nurse in a developing caring relationship, resulting in mutual trust and respect. Participants perceived the work of rehabilitation proceeded with these few caring nurses and

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therapists with whom mutual trust and respect was established. "Learning what I need to know," the next phase of a caring relationship, was a process of reciprocal behaviors and interactions in which the SCI individual acquired the knowledge and skills with which to begin performing or directing another in "taking care of my body" and making decisions. This phase of a caring relationship resulted in "knowing when I'm ready" to begin performing activities or making decisions on their own. The last phase of a caring relationship, "letting me find out," was also a process of reciprocal behaviors and interactions between the nurse and SCI individual, in which creative problem-solving and experimentation occurred. This phase of a caring relationship, however, was usually initiated by the SCI individual in the last few weeks prior to discharge from rehabilitation. "Finding out what works best" was the result of the last phase of a caring relationship.

Nurse caring, which contributed to "getting back together" or reintegration for SCI individuals in preparation for discharge from rehabilitation, also had positive consequences or outcomes for participants. One positive outcome of nurse caring early in rehabilitation, in which the SCI individual was invited to participate as a partner in the relationship and in the work of rehabilitation, was "lifting my spirits" or a sense of well-being; this facilitated a positive attitude, feeling
motivated, and wanting to move forward in rehabilitation. As participants moved into the work of rehabilitation and "learning what I need to know," positive outcomes of "taking care of my body" and "taking charge" began to emerge. Nurses perceived as caring unconditionally treated the SCI individual as a partner in the rehabilitation plan and decision-making, assisting with the acquisition of knowledge and skills, to ultimately assume responsibility for their rehabilitation. Finally, in the last few weeks of rehabilitation, nurse caring fostered feelings of independence and hope. These outcomes were achieved as nurses perceived as caring turned over responsibility and accountability for the rehabilitation plan over to the SCI individual and became a consultant or collaborator to the participant. Nurse caring communicated to the SCI individual their uniqueness, wholeness, and value as a human being, despite their disability, and contributed to feelings of hope that a meaningful life and relationships were possible after SCI.

Discussion

Through the constant comparative method of in-depth interviews and data analysis the substantive theory of nurse caring was refined and extended as it applies to SCI individuals in rehabilitation. The relationship of the concepts comprising the dimensions, process, and outcomes of
nurse caring which emerged from the descriptions of
participants are illustrated in Figure 7. The findings and
substantive theory resulting from this study are analyzed in
relation to the initial conceptual model synthesized from
the research and theory on nurse caring, illustrated in
Figure 1. This analysis will focus on the current knowledge
in the areas of SCI, rehabilitation, and chronic illness and
disability.

**Spinal Cord Injury**

**Background characteristics.** Although purposive
sampling was used for this study, to maximize variation in
results, the demographic characteristics are compared to
national statistics on SCI. Males comprised 73% of the
sample with 27% being female; this compares with 71% male
and 29% female nationally (Berkowitz, et al, 1992). The
mean age of participants in this study was 48 years compared
with a mean 30 years of age nationally. Caucasian
participants comprised 80% of the sample, whereas nonwhites
make up 11% of the SCI population nationally. 47% of this
sample were quadriplegic, which approximates national
statistics for SCI. MVAs (40%) and violence (7%) as the
cause of SCI were comparable to national statistics (45-48%
and 5-13% respectively), whereas falls were higher in this
study (40% compared with 20% nationally) reflecting the
older age of participants. Married individuals comprised
60% of this sample while single participants comprised 40%,
compare with 52% and 48% nationally, reflecting a younger population of SCI nationally. 47% of individuals in this sample were employed prior to their injury, whereas 53% were not working; this compares with 73% and 27% nationally, reflecting an older retired sample.

Participants in this study were older, more likely to be injured from a fall, and more likely to be retired at the time of their injury. Parents and friends were identified as the major sources of support by younger participants in this study, whereas spouse and family were support for the older individuals. This has tremendous implications for women since the majority of SCIs occur in males. Wives, mothers, and daughters were to be the major caregivers of quadriplegic participants after discharge from rehabilitation in this study.

Dimensions of caring. Four dimensions of nurse caring emerged from SCI individuals descriptions of important caring behaviors in this study: knowledge, interpersonal and technical skill, and competence. Previous research, primarily with hospitalized patients, described two dimensions of nurse caring: instrumental, which is comprised of knowledge and technical skill, and expressive or the interpersonal dimension (Swanson, 1988; Brown, 1986; Reiman, 1986; Wolf, 1986). Perhaps because of the highly specialized knowledge required by nurses working with SCI individuals, and the extreme vulnerability of SCI...
individuals early in rehabilitation, knowledge emerged as a distinct and crucial dimension of nurse caring. Important aspects of the knowledge dimension of nurse caring for SCI individuals were: having knowledge, sharing knowledge, and knowing what to assess. A unique aspect in this and other studies with SCI individuals is the openness and willingness of the nurse to freely share not only professional and practical knowledge, but also personal knowledge (Nelson, 1990; Laskiowski & Morse, 1993). This openness and willingness to share knowledge communicated to the SCI individual the invitation to become a partner in their rehabilitation and in a caring relationship. Sharing knowledge was essential to "learning the other," the first phase in the development of a caring relationship.

The technical dimension of nurse caring which emerged from SCI individuals descriptions was comprised of: physical care, comfort, anticipating needs, following through, surveillance, and responding. These are similar to descriptions of the knowledge and skill dimension of nurse caring by hospitalized patients (Brown, 1986; Larson, 1987; Wolf, 1986) and rehabilitation patients (Keane, Chastain, & Rudisill, 1987). However, in a more long term setting such as rehabilitation, the meaning of the technical dimension of nurse caring changed over time. Early in rehabilitation, before caring relationships and trust were established, the technical dimension of nurse caring was important.
Participants perceived that nurses who followed through, responded in a timely manner, accurately anticipated their needs, and picked up on things could be trusted. How well nurses performed the various facets of the technical dimension of caring in the early weeks of rehabilitation, communicated to participants whether trust and respect could be established with the nurse and a caring relationship developed. After a caring relationship was established with a particular nurse, the nurse's competence became more important than technical skill.

Attending, "getting me through," sensing, and using humor were important aspects of the interpersonal dimension of nurse caring for SCI individuals. Early in rehabilitation, attending and "getting me through" were important to the establishment of a caring relationship. If participants perceived that nurses were willing to spend time with them and were truly present to them during their interactions, a caring relationship was established. Attending and sensing were similar to aspects of the interpersonal dimension of nurse caring in previous studies (Brown, 1986; Larson, 1987; Wolf, 1986). Attending and sensing also corresponded with items from the first two dimensions of Wolf's (1994) Caring Behavior Inventory (CBI): respectful deference to others and assurance of human presence. Although the dimension 'respectful deference to others' in the CBI includes items such as attentively
listening, supporting the patient, spending time with the patient, which correspond with attending in this study, it also included items related to teaching, comfort, and treating the patient as an individual (Wolf, 1994), which in this study were conceptualized in the knowledge, technical and competence dimensions respectively. 'Assurance of human presence' from the CBI included items related to sensing such as being sensitive to the patient, helping the patient, and showing concern for the patient, but it also included items related to promoting independence, responding quickly, and helping to reduce pain (Wolf, 1994), which in this study were conceptualized as part of the competence, interpersonal, and technical dimensions respectively.

Wolf's study was conducted with hospitalized patients and nurses. In the rehabilitation of SCI individuals, because of the highly specialized knowledge and the long-term relationships with patients, knowledge, technical skill, and competence emerged as distinct dimensions of nurse caring, along with the interpersonal dimension. These dimensions of nurse caring would need to be confirmed in future studies of SCI and rehabilitation patients.

"Getting me through" and using humor seem to be aspects of the interpersonal dimension which are unique to SCI individuals. The tremendous emotional adjustment to the loss of bodily integrity following SCI presented the challenge of getting through the difficult times while
maintaining a positive attitude and motivation to move forward with rehabilitation. Nurses perceived as caring helped SCI individuals get through difficult times by intuitively using a repertoire of interpersonal skills, which included the use of humor.

Using humor was a unique and crucial aspect of the interpersonal dimension of nurse caring for SCI individuals in rehabilitation. The use of humor served two important functions. First, it enabled mutual sharing of personal knowledge, particularly areas of vulnerability. This occurred only after an authentic caring relationship was established in which mutual trust and respect were recognized. Secondly, it served as a means to dispel tension or awkwardness in unfamiliar or uncomfortable situations. When these feelings were acknowledged through the use of humor, the nurse and SCI individual could then concentrate on the work at hand. Using humor was described in a previous study of SCI patients in rehabilitation as a means of maintaining hope (Nelson, 1990). Using humor is a means of maintaining a positive outlook, sustaining a future orientation, and preserving dignity in otherwise undignified situations for SCI individuals.

"Getting me through" had a different meaning for men and women. For women, important demonstrations of nurse caring included the use of touch, such as hugging me or holding my hand to get through difficult times. For men
under 50 years of age, "getting me through" included similar demonstrations of caring such as being there, talking me through it, or telling me a story, but the use of touch was not described as important. For men over 50 years of age, "getting through" a difficult time was something they did on their own. It was important for the nurse recognize those difficult times and give the individual time and privacy to work through the situation on their own. Men over fifty described fewer difficult times since they felt they had to be strong and set an example for their families; something which had been an expectation throughout their lives. Nurses perceived as caring quickly sensed when an individual was facing a difficult situation and individualized their interactions based on their knowledge of the particular other. These age and gender differences in the perceptions of the interpersonal dimension of nurse caring need further research.

