

**“I’M AGING LIKE EVERYONE ELSE – JUST IN A
WHEELCHAIR”: A CASE STUDY OF ACCEPTANCE OF
SPINAL CORD INJURY**

By

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Abstract

Due to decreased mortality and increased longevity, the population of those aging with a spinal cord injury (SCI) is increasing in Canada. Little is known about the experience of aging with a SCI. In order to increase our understanding of this experience, I designed a qualitative research study to explore it. Using a case study approach, I both interviewed and observed a 65 year old man who has lived with paraplegia for 28 years. For this man aging with a SCI involved acceptance and normalization. Acceptance occurred first and was the incorporation of his SCI into his life. Then normalization, or the reconstruction of the self, took place. This involved minimizing the differences and redefining normal. As a result of acceptance and normalization, aging with a SCI became simply aging for this man.

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Chapter One: Introduction

Aging and Disability

Everyone gets older, and as we do, our bodies change. For instance, bone density, cardiac reserve, muscle bulk, and vital capacity all decrease as we grow older (Springhouse, 1997). As these changes occur, our risk of illness increases. Why these physical changes occur is not well understood. Biological theories propose that changes in the body at the cellular level result in the physiological decline that is seen in aging. Specifically, the body seems to become unable to maintain itself (Charlifue, 1993). This is thought to occur in a variety of ways such as normal wear and tear, molecular changes, or immune system dysfunction (Springhouse). There is also the theory that the accumulation of the effects of repeated stress eventually damages the body so that aging occurs. Finally there is speculation that our bodies are simply genetically programmed for a certain lifespan and that they begin to break down as we approach the end of that lifespan.

Austad (1998) approaches the biological changes that could result in aging from a different perspective. Instead of discussing theories, Austad refers to processes. The first process is oxidation. Austad attributes this to the damage done to the body by free radicals and calls it *rusting*. The second process is referred to as *browning* which impairs protein function and deoxyribonucleic acid (DNA) reproduction in the body by the attachment of glucose to these molecules. The term browning originated in the food industry and is “the chemical attachment of glucose ...at places it doesn't normally belong, which makes a yellow or brown product” (p. 135). The third process is related to cancer or the uncontrolled growth of cells within the body. There is speculation that the continued cell division seen in the repair of some body systems during life can ultimately lead to uncontrolled cell division in some of these systems.

The result of this is cancer, “ perhaps the most general disease of aging in the animal kingdom” (p.139).

While Austad and others focus on the biological issues of aging, other researchers are interested in the contexts in which aging occurs (Charlifue, 1993). Theories of aging such as age stratification, the political economy of aging, and critical gerontology address the management of aging at a societal level while those that address the individual management of aging include role theory, reference-group theory, socialization and social learning theory, labeling theory, activity theory, disengagement theory, and continuity theory (McPherson, 1998). Individual management of aging theories generally consider the interactions between individuals while theories of societal management of aging “ suggest that behavior is influenced by ...the relatively stable and enduring system of norms, values, and social relationships that occur in groups and institutions” (McPherson, p. 81).

In 1996, those aged 65 and older in Canada numbered 3,527,845 (Statistics Canada, 2000). This was 12.2% of the population. Now there are 3,849,897 people aged 65 or older. This is 12.5% of the population. Statistics Canada estimates that by the year 2001, there will be 3,945,700 people in this age group. This will be 12.7% of the population. Those above 75 years of age will number 1,796,400. These figures will continue to increase as Canada's population grows older and lives longer (Campbell, 1997). As a result, the prevalence of disabilities related to health problems or physical changes associated with aging will also increase (Campbell, 1997; Government of Canada, 1996).

The number of Canadians who are born with disabling conditions and those who acquire them early in life will also increase as these individuals not only survive the onset of their disabilities but also live longer with them (Campbell,1997).

Therefore, due to increased longevity and decreased mortality, the numbers of individuals *aging into disability* and those *aging with disability* are increasing in Canada (Campbell).

The World Health Organization (WHO) in its International Classification of Impairments, Handicaps, and Disabilities (ICIDH) defines a disability as “a restriction or lack ...of ability to perform an activity in the manner or within the range considered normal for a human being” (de Kleijn-de Vrankrijker, 1995, p.110). Brody (1990) defines those *aging into disability* as “those aged who have become disabled because of traumata [sic] ...or late-onset diseases” (p. 11). Campbell (1997) defines them as “adults, 65 years and over, with more recent onset of disability” (p. 3). They are also referred to as the frail elderly (Campbell).