Competence, the fourth dimension of nurse caring conceptualized from SCI individuals descriptions of nurse caring, was comprised of individualizing care, treating the whole person, respecting the uniqueness of the individual, and "breaking the rules." Demonstrating competence became an expectation of the nurses with whom SCI individuals established a caring relationship. Competent care was possible only after "learning the other" was achieved since knowledge of the particulars of the individual was required.
for competence. The first three aspects of competence were consistent with previous research of nurse caring primarily with hospitalized patients (Larson, 1986; Swanson, 1987; Wolf, 1986; Reiman, 1986). "Breaking the rules" was similarly characterized as manipulating the environment and going beyond the call of duty by oncology patients' descriptions of nurse caring (Clayton, et al, 1991) and by SCI patients in rehabilitation (Laskowski & Morse, 1993). Perhaps "breaking the rules" occurs in caring relationships that extend over a period of time, therefore developing more depth and complexity than a typical hospital setting allows.

**Process of a developing caring relationship.** For the spinal cord injured individual, the work of rehabilitation results in "getting back together" or reintegration of the emotional and psychological self with the physical body which was broken in the injury. Reintegration of the self, the return of a sense of wholeness and humanness, prepares the SCI individual for the next steps in recovery, reintegration into the family and community. Nurse caring facilitates reintegration for the SCI individual through a process of three phases resulting in positive outcomes which contribute to the attainment of reintegration.

Nelson (1990) also conceptualized the optimal outcome of rehabilitation for SCI individual as the process of reintegration. From an ethnographic description of a SCI unit, four phases of an individualized and creative process
of reintegration were reported: buffering, transcending, toughening up, and launching (Nelson, 1990). The particulars of how and when learning occurred with SCI individuals in rehabilitation, however, remained unknown after the previous study of a SCI unit environment. This study of nurse caring provides previously unknown details of the reciprocal interactions between a nurse and SCI patient in rehabilitation during the acquisition of knowledge and skill required for self-care, autonomy, independence, and hope which contribute to reintegration.

An initial conceptual model of nurse caring proposed by this investigator from a synthesis of the current research and theory was presented in Figure 1. A refined conceptual model of nurse caring, conceptualized by this researcher from the experience of SCI individuals in rehabilitation, is presented in Figure 7. In the initial model, both the nurse and the patient brought to the relationship knowledge, values, history, goals, and needs which were shared in an unfolding caring relationship, reflecting the uniqueness of the two individuals (see Figure 1). As the patient's confidence in the nurse's competence grew and the patient acquired knowledge, the patient began to participate in decision-making and began to feel like a partner in the relationship and the plan of care. From the experience of SCI individuals in rehabilitation, the particulars of how a nurse and participant contribute to an
unfolding caring relationship are now more clearly elucidated.

For SCI participants in rehabilitation in this study, a caring relationship began with "learning the other" an invitation by the nurse to enter into both the relationship and the work of rehabilitation by freely and openly sharing professional and personal knowledge with the individual. Through the process of sharing, the nurse's knowledge, interpersonal and technical skills become apparent to the SCI individual, who, in turn shared personal knowledge and preferences for the rehabilitation plan. Whether a relationship developed further, that is, whether the real work of rehabilitation occurred within this particular relationship, depended on the establishment of mutual trust and respect between the nurse and the SCI individual. Mutual trust and respect were the result of "learning the other," the first phase of a caring relationship in rehabilitation. When mutual trust and respect were achieved there was a commitment to the relationship by both the nurse and the SCI individual, and expectations of the individuals in the relationship moved to a new level.

The importance of sharing knowledge of a personal nature by the nurse is not widely known from the research, although Mayeroff (1971) identified this aspect of caring as humility; sharing of oneself honestly without pretense.
Nelson (1990) found that nontraditional relationships based on friendship between SCI individuals in rehabilitation and caring nurses were very meaningful and facilitated

![Diagram showing the dimensions, process, and consequences of nurse caring contributing to the reintegration of self.]

**Figure 8.** The Dimensions, Process, and Consequences of Nurse Caring contributing to the Reintegration of Self.

motivation and enthusiasm to participate in the rehabilitation program. Laskiowski and Morse (1993) also found that nurses perceived as genuinely caring shared personal information with patients which contributed to
feelings of hope.

Another aspect of the model which was more clearly delineated by SCI participants in this study is goal identification. A nurse, usually the nurse who admitted the SCI individual to the rehabilitation unit, generally asked the participant what they wanted to accomplish by the time they were discharged. Because SCI is such an overwhelming and unknown entity, and rehabilitation is also very foreign, participants were only able to identify a very broad, general goal upon admission to rehabilitation. Participants felt this goal reflected a number of things about themselves: their overall approach to life and its many challenges, their work ethic, their current understanding of their injury and its implications, and their understanding of rehabilitation. The admitting nurse usually provided immediate feedback about how realistic the goal was, teaching about rehabilitation and what each member of the rehabilitation team's role entailed. The manner in which this initial encounter was handled by the admitting nurse was perceived as being crucial to the participant's approach to SCI injury and rehabilitation.

Goal identification then proceeded on a much more minute level, either on a daily or weekly basis. The nurse and participant would identify much smaller goals, or "baby steps", which could be accomplished in a much smaller time frame, usually in a day or two or in a week. This enabled
the SCI individual to sense that progress was being made, however minuscule the accomplishment. This process of ongoing goal identification required trust on the part of the participant that the nurse knew what (s)he was doing, and trust on the part of the nurse that the participant would work toward the goal. In this way, identification of incremental goals toward the SCI individual's overall goal for rehabilitation, fostered a sense of moving forward even though progress often seemed imperceptible.

In the initial proposed model, the next phase of a caring relationship involved identification of actions which would accomplish the desired goal(s), with both the nurse and patient assuming responsibility for their respective agreed upon actions. In rehabilitation, this process occurs over several weeks to months and is comprised of two phases: "learning what I need to know" and "letting me find out." Due to the complexity of the knowledge and skill required by SCI individuals for the activities of rehabilitation, and the foreign and often initially repugnant nature of these activities, this phase of a caring relationship is protracted in rehabilitation compared with the hospital setting. When this part of the work of rehabilitation occurred within a caring relationship, the SCI individual was able to assimilate the information and skills into the newly emerging self while maintaining a positive attitude and feelings of hope.
Outcomes. The outcomes conceptualized from descriptions of nurse caring by SCI individuals in rehabilitation included: "lifting my spirits" or well-being, "taking care of my body" or self-care, "taking charge" or autonomy, independence, and hope. Outcomes consistently described from previous research and theory were self care and autonomy, which were reflected in the initial conceptual framework in Figure 1. Additional outcomes identified in this study are well-being, independence, and hope. What this study contributes to our understanding of nurse caring is when and how these outcomes are realized by SCI individuals throughout the course of rehabilitation.

"Lifting my spirits" or feelings of well-being began with the development of a caring relationship. As the nurse and the SCI individual were "learning the other," nurses eventually perceived as caring communicated to participants on two levels: as a person, and as an ensuing partner in rehabilitation. The openness and honesty with which the nurse approached the SCI individual, on a personal and professional level, communicated a sense of value to the person, which contributed to a reemerging feeling of wholeness. These feelings of well-being which emerged, contributed to a positive attitude and a willingness to move forward in the rehabilitation process.

As mutual trust and respect were established between a
nurse and SCI as a result of "learning the other," feelings of well-being also ensued. The creation of a meaningful relationship and the connection established with a nurse or therapist, resulted in positive feelings from the realization that despite having a body which was no longer functioned the same as before the injury, their personhood and value as a human being was not diminished. Positive feelings of well-being were necessary to maintain the energy and internal resources to proceed with the difficult but often overwhelming task of rehabilitation (Nelson, 1990; Laskiwski & Morse, 1993). "Lifting my spirits" is similar to what Mayeroff (1971), Watson (1988), Leininger (1988) and Larson (1984) describe as well-being in that personal growth ensued and a positive sense of self resulted from the caring relationship.

With the initiation of the rehabilitation process, the SCI individual is confronted with the issues of disability and impairment of the body (Nelson, 1990; Laskewski & Morse, 1993). Like stroke patients in rehabilitation, the SCI individual also experienced loss of bodily integrity; the loss of self as they knew it (Doolittle, 1991; Kaufman, 1988). SCI individuals experienced helplessness, fear, and dependency upon entering rehabilitation, which resulted in feeling less than a fully functioning, valued human being; this reflects society's attitude toward persons with disability. With the establishment of caring relationships,
and the emergence of feelings of well-being, the process of reintegration could begin. Within a relationship in which the SCI felt valued and respected as a person, the nurse began a process in which participants would learn to interact with members of society which would underscore their value and dignity as a person, while downplaying their disability. These first caring relationships in rehabilitation contributed to well-being by providing a means of exploring how to interact with the newly emerging self in a protected, nurturing environment (Nelson, 1990; Laskiowski & Morse, 1993).

During the phase of "learning what I need to know," the acquisition of self-care knowledge and skills began. SCI individuals' descriptions of reciprocal interactions and behaviors between the nurse and participant detail how self-care is learned within the context of a caring, trusting, supportive relationship. Although the nurse shared knowledge with the SCI individual since the initial interaction during admission to rehabilitation, sharing of knowledge by the nurse in the "learning the other" phase communicated an invitation into a partnership relationship, rather than actual teaching/learning. During the second phase of a caring relationship, "learning what I need to know," teaching/learning occurred within a different context. The nurse and participant, in a partnership, worked together creatively to individualize the acquisition
of self-care knowledge and skills. Learning occurred in a safe, secure relationship in which mutual trust and respect between the nurse and participant were prerequisite.

The complexity of "knowing when I'm ready" or readiness to actually begin performing self-care tasks has been elucidated somewhat by this study. According to SCI individuals' detailed descriptions, two types of knowledge are required by the nurse to recognize 'readiness.' First, is the nurse's knowledge of the specific physical skills required for the performance of a task, and whether the individual has acquired these skills. Second, the nurse's sensitivity and respect for how success or failure in performing the task will affect the individual emanates from the nurse's knowledge of the particular other. The nurse balances the need for increasing independence and incremental successes in the performance of skills required for self-care, with the potential for frustration and a negative attitude which might result from premature attempts or failure to perform the task (Nelson, 1990; Laskiowski & Morse 1993). The nurse's knowledge of SCI rehabilitation combined with the knowledge of the particular other contributes to the intuition required to achieve this delicate balance (Benner, 1986).

"Knowing when I'm ready" however, warrants continued research. Some participants took the initiative to identify when they were ready to begin performing self-care
activities. Other participants waited until the nurse or therapist identified that they were ready to begin performing the task. Comparisons among background factors failed to elicit a pattern for which individuals took the initiative to identify when they were ready to begin performing self-care activities. Treischmann (1988) recognized that SCI individuals with a more external locus of control were more passive in the rehabilitation process, whereas individuals tending toward a more internal locus of control were more active and took more initiative in rehabilitation. She hypothesized that "readiness" was related to the external versus internal orientation. This hypothesis, however, remains to be tested. In addition, studies need to explore whether a certain environment or experiences or relationships in rehabilitation could move an individual toward a more active participation in the rehabilitation plan.

Self-care was also an important outcome of nurse caring for participants by Swanson (1986), Larson (1986), Benner (1989), and also theorists (Orem, 1985; Wolf, 1986). Nursing care initially began as doing things for patients that they were unable to do for themselves because of illness or injury (Orem, 1985; Henderson, 1976). As patients became less ill, stronger emotionally, and more knowledgeable, nurses eventually turned responsibility over to the patient for their own plan of care. The process of
how this actually occurred had not been fully elucidated for rehabilitation patients prior to this study.

The next phase of a caring relationship, "letting me find out," resulted in the SCI individual finding out what worked best or felt best in the performance of self-care activities. During this phase, autonomy began to emerge as an outcome as the SCI individual began to take charge and experiment with what worked best. Creative problem-solving was fostered by nurse caring during this phase. Nurses perceived as caring encouraged and supported experimentation in self-care activities, thereby facilitating the participant's autonomy and decision-making. Nurses perceived as noncaring became angry and defensive when they found out that participants were hiding the fact that they were doing something different than what they were taught.

As participants began to exercise their autonomy, caring nurses gradually relinquished their role as coordinators and directors of the rehabilitation plan, moving into the role of consultant and collaborator with the SCI individual in the rehabilitation plan. Within a relationship of trust and respect, the SCI individual was able to make mistakes and learn the consequences of choices made, thereby facilitating autonomy. Direct and honest feedback by the nurse in a caring relationship fostered learning and enhanced decision-making. Nurses perceived as noncaring continued to control the activities of
rehabilitation, stifling decision-making and creative problem-solving, often eliciting feelings of anger and continued dependency. What is unknown is the outcome or long-term consequences for a SCI individual who was unable to experiment and develop creative problem-solving strategies during rehabilitation, finding out what worked best in a protective environment. Achieving the desired degree of self-care, along with active participation in decision-making, contributed to feelings of autonomy, or "taking charge." This is consistent with the findings of Ailinger (1993) and Ladewig (1989), in which self-care fostered autonomy.

The development of self-care behaviors and autonomy in decision-making, promoted a growing sense of independence. As the SCI individual relied less on the nurse for physical care and decision-making, or directed family members or another caregiver in the particulars of their rehabilitation program, increasing self-reliance became apparent. How the SCI individual's decreasing dependence and increased autonomy occurred in rehabilitation is more clearly delineated by this study. How the nurse's role changed as the SCI individual assumed more responsibility for self-care and autonomy has been clarified. Independence as a major rehabilitation outcome was verified; it was also a goal to which SCI individuals aspired from the time of admission to a rehabilitation facility.
An outcome which participants described more toward the end of rehabilitation was hope. This was described as knowing there is life after spinal cord injury which can be productive and meaningful. Nurse caring contributed to hope by keeping at the forefront future possibilities for recovery and individual accomplishments. Participants perceived that family members often took cues from the nurse on how to keep hope alive.

Laskiwski and Morse (1993) found that hope was present in all phases of rehabilitation for SCI individuals, their family members, and also staff. They found that the focus of hope changed for each phase of rehabilitation post-injury. Initially, there was hope of walking again. Then, there was hope of dying rather than living the remainder of life paralyzed. During the main stay of rehabilitation, the major focus of hope was for maximum return of function. Prior to discharge home, there was hope that they would be able to manage at home and when returning to society. Hope was found to played a major role in allowing the SCI individual to go on after their injury. Moments of despair in which patients lost control were described as essential to the modification of hope and the "process of learning to accept a changed life" (Laskiwski & Morse, 1993).

Previous theories of recovery from SCI proposed that depression and denial were experienced by most or all SCI individuals during the period of adjustment to the injury.
Research has shown that the prevalence of depressions is no greater in SCI individuals. It is now widely believed that a grieving process occurs for the losses suffered as the result of a SCI. The role of hope in the grieving process, and how these two factors interrelate in the process of reintegration for SCI individuals is an area for future study. Most SCI individuals reported knowing from the moment of injury that they were paralyzed, at least on an intellectual level (Treischmann, 1988).

It is now being proposed that hope, not denial, is the major factor which enables SCI individual to maintain a forward looking attitude, while coming to terms with the devastating consequences of SCI and the loss of the former physical self (Laskiwski & Morse, 1993). The phenomenon of hope has only recently been identified as a positive force contributing to the reintegration of self following SCI. More research is needed to determine the role of hope in the recovery following SCI.

**Summary.** A substantive theory of nurse caring was developed by the investigator from SCI individuals' descriptions of the meaning, process, and outcomes of nurse caring while in rehabilitation. The core variable, reintegration of the self, resulted from the major work of rehabilitation, which occurred with health professionals perceived as caring. Four dimensions of nurse caring, knowledge, technical skill, interpersonal skill, and
competence, were comprised of many elements consistent with previous studies of nurse caring. The dimensions of nurse caring themselves, however, were conceptualized uniquely in this study, perhaps because of the long-term and intense nature of the nurse-patient relationship in rehabilitation.

Elements of nurse caring found to be unique in the relationship with SCI individuals were sharing of personal knowledge, using humor, and "breaking the rules." Competence emerged as a separate dimension of nurse caring in this study, perhaps because of the highly specialized knowledge and skill required in the rehabilitation of SCI individuals, and also perhaps because of the overwhelming vulnerability resulting from feelings of utter helplessness and dependency which occurred initially following this devastating injury.

Three phases of a caring relationship in rehabilitation were conceptualized as: "learning the other," "learning what I need to know," and "letting me find out." Each of these phases resulted in intermediate consequences toward the achievement of the overall outcomes of a caring relationship between a nurse and SCI individual in rehabilitation: well-being, self-care, autonomy, independence, and hope. Well-being created a positive outlook, feelings of motivation, and a desire to move forward with the work of rehabilitation. The process of how the SCI individual acquired independence in self-care and
autonomy in decision-making is detailed in this study. Hope as an outcome of rehabilitation has only been identified recently, and the contribution of nurse caring to feelings of hope is elucidated in this study.

Rehabilitation

The discussion of nurse caring in relation to rehabilitation will focus on seven areas: the specialized knowledge required, continuity, communication, the teaching/learning process, timing, the role of the patient, and finally the model used in rehabilitation. Discussion will begin with findings from this study with SCI individuals and move into a general discussion of rehabilitation.

Specialized knowledge. Knowledge of SCI rehabilitation was the most important aspect of nurse caring for participants in this study. Not only were nurses expected to possess professional knowledge of the care of SCI individuals, but the ability to share practical knowledge was also critical. This repertoire of knowledge is built through experience in working with SCI individuals. Participants recognized immediately when a nurse was new or had been reassigned from another area of the rehabilitation facility. Nurses who were not experienced in the care of SCI individuals often had to be taught by the patient themselves what was required for their plan of care. This could not only hinder the participants progress in
rehabilitation, but it could also be detrimental if the inexperienced nurse did not listen to or follow the directions given. Experienced nurses were essential to facilitating the work of rehabilitation and also the efficient achievement of optimal outcomes.

Experienced nurses also possessed a repertoire of interpersonal skills which enabled them to better meet the emotional and psychological needs of the SCI individual and their family. The rehabilitation experience entailed many embarrassing, degrading, or humiliating situations. Nurses who were experienced in the management of SCI individuals were able to quickly assess these situations and pick up on what was happening. Their knowledge, together with their knowledge of this particular patient, contributed to successful technical and interpersonal interventions which maintained the dignity and positive attitude of the SCI individual.

**Continuity.** The same nurses working with the same patient contributed to the establishment of a caring relationship and the attainment of rehabilitation outcomes. Continuity in assignments facilitated "learning the other," which in turn contributed to competent caring. When an unfamiliar nurse was assigned to participants, rather than concentrating on the work of rehabilitation in order to move forward, the SCI individual had to concentrate on teaching the nurse the care required, and overseeing this caregiver
to insure safety was maintained.

Not only did continuity in assignments contribute to "learning the other," but it also facilitated the teaching learning process in the second phase and decision-making in the third phase of a caring relationship. Consistency in the process of "learning what I need to know," facilitated the acquisition of self-care knowledge and skills as well as the identification of readiness to begin performance of self-care activities. Each day, the participant and nurse built on what was achieved the previous day or session, rather than assessing anew where the patient is in the learning process, which would occur with a new nurse. Once the patient entered the third phase of the caring relationship with a nurse, "letting me find out," decision-making and creative problem-solving proceeded without interruption, rather than perhaps an unfamiliar nurse not allowing participation in decision-making or problem solving. In addition, the reintegration of self, identified by participants and other research as the major work of rehabilitation, was fostered in a caring relationship in which individuals in rehabilitation were treated as unique persons, experience a sense of wholeness, and were able to maintain hope for the future.