Canadians *aging with a disability* constitute a second emerging group of aging individuals. This group is defined as “children and working-aged individuals with impairments that are longterm, acquired primarily at birth or through the onset of disease or injury prior to middle age” (Campbell, 1997, p. 3). People with “developmental or early-life onset of disability, including cerebral palsy, mental retardation, polio, and multiple [sic] dystrophy, and those aging with young adult onset of disability such as spinal cord injury, traumatic brain injury, and rheumatoid arthritis” (Campbell, 1996, p.1) are included in this group.

Approximately 500,000 to 1,000,000 Canadians are aging with a disability (Campbell, 1996). Canadian estimates based on American data indicate some of the specific disabilities mentioned above as well. For instance, in Canada there are 20,000 individuals aging with spinal cord injury (SCI) and 50,000 aging with cerebral

palsy (Campbell, 1997). These numbers will continue to increase, thereby significantly changing the demographics of the population of Canada.

This demographic shift will have implications for many areas of Canadian life especially the provision of health care and is occurring when limited information concerning aging with a disability is available. Obtaining a greater understanding of the process of aging with a disability is the first step in providing appropriate healthcare services to this group of Canadians and is the purpose of this study. Spinal cord injury is the disability I have chosen to study due to my extensive rehabilitation nursing experience with individuals with this condition. The objective of the study is to describe the experience of aging with a SCI.

Spinal Cord Injury

A SCI can be defined as an injury to the spinal cord which results in the physical disability of either paraplegia or quadriplegia (Zejdlik, 1992). Currently there are approximately 3,000 people with a SCI living in British Columbia (B.C.) (B.C. Paraplegic Association; Vital Statistics, 1989; Zejdlik & Forwell, 1993) and approximately 100 new spinal cord injuries occur each year in B.C. (B.C. Paraplegic Association, 1998). A full discussion of SCI will follow in chapter two.

The Research Question

The changes associated with aging and the management of those changes are currently issues for those living with SCI in B.C. (Zedjlik & Forwell, 1993). Zedjlik and Forwell surveyed this population and found that changes such as the occurrence of reduced strength and increased pain associated with aging are common concerns. These changes may lead to a loss of independence which is another common concern. For

instance, changes in strength and in pain may result in physical problems such as skin injury during transfers in and out of the wheelchair as the individual struggles to maintain independence. Ultimately, the ability to transfer independently may be lost and the individual will be faced with the ongoing need for assistance with activities of daily living as well as the management of the skin injury which could require a period of bedrest, or surgery, or both.

As the population of those living with SCI expands, concerns such as these will bring these individuals into contact with the healthcare system and into contact with nurses. The management of the changes associated with aging and the impact of these changes on the individuals' lives will form the basis of nursing practice with individuals aging with SCI. However, in order to establish a nurse-client partnership from which to build this practice, nurses must first understand the experience of aging with a SCI. Therefore, the research question I wish to investigate is 'What is it like to grow older with a SCI?'. To answer this question, I plan to use a case study methodology to gather data on this experience from an individual who has lived with SCI for 28 years.

Summary

As statistics demonstrate, the lifespan of those with SCI has expanded to the point that people are actually aging with this disability. While SCI used to be a death sentence, it is now a fact of life for an increasing number of individuals and is one of a number of disabilities with which people are aging.

What is it like to grow older with a SCI? How do those with a SCI manage this process? We understand the spinal cord and injury to it. We can successfully treat these injuries. However we are unsure what happens after that. Although we are uncertain

what the outcomes of this aging process are or what the process itself is like, we have access to individuals who can answer our questions. Therefore, we can begin to explore the process of aging with a SCI.

Chapter Two: Literature Review

This chapter will review the history of SCI and what we know about living with SCI. The research concerning aging with a disability, aging with SCI, and the experience of SCI will also be discussed.

The History of Spinal Cord Injury

SCI has long been recognized as both a life changing event and a potentially fatal event. Early Egyptians and Greeks identified common mechanisms of injury and described typical outcomes of SCI. For example, Hughes (1987) notes that the early Greek physician Galen (A.D. 131-201) “made observations on patients with spinal injuries notably gladiators falling from chariots surely the earliest recorded spinal injuries from road accidents” (p.169). The anatomical details of the spinal cord such as the different types of nerves in the cord and its blood supply were later discovered by Harvey (1578-1657) and Stensen (1648-1686).