**Communication.** Competent caring of the SCI individual was facilitated by the communication of consistent, complete, current information among members of the health
care team. Nurses perceived as caring were up-to-date on exactly where participants were in their rehabilitation plan. Knowledge of the nuances in the rehabilitation plan of the particular individual was necessary to facilitate forward momentum toward the achievement of goals. Nurses perceived as caring readily shared information, important to the rehabilitation plan, with other members of the health care team in a manner that preserved the dignity of the SCI individual. Following through with other members of the health care team to insure that proper orders were received or the rehabilitation plan was appropriately modified, was also an important aspect of nurse caring.

In addition to good communication among team members in rehabilitation to insure optimal physical recovery, the emotional and psychological contribution to the reintegration of self was facilitated by team members who had established a caring connection with the SCI individual. Particular nuances learned about the other in the first phase of a caring relationship, were used intuitively by team members to help SCI individuals get through especially difficult times, without becoming too frustrated or discouraged. In addition, knowledge of the particular other was shared and used by team members to enhance motivation, maintain a positive outlook, and strengthen feelings of well-being. Without this positive orientation, individuals in rehabilitation could not focus their internal resources
to move forward through the rehabilitation process.

Teaching-learning process. From the moment of entering the rehabilitation facility, the SCI individual is learning, unlearning, or relearning what will be necessary for successful adjustment to a devastating injury. Rehabilitation focuses on the recovery of the physical body—mobility, skin care, bladder and bowel retraining, because that is visible, measurable, and reimbursable (Treischmann, 1988). How and when a SCI individual learns self-care and autonomy in decision-making is delineated in this study.

Not only must the SCI individual learn how to manage an altered physical self, but also how to manage social situations in which a person with a disability may not be viewed as a fully functioning and contributing member of society. Emotional recovery is thought to mirror or follow physical recovery, although very little time in rehabilitation is devoted to the psychological adjustment following SCI. It is in caring relationships with members of the health care team, that SCI individuals come to the realization that their inner self remains the same. It is also in caring relationships in rehabilitation that feelings of wholeness, humanness, and dignity reemerge. In rehabilitation, SCI individuals begin to learn how to relate to others as a person with a disability. This may or may not be a positive experience; some health professionals
reflect society's attitude toward persons with disability. In caring relationships with members of the health care team, however, SCI individuals learn to relate to others in a way that preserves their individuality and dignity as a person. This may or may not prepare them for what lies ahead after discharge from rehabilitation, but while in rehabilitation it enables the SCI individual to focus internal energies and resources on the work required for the achievement of identified goals.

**Time.** The establishment of caring relationships in rehabilitation and the subsequent work which is accomplished in these relationships occurs in phases. Each of the phases in a caring relationship roughly corresponds with the various phases of rehabilitation, which occur over time. "Learning the other" occurs over a period of two to four weeks, depending on how often the nurse works with the SCI individual. This corresponds approximately with the initial evaluation period in rehabilitation, which for an incomplete paraplegic could be one week and for a complete paraplegic might be two weeks. The evaluation period might be extended for a quadriplegic, depending on the complexity of the involvement. For a quadriplegic who has a tracheostomy or is on a ventilator, learning the other would take several weeks, as a means of communication must also be established.

"Learning what I need to know," corresponding to the period in which the major work of rehabilitation occurs, may
take weeks to months, again depending on the number and complexity of the skills and knowledge required prior to discharge. It must be stressed that the process of "learning what I need to know," or the teaching-learning period is repeated for each of the major activities the SCI individual must learn. Although participants report there is a point at which a snowball effect seems to occur, in which success in learning in one area may suddenly result in learning in several other areas.

The learning process moves to a new level when participants are ready to begin performing self-care activities. Nurse caring facilitated the teaching learning process, since SCI individuals are able to learn, question, and the nurse breaks the activities down into manageable components, in a safe supportive atmosphere. What all contributes to readiness is yet unknown, and therefore it is also unknown whether certain activities or approaches might facilitate or hinder an individual's readiness to begin self-care.

"Letting me find out," the final phase of a caring relationship, generally occurred in the last weeks of rehabilitation as individuals are preparing for discharge. During this phase of experimentation and "finding out what works best" or feels best, a caring relationship is essential to successfully assuming responsibility for one's own rehabilitation and recovery. Within the caring context,
learning continues as the individual receives timely and honest feedback on whether actions or modifications chosen are likely to result in beneficial or harmful consequences in the long term. Health care professionals viewed as noncaring foster dependence and following the rules, which does not contribute to self-care, autonomy, and independence, and which may delay discharge from rehabilitation.

**Role of the patient.** In a caring relationship, SCI individuals were invited to become partners in their rehabilitation experience. This role of partner extended from the initial phase of "learning the other" through "finding out what words best." The partnership between a participant and nurse facilitated an active role of the SCI individual in establishing and developing a caring relationship, the teaching-learning process, and the determination of readiness to begin self-care activities. In noncaring relationships, the SCI individual was the passive recipient of instructions and was dependent on others for when and how care would be provided. This study delineates the attitudes, interactions, and behaviors required to establish a partnership role with the patient in rehabilitation.

Active participation in a relationship which can result in positive outcomes becomes the model for future relationships both during and after rehabilitation.
Initially family members may not know how to approach the SCI individual or what to say. Observing the interactions within a caring relationship and receiving feedback from these same caring individuals often helps to dissipate fear and help families realize their loved one is the same person, that only their body has changed. SCI individuals also learn from these caring individuals how to put people at ease with their disability, explain to others about their injury or its consequences, and use humor to diffuse uncomfortable or embarrassing situations. Caring relationships in which the SCI individual is treated with respect and dignity, and in which they are an active partner in their rehabilitation program, foster the achievement of positive outcomes and contributes to the reintegration of self in preparation for return to family and community.

**Model of rehabilitation.** For the past two decades there has been controversy in the rehabilitation literature and reimbursement arenas over what model should drive rehabilitation programs (Treischmann, 1980; 1988). Currently the medical model predominates in which SCI is viewed as a patient with a disability, similar to a disease. If the physical or biological aspects of the disability or disease are managed, the patient is considered cured or recovered. In the 1980's, there were rehabilitation programs based on an illness model, in which the injured person was viewed as a whole, and the psychological and
social aspects of recovery received equal attention with the physical recovery. The long-term effectiveness of these programs were not able to be demonstrated, based on their cost effectiveness or prevention of complications, before reimbursement schemes changed. Only the physical aspects of disability, which were visible and measurable were deemed important. Length of stay and reimbursement were based on the achievement of measurable outcomes such as mobility, skin care, and bowel and bladder retraining. The emotional and psychological dimensions of recovery became secondary.

Research has shown that the emotional and psychological component of recovery from SCI are closely related to physical recovery and complications (Larson, 1978; Treischmann, 1988). SCI individuals who maintain a positive attitude, a future orientation, and a sense of hope have better rehabilitation outcomes and fewer long term complications. Adequate support systems facilitate the psychological and emotional adjustment to SCI (Treischmann, 1988). What has been unknown is role of health care providers in the adjustment to SCI. This study provides evidence that caring relationships with members of the health team during rehabilitation facilitated the achievement of rehabilitation goals and reintegration of self following SCI. The illness model, in which the person in rehabilitation is viewed as a whole entity in relation to their family and support systems, the rehabilitation
environment, and members of the rehabilitation team has some merit in enhancing rehabilitation outcomes and needs continued research.

**Summary.** The current study of nurse caring contributes to our knowledge of rehabilitation in several areas, the: 1) specialized knowledge and experience required of members of the health care team in the management of SCI; 2) importance of continuity in the assignment of health care workers to facilitate rehabilitation outcomes; 3) role of timely communication of the unique needs of the individual among members of the health care team to insure competent care and efficient achievement of goals; 4) delineation of the process of acquisition of self-care knowledge and skills and autonomous decision-making; 5) timing of the phases of a caring relationship which roughly correspond with the major phases of a rehabilitation program; 6) crucial role of the SCI individual as an active partner which facilitates the rehabilitation plan; and 7) the contribution of a model of rehabilitation which views the patient as a whole person, not simply a biological entity. Nurse caring contributes to the effective and efficient achievement of rehabilitation goals by recognizing the unique qualities, needs, and goals of the whole person, while implementing the rehabilitation plan in a manner that fosters well-being, self-care, autonomy, independence, and hope.

*Chronic Illness and Disability*
Recovery from SCI is in many ways similar to the adjustment to a chronic illness or other disabilities. There are also some striking differences. This next section will explore the early process of adjustment in SCI individuals with that of oncology, cardiac, and stroke patients. Age and gender differences are examined within the context of chronic illness and disability. The role of hope, well-being, and autonomy will be reviewed from the perspective of their contribution to the process of adjustment and rehabilitation.

Process of adjustment.

During rehabilitation the SCI individual begins the process of recovery from and the adjustment to the effects of SCI. Conceptualized as reintegration of self, from participants' descriptions of "getting back together," these findings are consistent with another recent study of the rehabilitation phase of recovery from SCI (Nelson, 1990), and also stroke (Doolittle, 1991). Participants in all three qualitative studies described feeling disintegrated, disconnected, or unable to reconcile their current self with their former self in the early period of rehabilitation. Although only this study specifically examined the nurse-patient relationship, participants in these three studies described the contribution of nurses perceived as caring to the process of reintegrating the self. The long term affects of these special relationships in the recovery
process, and the impact of the resultant outcomes of caring relationships in rehabilitation on the overall adjustment to SCI remain unknown.

Long term studies of chronic illness with cardiac and oncology patients, describe a process of normalization, symptom control, and managing the trajectory of the illness (Morse & Johnson, 1991; Kleinman, 1988; Anderson & Bury, 1988; Strauss, et al, 1984). Whether reintegration of the self is actually the initial phase of normalization for SCI individuals and others with disability remains to be answered with future research.

While in an inpatient setting, such as rehabilitation, patients are expected to assume certain roles. The predominant view in health care today, including rehabilitation, is one in which the patient has little knowledge and power compared with health professionals, and the role of cooperation with the medical plan of care is expected. This contrasts with the outpatient model of health care in which the individual is expected to be knowledgeable about the disease or disability and its management, and take an active role in determining the treatment plan.

Strauss et al (1984) proposed a chronic illness model in which individuals proceeded through a series of crisis work, body work, and comfort work early in rehabilitation, to that of managing a regimen, safety, and decision-making
in preparation for discharge, and the work of maintaining relationships in the family and community. Another model, that of nurse caring, in which the individual becomes responsible for the management and decision-making of a long-term disability has been elucidated in this study. Through the process of "learning what I need to know" and "letting me decide" SCI individuals in caring relationships, assumed responsibility for self-care and self-determination in decision-making, as the nurse and other health care providers relinquished those responsibilities and assumed roles of collaborator and consultant. The contribution of nurse caring to the progression of the patient's role from that of partner in the rehabilitation plan to that of active manager and decision-maker conceptualized in this study needs validation in future studies.

Patient teaching in chronic illness traditionally served to foster adherence to the medical plan through a process of information sharing, persuasion, and negotiation about skills which are primarily of a technical nature (Kleinman, 1988). This study of nurse caring illustrated another model of the teaching learning process in which an authentic relationship is established between the health care provider and SCI individual. An individualized approach to patient education which reflects the totality of the disability experience, physical as well as psychological and social needs, facilitated a more systematic and complete
picture of progress in rehabilitation. The long-term consequences of the proposed model of nurse caring, on patient education outcomes for individuals with chronic disability and illness require further research.

**Age and gender.** Most studies of chronic illness are conducted with middle aged or older adults, who have well developed coping strategies and support systems, and well established careers and identities (Morse & Johnson, 1991; Strauss, et al, 1984; Kleinman, 1988; Anderson & Bury, 1988). SCI individuals are predominantly young males, who do not have well established support systems, coping strategies, careers, and identities (Treischmann, 1988). Whether models of chronic illness and disability apply in this patient population is unknown. The illness model which emphasizes the entirety of the patient's illness experience as well as relationships with health care providers, significant others, and the environment, has many similarities with the conceptualization of nurse caring. In addition, future research on nurse caring must explore whether it relates, contributes to, or is separate from the illness model currently proposed for theory development in chronic illness and disability.

**Hope.** Hope is a recurrent theme in studies of chronic illness and disability (Gaut & Boykin, 1994; Morse & Johnson, 1991; Doolittle, 1991; Kaufman, 1988; Kleinman, 1988). Only recently has hope been identified by SCI
individuals as important in their recovery (Nelson, 1990; Laskiowski & Morse, 1993). In the chronic illness context, hope is defined as the integration or reintegration of self in the presence of suffering, and has the following dimensions: perception of an experienced threat, an individual's inner force which desires survival, a future orientation, the expectation of attaining a desired outcome, and a relationship with an important other (Gaut & Boykin, 1994; Kleinman, 1988). Whether SCI individuals experience hope in the presence of suffering, or whether their experience is one of grief or mourning requires further study. In addition, future research could determine whether the dimensions of hope in chronic illness are also present in disability.

Well-being. Psychological well-being is described as part of the illness experience of individuals with chronic illness (Kleinman, 1988). Health care professionals who took time and listened to the illness narratives of persons with chronic illness, assisted individuals discover meaning or making sense of their illness, thereby contributing to well-being. SCI individuals in this study described feelings of well-being with the initiation of a special relationship with a nurse perceived as caring. This sense of well-being contributed to a positive outlook and self-esteem, and also had a positive affect on the person's motivation toward the work of rehabilitation. Continued
research is needed to determine the psychological affect of SCI individuals sharing their disability experience with an important other, including members of the health care team.

**Autonomy and independence.** The return of autonomy and independence are important in the adjustment to chronic illness and disability (Morse & Johnson, 1991; Doolittle, 1991; Kleinman, 1988; Kaufman, 1988). In chronic illness, however, autonomy and independence are included as part of the substantive theory of regaining control over one's life and body. Autonomy and independence were perceived by SCI individuals in this study as important outcomes of nurse caring while in rehabilitation, contributing to the reintegration of self. Since findings from this study were from the early phase following SCI, during rehabilitation, further research is necessary to determine whether in fact, autonomy and independence are part of the larger construct of regaining control for SCI individuals as well.

**Summary.** Current philosophies of chronic illness incorporate the theory of the illness experience. This theory views the physical as well as the psychological and social responses to chronic illness as important. In addition, the interactions of the person with chronic illness with significant others and the environment are included in the illness experience. This model contrasts with the medical model which values only the biological response to disease. A conceptualization of caring nurse-
patient relationships in rehabilitation in which SCI individuals are made to feel whole and are treated with dignity, and in which there is mutual trust and respect, suggest that the medical model of rehabilitation is inadequate to the effective and efficient achievement of desired outcomes.

Limitations

The findings of this study are bounded by the following limitations. Only the patients' perceptions of caring was studied. Ideally, since caring occurs in a relationship, the perspective of both the nurse and patient should be studied. Since this study was designed to be the initial step in a series of studies to explicate and delineate caring as it occurs between a nurse and a SCI individual in rehabilitation, only the patient perspective was examined at this time. Therefore, the perspective of caring which emerged from this project, along with the process and consequences of a caring relationship between a SCI individual and nurse, may be incomplete.

Interviews for this study were conducted while the SCI individual was in the rehabilitation setting. Perhaps this was not the best time to study the consequences of nurse caring. After the person returns to their home setting, and has had time to reflect on the rehabilitation experience, may be a better time to study nurse caring. Findings from this study reflect the SCI individuals' perspective of nurse
caring only while in rehabilitation, and therefore the theory which emerged may not be complete.

The instrument for this study was the researcher. The quality of the data collected and the theory refinement and expansion which resulted are limited by the skills of the researcher. Interviewing skills of the investigator determined the quality of the data collected. The ability of the researcher to analyze, conceptualize, hypothesize, and compare findings with emerging theory determined the quality of the research findings.

Questions developed for the broad framework of the interviews, were generated from the theoretical perspective proposed by the researcher from the literature. Whether these theoretical suppositions were accurate and complete, and whether the questions generated for this study produced data which can be used to refine, expand, or refute this theoretical perspective, were determined by the quality of the conceptualizations of the researcher to this point.

Data generated for this study were collected from SCI individuals while they were residents of a specialized SCI unit in one of two large rehabilitation centers in Southwestern Pennsylvania. Because of the nature of descriptive research, results from this study reflect the perspective of these individuals only at this point in time. Although results from this study will be used to design future research to further study the construct of caring,
these immediate results cannot be generalized beyond the participants in this study.

This qualitative study was designed to describe the meaning, process, and consequences of nurse caring for SCI individuals while in rehabilitation. Although limited in scope, this project contributed to refining, clarifying, and expanding our knowledge of the substantive theory of nurse caring, which can be used as a basis for future research.
CHAPTER 6

Conclusions, Implications, and Recommendations

In the last section of this paper, the conclusions, implications, and recommendations resulting from the findings of this study are presented. In the conclusions, findings from this study of nurse caring are summarized in relation to the initial conceptual framework, the theoretical conceptions of nurse caring, the link between nurse caring and rehabilitation outcomes, and finally the quality of relationships between health care providers and recipients. Implications of the perceptions of nurse caring by SCI individuals in rehabilitation are addressed for patients and families, nursing staff, nursing administration, rehabilitation facilities, and the health care system in the United States. Lastly, recommendations for further research on nurse caring are discussed.

Conclusions

This study contributes to the knowledge and substantive theory of nurse caring in several ways. First, the meaning, process, and consequences in a model of nurse caring are more clearly and completely delineated. Second, many of the theoretical suppositions of nurse caring are supported by SCI participants' descriptions of important aspects of nurse caring. Third, nurse caring is linked to important rehabilitation outcomes by SCI individuals during rehabilitation. And lastly, there is evidence that the
quality of relationships between rehabilitation patients and members of the health care team can positively or negatively influence the achievement of rehabilitation outcomes.

Model of Nurse Caring

Dimensions. Several aspects of nurse caring have been elucidated by this study. First, the dimensions of nurse caring and the elements of each dimension are more clear from SCI individuals' descriptions. The importance of sharing professional, practical and personal knowledge by nurses as a means of issuing an invitation into a partnership in the rehabilitation experience was previously unknown. Elements of the technical dimension of nurse caring validated previous research findings. Two elements of the interpersonal dimension, however, are new: getting me through, and using humor. How nurses perceived as caring helped SCI individuals get through emotional, difficult or embarrassing situations with dignity, is clarified in this study. Also, the use of humor to communicate wholeness and humanness, as well as dissipate tension in difficult situations is new to the concept of nurse caring. Lastly, the dimension of competence, initially proposed by Benner (1984) from studies with nurses, has been validated by patients. The interaction of the nurse's knowledge and experience which facilitates competent caring, is elucidated in this study.

Process. The process of an evolving caring
relationship is conceptualized in three phases from SCI individuals descriptions of nurse caring. Each process of "learning the other," "learning what I need to know," and "letting me find out" is a series of reciprocal behaviors between the nurse and patient which culminate in intermediate outcomes, move the patient into the next phase, and contribute to the reintegration of self and the attainment of well being, self care, autonomy, independence, and hope. The process of how individuals in rehabilitation move from dependence to independence in preparation for discharge was previously unknown.

Consequences. The core concept of "getting back together" or reintegration of self, affirms the findings of two other recent rehabilitation studies; one with SCI patients and one with stroke patients. How nurse caring contributes to reintegration of self was previously unknown. This study identifies the process or the work of rehabilitation accomplished with nurses and therapists who are perceived as caring, which contributes to the reintegration of self. Also, the contribution of nurse caring to the achievement of rehabilitation outcomes, their synergistic relationship, and the role of these outcomes in the reintegration of self was previously unknown.

Theoretical Support

Many theoretical suppositions in the formal theory of nurse caring have not been demonstrated in research. In
this study, support for the concepts of goal identification, actions of the nurse and patient to achieve the desired goal, and outcomes of well being, self care, and autonomy is evident. The substantive theory of nurse caring developed from this study provides previously unknown details for many of the elements of the formal theory of nurse caring.

**Contribution of Nurse Caring to Rehabilitation Outcomes**

Nurse caring is perceived by SCI individuals in rehabilitation as central to recovery and to a positive attitude toward disability. The work of rehabilitation was accomplished with nurses and therapists perceived as caring. Noncaring nurses and therapists slowed the rehabilitation process or contributed to complications. Caring contributed to a positive attitude by communicating wholeness and dignity despite situations viewed as disgusting or degrading. Respect for the person was communicated by recognizing the uniqueness of the individual. Often nurse caring contributed to family adjustment. By observing caring interactions, family members knew how hard to push their loved one, how to talk and joke about their disability, and how to treat the individual when they were feeling down. Nurse caring contributed to the important rehabilitation outcomes of reintegration of self, well being, self care, autonomy, independence, and hope.

**Quality of Relationships**

The philosophy which drives the model of rehabilitation
or health care in this country must include a recognition of the importance and quality of the relationship between the health care provider and the recipient of health care. A model of health care which fails to recognize and account for the unique and individual needs of each person can result in either too much or too little health care, increased costs, and a diminished moral sense of the individual. A health care system which ignores the importance of the quality of the relationship between the provider and the recipient of care will benefit no one and will not decrease costs.

Implications

In this next section, the implications from the findings of the meaning, process, and outcomes of nurse caring with SCI individuals during rehabilitation are explored. The implications of nurse caring will be discussed from the perspective of the patient and family, nursing staff, nursing administration, the institution, and the health care system.

Patient and Family

Findings from this and other studies of nurse caring have tremendous implications for patients and families interacting with the health care system in rehabilitation. First, the role of patients and families, viewed from a framework of nurse caring, is one of active partnership rather than that of passive recipient of health care. The
invitation into the partnership is issued by the nurse in
the initial interaction with the patient and family and
continues throughout the encounter with the system. The
nurse shares professional, practical, and personal knowledge
as an invitation for the patient to share personal knowledge
and values, as well as the meaning of the illness or
disability experience itself. From this mutual sharing, the
nurse can assist the patient identify a realistic, desirable
goal for this health care experience. Throughout the health
care experience the nurse demonstrates interpersonal and
technical skill in the delivery of competent caring
activities. The active partnership between the nurse and
patient continues through the teaching-learning process,
with the goal being the empowerment of the patient to
achieve the identified level of self-care, autonomy, and
independence.

How is this caring relationship different from other
interactions the patient may experience while in
rehabilitation? Relationships based in caring seek to
diminish the patient's vulnerability (Gadow and Ray, 1988).
Through mutual sharing the nurse experiences the subjective
reality of the patient; mutual trust and respect emerge as
the guiding force for the relationship. The patient
experiences a sense of wholeness, humanness, and dignity
throughout the caring experience, rather than being the
object of nursing care. Also, shared responsibility for the
outcomes of the caring experience is required as the nurse moves from the role of coordinator, teacher, and guide to the role of collaborator and consultant with the patient. Patients and families should expect authentic caring interactions in their relationships with nurses.

Although the role of the significant other was not the specific focus of this study, it is the most important relationship for the patient in rehabilitation. Because the support of the significant other is crucial to the successful attainment of rehabilitation goals, the web of nurse caring must extend to the family of SCI individuals. Not only do caring nurses share the patient's experience of loss and reintegration, but they can also be open to share the family's sense of loss and fear, and assist the family to facilitate the SCI individual's reintegration of self. In addition, the nurse must be open to suggestions and ideas from the family on how to individualize the rehabilitation plan for their particular other. Just as the caring nurse provides anticipatory guidance in the form of creative problem-solving for the SCI patient in preparation for the return home, this process can also be used with families to assist the SCI person live as normally as possible despite their injury and resulting disability.

Nursing Staff

Implications for nursing staff based on the findings of nurse caring from perceptions of SCI individuals include the
role of the nurse, the role of the patient, the importance of the admitting nurse and admission process, and finally primary nursing and the process of assigning nurses to patients. The role of the nurse is dramatically different viewed from the perspective of caring. First, the difference in knowledge and power between the nurse and patient becomes insignificant in a relationship of partnership. The goal in a caring relationship is to provide as much knowledge and empowerment as possible to enable the patient to take over self-care activities (or direct another in those activities), and decision-making. Second, the sharing of personal information exposes the nurse's vulnerabilities to the patient. It is through mutual sharing that mutual trust and respect result. Third, the role of teacher takes on a different meaning. Rather than simply giving information to patients, there is a series of reciprocal interactions between the nurse and patient in which both benefit. The nurse gains practical knowledge for future use and the patient becomes ready to assume responsibility for the rehabilitation plan. Finally, the nurse relinquishes the role of teacher and decision-maker and becomes a consultant and collaborator as the patient assumes the role of decision-maker. Allowing the patient the freedom to make mistakes, experiment, and find out what works or feels best can be threatening to some nurses as well as frightening.
Just as the nurse's role changes in a caring relationship, so does the patient's. The role of patient is transformed in a caring relationship into that of an active partner in the rehabilitation plan. In order for the patient to become an active partner, (s)he must become knowledgeable in all aspects of the rehabilitation plan and assume responsibility for decision-making. This requires an openess and honesty between the nurse and patient based on mutual trust and respect, as well as the nurse's willingness to share personal and practical knowledge. Knowledge of the particular other requires the nurse to strive for positive experiences for the patient that will enhance well-being and maintain hope. Competent caring also requires the nurse to 'break the rules' in order to individualize the rehabilitation plan for the particular patient. This level and complexity of care requires an emotional investment in the nurse-patient relationship as well as risk-taking. Not all nurses are willing or capable of this level of competent caring.

In a setting where the initial interaction communicates the entire philosophy of the treatment plan and nursing approach, the role of the admitting nurse is paramount. In the admission process, the nurse communicates a number of things to the patient and family. The role of the nurse and patient is demonstrated throughout the admission process. The role of the patient in relation to the rehabilitation
team is explained. Additionally, the purpose and process of rehabilitation is explained along with the role of the patient in the context of the entire rehabilitation program. How the nurse conducts the admission process sets the stage for how the patient perceives the rehabilitation experience and whether rehabilitation will focus on physical recovery or the entirety of the disability experience.

Most institutions utilize a form of primary nursing today. Although a patient is assigned a primary nurse from the time of admission, caring relationships are often established with nurses other than the primary nurse. This process of 'self-selection' between the patient and nurse occurs during the first few weeks of rehabilitation. Often it is based on the patient's perception of the nurse's caring capacity and how frequently the nurse works with the patient during the initial weeks. Although the primary nurse is viewed by the institution as the person responsible for the patient's plan of care, it is often another nurse who knows the patient's goals, values, and disability experience more intimately. How the role of the primary nurse assigned to the patient versus the nurse who has made a moral commitment to the patient can be reconciled at this point is unclear.

Nursing Administration

Implications for nursing administration in a rehabilitation facility involve three areas: staffing,
nurse/patient ratios, and an environment which fosters a philosophy of caring. Competent nurse caring requires experienced nurses. Competent caring also facilitates the achievement of rehabilitation outcomes in an efficient manner, as perceived by SCI individuals. In an era of cost cutting, replacing experienced nurses with inexperienced nurses does not seem wise. Not only are experienced caring nurses required for the efficient and effective attainment of rehabilitation outcomes, they are also required to mentor and provide role models for less experienced staff and nursing students.

Nurse patient ratios must also support nurse caring. A caring relationship requires time and continuity. If nursing care is to entail more than just the physical care of the patient, there must be adequate numbers of nurses and support personnel in relation to the number and complexity of patients. If nurses are allowed time to care, their practice will be enhanced as well as patient care, and burn out will be reduced (Fry, 1988; Kleinman, 1988).

In order for nurse caring to become the standard, the environment of the nursing unit and the philosophy of nursing administration must support an atmosphere of caring. First, nurses must feel cared for themselves; collegial relationships and relationships with nursing administration must demonstrate caring. Second, the expectation for caring relationships with patients, families, and colleagues must
be clearly articulated. Third, nursing administrators must support bedside nurses in individualizing care and "breaking the rules." Fourth, acknowledgment within the system must recognize and reward nurses who provide competent caring. **Institution**

Implications of nurse caring for the rehabilitation institution include the role of the patient, an individualized versus standardized care approach, communication among members of the health care team, and attention to the emotional recovery as well as physical recovery of patients. It is clear from patient reports that caring by nurses as well as other health professionals is essential to the efficient accomplishment of rehabilitation objectives. Therefore the philosophy of the rehabilitation institution should reflect the role of the patient as an active partner in the rehabilitation plan. This philosophy includes the patient in setting goals, determining plans of action, and decision-making. How the rehabilitation team operationalizes this partnership approach determines the degree to which the patient actively participates in all aspects of the rehabilitation program.

Today, in health care, the trend is moving toward standardized managed care plans. This movement does not take into account the individualized situations of each patient in rehabilitation. Hopefully, as these standardized managed care plans or clinical paths are introduced, the
institution will adopt the approach that individualization is necessary and possible. Research is necessary to demonstrate that individualization may actually facilitate the attainment of rehabilitation goals. Adopting a caring philosophy within an institution may facilitate the rehabilitation process, as communication and collaboration among the members of the health care team is enhanced in an effort to meet the patient's physical, psychological, and social needs.

Communication among members of the rehabilitation team must be current, accurate, and complete in order for effective caring to occur. Following through on patient needs or problems in an appropriate, timely manner will facilitate the resolution of problems and prevent potential complications. Paying attention to detail and picking up on potential problems in a proactive manner will facilitate the rehabilitation process. All members of the health care team must communicate effectively to meet the needs of individuals in rehabilitation in a holistic manner.

Reimbursement for rehabilitation programs is currently based on the attainment of specific physical goals: mobility, skin care, bowel and bladder retraining, and performance of activities of daily living. The psychological and social responses of individuals to SCI are secondary, primarily because they are less obvious and less measurable. In an institution where a caring philosophy of
rehabilitation exists, documentation would reflect the entirety of the rehabilitation experience. This caring approach would legitimize the emotional and psychological responses to SCI in addition to the physical disability (Kleinman, 1988). In addition, the approaches of team members which contribute to reintegration, feelings of well-being and a sense of hope, and the effects of the caring interventions would be recorded. A more complete and systematic rehabilitation record would be available for research and reimbursement purposes.

Health Care System

Implications of nurse caring for the health care system includes two areas: the use of the medical model versus the illness model and issues of cost and reimbursement. The current health care system is built on the premises and assumptions of the biological medical model. Illness is viewed simply in terms of disease and pathology of the biological systems. The complex nature of the entire illness experience, which includes the psychological and social aspects of illness as well as the resultant interactions with significant others and the environment, is ignored (Ray, 1994; Morse & Johnson, 1991; Kleinman, 1988; Strauss et al, 1984). To address many of the inequities of the current health care system, where people of chronic illness and disability are disenfranchised because of the chronicity of their illness and subsequent poverty, a more
comprehensive view of health care is necessary, as well as a change in focus from acute illness.

The current health care system is structured around tasks, procedures, and pharmacologic agents to manage acute illness. We can build a better health care system, but fundamental change in the values underlying the current system is required. Values must shift from cure, technology, and avoiding death to encompass care, community, and dignity during life. We must make a moral commitment to understand not only disease, but also to understand the individual, family and community response to illness. Genuine responsibility and accountability for the social and psychological aspects of care throughout the illness experience must be as significant as the completion of tasks and tests. Finally, a society which espouses the values of self care, autonomy, and independence must put into place the social and environmental structures to make these accessible to individuals with chronic illness and disability: education for informed self-care and decision-making, assistance to remain in the home setting if desired, transportation, counseling, tutoring, education to change occupations when necessary, technical services for the maintenance and repair of equipment for mobility and self-care, and research and development on products which will enhance the quality of life for those with chronic illness and disability (Toombs et al, 1995; Morreim, 1995).
Current reimbursement schemes for rehabilitation, such as managed care, are based on the time required to acquire physical skills in preparation for discharge. Because the individual with SCI is not viewed as a whole by the health care system, where psychological and social responses to disability are given secondary consideration, complication and readmission rates remain steady. Also, the medical model predominates in rehabilitation facilities in which patients are expected to follow the prescribed medical plan. SCI individuals in this study reported that they were able to move forward more quickly when they became a partner in the rehabilitation process and when they were treated as a whole person. Participants perceived that noncaring nurses and therapists actually hindered the attainment of rehabilitation outcomes or contributed to complications. Studies need to be conducted in which outcomes from an alternative model of rehabilitation, such as one which incorporates the construct of caring, are followed long-term in relation to length of stay, complication and readmission rates, and overall costs, in addition to measures which reflect the psychological and social adjustment to SCI. Restructuring reimbursement schemes to reflect the entire spectrum of physical, psychological and social adjustment to disability, as well as incorporating the concept of patient work that occurs in a partnership may actually increase the productivity of services and decrease total costs.
Summary

The implications of incorporating the construct of caring into rehabilitation programs for patients and families, nursing staff, nursing administration, rehabilitation institutions, and the health care system have been explored. Fundamental changes in the values underlying the health care system are required, as well as in the roles of patient, families, communities, and health care providers. The totality of the illness or disability experience would be legitimized by society, and supports and services which would enhance the quality of life for those with chronic disability or illness would be necessary. In addition, implications of the role of the patient as an active partner in their health care endeavor were examined.

Recommendations for Research

The last section of this paper will include recommendations for research in the area of nurse caring. First, recommendations for improvements in this study are suggested. Then, recommendations for replication of this study are detailed. Finally, recommendations for future research in nurse caring are outlined.

Recommendations for Improvements in this Study

The first recommendation is aimed at including a greater variety of participants. Data collection would occur at more sites over a greater period of time. Therefore, more women and older individuals would be
included as participants. Having a greater variety of participants would increase the theoretical generalizability of the findings (Morse, & Johnson, 1991; Denzin & Lincoln, 1994; Strauss, 1993; Glaser, 1992; Strauss & Corbin, 1990).

A second recommendation would be for additional data to be included in the background information. Initially, the time from injury and the time in rehabilitation were not recorded. But as it became obvious that various aspects of nurse caring were important at different times during rehabilitation process, that information was then recorded by the researcher and retrieved for previous participants.

Educational level was not recorded by the researcher as part of the background information. Previous research demonstrated that educational level influenced long-term recovery and adjustment to SCI. Individuals with more education had available to them a greater variety of employment opportunities post-injury and were therefore more likely to return to gainful employment. Whether participants were employed prior to their injury was recorded in this study and the type of employment became obvious during the interviews. Employment was explored in relation to "knowing when I'm ready," and whether certain individuals took the initiative to identify their readiness to begin self-care and decision-making. Whether education influences the early rehabilitation process is unknown.

Whether participants experienced a complete versus and
incomplete SCI was not recorded and included in data analysis. Although it became obvious to members of the rehabilitation team and the researcher, who was experienced in working with SCI individuals, over time whether an injury was complete or incomplete, this information was not recorded at the time of admission. SCI individuals with incomplete injuries recovered function and progressed more quickly through rehabilitation. Whether an injury is complete or incomplete and the rate of recovery could certainly influence feelings of well-being, hope, and independence, as well as the attainment of self-care goals.

Recommendations for Replication of this Study

Several recommendations are provided for future replication of this study to enhance the depth and breadth of the substantive theory development. These include: planning interviews with participants throughout their rehabilitation stay, exploring certain factors more in-depth with participants, examining the core concept of reintegration more fully, and exploring the outcomes in relation to the phases of rehabilitation. Interviews should be planned during the various phases of rehabilitation, that is, individuals could be followed throughout their course of rehabilitation. Conducting interviews with the same individuals throughout their rehabilitation stay would add credibility and coherence to
the findings of the meaning, process, and outcomes of nurse caring with SCI individuals.

Now that certain factors have been identified in the process of a caring relationship, these factors could be explored more in-depth in a subsequent study. Additional knowledge and insight could be gained by exploring the following factors more in-depth: "getting me through," the role of support systems and religion in the reintegration of self, and the influence of perceptions of the attribution of the injury on "getting back together."

The core concept of reintegration of self needs to be explored further in a future study. What aspects of nurse caring facilitate and inhibit reintegration need to be examined more fully. Also, other factors such as the environment and the influence of other SCI individuals need to be explored in relation to reintegration of self. "Learning the system," which participants identified as occurring outside the caring relationship, needs to be examined further, and also whether it influences reintegration.

Last, it is recommended that a future study explore the outcomes more in-depth in relation to the phases of rehabilitation and also their influences on each other. For example, participants in this study described feelings of hope occurring toward the end of the inpatient rehabilitation period. A previous study found that hope was
present throughout the hospitalization period as well as rehabilitation (Laskiowski & Morse, 1993). Perhaps the influence of nurse caring on hope emerges toward the end of rehabilitation. The influence of the other outcomes on hope, such as self-care, autonomy, and independence also need to be explored more in-depth in a future study.

Future Research

Several recommendations are made for future research on nurse caring to extend the findings of this study. These include continued qualitative work, beginning to measure or refine measurements of nurse caring and the outcomes identified in this study, and finally recommendations for future controlled studies of nurse caring.

Additional qualitative work. Continued qualitative study of nurse caring is suggested in several areas. First, future studies of nurse caring need to include both the patient's and the nurse's perspective. Credibility and confidence in the findings are increased when both perspectives are explored simultaneously. Concepts which emerge from patient data can be verified and explored with the nurse and similarly, concepts which emerge from the nurses' data can be examined and validated with patients.

Another recommendation for future qualitative work is to make the study more longitudinal, that is, extend over a greater period of time. Ideally, patients could be followed for a year after their injury. The influence of a caring
relationship with a nurse can be placed in perspective over time. The outcomes of nurse caring and rehabilitation could be followed over time to determine if they change, how they change, and what influences these changes. Additionally, the influence of nurse caring on outcomes and reintegration could be explored over time in relation to complication and readmission rates. Finally, the role and needs of the caregiver after discharge could be studied. Since the majority of caregivers in this study were female, the needs of male and female caregivers could be examined, in addition to studying if there are ways to better prepare and support caregivers after SCI.

Model building. Continued refinement of the model of nurse caring would occur with a larger more varied sample, exploring new findings from this study more in-depth with participants, and participants studied longitudinally. Studies of nurse caring could also be conducted with other patient populations in rehabilitation to determine if the dimensions, process, and outcomes are the same as with SCI patients. Since the SCI population is unique in several respects from other patient populations typically found in the rehabilitation setting, such as gender and age, a determination would need to be made whether nurse caring is perceived similarly in other rehabilitation patient populations, such as older patients or female patients.

Measurement of nurse caring. From the findings of this
and continued qualitative work, measurement of nurse caring could then be refined or developed for rehabilitation. Existing instruments could be refined or new instruments developed to measure the dimensions, process, and outcomes of nurse caring. Reliability and validity of the instruments could be established with SCI patients as well as other patient populations in the rehabilitation setting.

Once adequate reliability and validity of instruments to measure nurse caring and outcomes are established, correlational studies could be designed to test the relationships with the desired outcome variables. These studies could explore how and when to best achieve the outcomes, as well as patient and nurse differences which might influence the attainment of outcomes. In addition, these relationships could be tested in older rehabilitation populations such as stroke patients or with a primarily female population.

**Controlled studies.** After the strength of the relationships between nurse caring and the desired outcomes is established, controlled studies could be designed to test specific caring interventions or strategies on outcomes during and following rehabilitation. In addition, the influence of intervening variables such as support systems, educational level, the attribution of injury, emotional response to SCI, or spiritual influence on recovery could be studied.
Summary. In the last section of this paper, recommendations for continued research on nurse caring have been outlined. Suggestions for the improvement of this study were included such as increasing the number of sites and length of time for data collection. Recommendations for studies which would replicate this study included a more longitudinal approach with interviews planned throughout the phases of rehabilitation, and exploring the core concept and outcomes more in-depth in relation to the phases of rehabilitation. Finally, recommendations for future research included continued qualitative explorations, subsequent measurement of nurse caring and outcomes, as well as future controlled studies which could demonstrate the contribution of nurse caring to the achievement of rehabilitation outcomes.
Appendix A

Informed Consent
CONSENT FORM

The University of Maryland at Baltimore

Title of Research Project: The Relationship among Nurse Caring and Perceived Self-Care Ability and Perceived Autonomy in Spinal Cord Injured Individuals during Rehabilitation

Principal Investigator: Kathleen T. Lucke Phone: (W) (H)

Explanation of Research Project to Participants:

PURPOSE OF STUDY:

The purpose(s) of this research project are to: 1) describe the meaning, process, and consequences of a caring nurse-patient relationship during rehabilitation, 2) explore the relationship(s) among nurse caring, self-care, and autonomy as viewed by spinal cord injured individuals in rehabilitation.

You are being asked to join this study since you are in rehabilitation after having suffered an injury to your spinal cord, are able to understand and speak English, and do not also have a head injury.

PROCEDURES:

If you agree to join this study, you will be asked to talk with the nurse researcher about what you feel is important about how the nurse takes care of you in the rehabilitation center. The first interview will last about one to one and one half (1-1 1/2) hours. The interview will be tape recorded to help the nurse researcher remember the important things you say. After the first interview, the nurse researcher may ask to talk with you again. This time, the nurse researcher will be checking with you to make sure she understood correctly what you meant during the first talk.

Talking with the nurse researcher in the interviews, should you agree, are solely for purposes of this research study. In this project we will try to learn what is important to you about how your main nurse cares for you, and whether you feel this affects your ability to care for yourself or make decisions about your care while you are in rehabilitation.

RISKS/DISCOMFORTS:

There is little risk to you if you agree to join this study. You may become tired during the interview. If that happens, we will stop and schedule another time to finish. Also, thinking about and talking about what is happening to you may be difficult at
times, and you may want to stop. Any time you want to stop, we will stop, and schedule another time to finish the interview, when it is convenient for you. If you find that you no longer want to stay in the study after it has started, you may withdraw at any time and it will in no way effect the care you are receiving at the rehabilitation center.

BENEFITS:

This study will help nurses in the future understand important ways to care for individuals, who have an injury similar to yours, while they are in rehabilitation. Some people who joined in studies like this in the past, found it helpful to talk about what they were going through.

ALTERNATIVES TO PARTICIPATION:

If you choose not to join the study, it will in no way effect the care you are receiving while you are in the rehabilitation center.

COSTS/COMPENSATION:

If you agree to join the study, you will not be paid for your time while you are being interviewed.

CONFIDENTIALITY:

This study may involve confidential information about you. Forms (background information), interviews, tapes, and transcripts will be coded so your name and any other identifying information will not be used in the collection, analysis, or reporting of data. Only the researcher will have access to the names of the participants, which will be kept in a locked file. At the completion of the study codes and audio tapes of the interviews will be destroyed. Confidentiality of data will be maintained at all times to the fullest extent of the law.

UNIVERSITY STATEMENT

During your participation in this research, if you suffer physical injury, the University of Maryland at Baltimore (or the site where this research is being conducted) will provide acute medical treatment and provide subsequent referrals to appropriate health care facilities. Acute treatment will be charged to your insurance carrier, to any other party responsible for your treatment costs, or to you. The University of Maryland at Baltimore cannot provide any financial compensation due to any injury suffered during this research study. Information regarding research may be obtained from the IRB.
If you agree to join this study, please sign your name below.

NOT VALID WITHOUT THE IRB STAMP OF CLARIFICATION

Participant's signature
I have read and understand the information on this form.
I have had the information on this form explained to me.

Signature of Parent/Guardian
(When applicable)

Witness to Consent Procedures*

Signature of Investigator

Date

*Optional unless subject is illiterate, or unable to sign.

NOTE: Copies of this Consent Form with original signatures must be a) retained on file by the Principal Investigator; and b) given to the participant. A copy must also be deposited in the patient's medical record.
To:      MARIETTA MILLS, Sc.D.
UMAB CAMPUS

From:    Institutional Review Board
Assurance Number M1174-01NR

Date:    November 30, 1994

RE:      RELATIONSHIP AMONG NURSING CARING AND PERCEIVED
SELF-CARE.....
446028-109401

This is to certify that the Institutional Review Board received your response to the additional
information requested. Your response was considered sufficient to grant final approval.

Your approval date for this protocol remains 10/07/94.

It is your responsibility to provide all information concerning the protocol directly to the
Executive Secretary of the assigned Study Section, if applicable, and any other funding source
as appropriate. It is also your responsibility to forward a copy of this certification to the
appropriate official at the granting institution.

Approval of this protocol by the UMAB IRB does not exempt you from complying with all
policies that apply to the site(s) at which you intend to conduct your research. Departmental,
hospital, medical system, university, governmental and general professional guidelines, for
example, must all be followed during the course of your research.

Attached is a copy of the RPN information as it is currently recorded in the IRB Office. Please
review this for accuracy and return the form only if corrections are necessary. This is the official
record of your approved Protocol.

If you have any questions, please do not hesitate to contact the IRB Office

[Signature]
Robert K. Conley, M.D.
Chairman, IRB
Appendix B

Interview Guide
Interview Guide

I am a nurse who has worked with people with injuries similar to yours for 23 years. This study is being done to learn more about what is important to you, while you are in rehabilitation, about how the nurse takes care of you: what does the nurse do, what does the nurse say, how does the nurse act, how does this affect you, and how does this make you feel? What I learn from you and other people that I talk with, will help nurses understand better how to take care of persons with an injury similar to your, while they are in rehabilitation, and perhaps improve the way in which we take care of people in the future.

Baseline Data:

1. Tell me what brought you to the rehabilitation center. How have you been feeling about that? (Probes: What does that mean to you? Why is that important to you?)

Caring:

2. Tell me about a particular nurse that is special to you.
3. Tell me about the kinds of things the nurse does? (Probes)
4. How does that make you feel? (probes)
5. What does this mean for you? (Probes)

Consequences:

6. Tell me what happens to you when this nurse works with you. Tell me more about that. (Probes)
7. Tell me about how you take care of yourself while you are here? How has that been for you? (Probes) What affects how
you take care of yourself? Tell me more about that.

8. How do you make decisions about your care? Tell me some more about that. (Probes) What affects how you make decisions about your care? Tell me more about that. (Probes)

9. How does your ability to care for yourself affect how you make decisions about your care? (or, How does your ability to make decisions about your care affect your ability to care for yourself?)

**Process:**

10. This nurse has been taking care of you since you were admitted to the rehabilitation center. As you got to know him/her, what were some important events or things that happened between you? Tell me more about that.

11. As s/he got to know you, how did you let him/her know how you wanted him/her to take care of you? (Probes)

12. Are there ways that s/he takes care of you that you did not or do not like? Can you tell me about that? (Probes, e.g., How did that make you feel? What did you do then? Tell me what the nurse did when you.... How did it make you feel then, after the nurse...?)
Appendix C

Background Data Collection Sheet
Background Information

Participant Code: _______ Age: ___ Gender: ___ Male

___ Female

Mechanism of Injury: ___ MVA Level of Injury: ___ Cervical

___ Fall ___ Thoracic

___ Sports ___ Lumbar

___ Other ___ Coccygeal

Previous Employment: ___ Student

___ Employed full-time

___ Employed part-time

___ Homemaker

___ Unemployed

Living Arrangements: ___ Lives alone

___ Lives with spouse

___ Lives with parents

___ Lives with children

___ Lives with friend(s)/others

Cultural Background:

Religious Affiliation: ___ Protestant

___ Catholic

___ Jewish

___ Other

___ None

Ethnic Affiliation: ___ African American

___ Caucasian
Hispanic
Asian American
other

Support System: Spouse
Parents
Significant other
Friend(s)
None
Appendix D

Script for Introduction of Study
August 14, 1994

Dear

This is to inform you of the opportunity to participate in a research study while you are in rehabilitation. The study is being conducted by a nurse who is a doctoral student at the University of Maryland at Baltimore, who has worked with individuals experiencing spinal cord injuries for 23 years.

This study is being done to learn more about what is important to you, while you are in rehabilitation, about how a nurse takes care of you: what the nurse does, what the nurse says, how the nurse cares for you, and how this affects you. What we learn from you, if you choose to join the study, and from other people in the study, will help nurses understand better how to take care of persons with a spinal cord injury while they are in rehabilitation, and improve the way we take care of people in the future.

If you choose to join in the study, you will be interviewed by the nurse researcher at a time convenient to you. The interview will last about one to one and a half hours. During that time, the nurse researcher will talk with you about what is important to you about how a nurse cares for you in rehabilitation. If you agree, the interview will be tape recorded to help the nurse researcher remember the important things you say.

If you are interested in learning more about this study or if you are interested in joining the study, please let your nurse know. She will contact the nurse researcher, who will talk with you more about the study and answer any questions you may have. Thank you for your time and consideration of this matter.

Sincerely,

[Name Redacted]

Kathleen T. Lucke, RN, MSN, CNRN, CCRN
Doctoral Candidate, School of Nursing
University of Maryland at Baltimore
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