Attempts to treat SCI began in the eighteenth century but knowledge in this area were greatly expanded by the experiences of military surgeons in both the American Civil War and the First World War (Bedbrook, 1987; Dick, 1969; Guttman, 1976). However, despite the best efforts of those working with the wounded, “only 1 per cent survived for more than 20 years” (Dick, p. 173). Dick points out that drug addiction and ill health were common outcomes of longterm survival. Guttman’s (1976) description of the plight of longterm survivors during this time is poignant. Guttman states “most of those...who managed to survive dragged out their lives as useless and hopeless cripples, unemployable and unwanted” (p. 6).

In the early 1940s the situation began to improve. Individuals with SCI began

to be treated at specialized hospitals (Dick, 1969). Treischmann (1987) speculates that this was because the discovery and use of antibiotics in the decade prior to World War II and during the war itself resulted in “a sizable and visible population of persons with major physical disabilities incurred during active military service” (p. v). But the idea of rehabilitation of individuals with SCI was yet to be developed despite “the fact that the modern principles of rehabilitation had been successfully applied for a number of years to other forms of disablement” (Guttmann, 1976, p.6-7).

Living with Spinal Cord Injury

In 1944 England, in an effort to consolidate treatment of SCI and research, opened the Stoke Mandeville Center under the direction of Ludwig Guttmann (Bedbrook, 1987). Guttmann (1899 -1980) believed in the “concept of the paraplegic as a disabled but healthy independent person, with an independent future in society” (Dick, 1969, p. 177). Guttmann’s five basic principles for the successful establishment of a spinal treatment center were:

- (a) Management of a unit by an experienced physician who is prepared to give up part, or all, of his own specialty.
- (b) Sufficient allied health professionals, e.g. nurses and therapists to cope with details of care.
- (c) Technical facilities to establish workshops and vocational outlets.
- (d) Attention to social, domestic, and industrial resettlement.
- (e) The regular aftercare, or extended care, over the lifetime of each individual. (Bedbrook, p. 175)

This was the beginning of what we consider to be SCI rehabilitation and the first recognition that there could be more to life after a SCI.

In the 1950s and 60s, the focus of SCI rehabilitation shifted from successful

institutional living to a successful return to home and community (Menter, 1993). In the 1970s, rehabilitation began to focus on independent community living, less support from families, and quality of life issues (Menter). During the 1970s there appeared to be unlimited money available for SCI rehabilitation, however, in the 1980s and 90s, funds decreased and hospital stays became shorter (Stover, 1994). Measurement of functional goals and keeping costs low became priorities. These changes occurred just as a cohort of longterm survivors of SCI began to emerge and aging with SCI was recognized as a significant healthcare issue (Menter).

Living with SCI is a unique experience. The occurrence of SCI can be similar to dropping a pebble into a pond. Change ripples out from that one event to affect every area of life. The most obvious changes that I have noticed during my clinical experience working with those who have SCI are learning new ways to be both dependent and independent, managing health problems, and thinking about, planning around, and anticipating bodily functions that were previously taken for granted. For instance, after most spinal cord injuries it is no longer possible for an individual to rely on his or her body to accurately indicate the need to empty the bowel or bladder or to be able to control these processes. Therefore, new techniques and routines involving physical skills, medications, and equipment must be established in order to ensure adequate function in these areas. The need to perform these routines means that the activities of daily life must be carefully planned. Schedules must be developed and followed and complications can easily disrupt the day. This change is not readily apparent to those without SCI. A young male client once commented to me that his friends had no idea that he could no longer control his bowel and bladder. They thought he simply could no longer walk.

The impact of living with SCI was investigated in a qualitative study of those

with SCI living in the community. Steichele (1995) found that a lack of spontaneity due to the need to adhere to schedules was identified as a stressor. The desire to avoid bowel and bladder accidents made the participants in this study reluctant to skip routines and unable to act impulsively. The individuals I worked with in SCI rehabilitation often told me that they worried about having a bowel accident. According to them, a bladder accident could be camouflaged while a bowel accident could not. Urinary incontinence can also be an issue for aging individuals. In this population incontinence can be related to acute illness, cognitive changes, or physical changes (Jaffe, 1991).

After a SCI, health concerns change for most people. Instead of worrying only about catching a cold or the flu, those with SCI may worry about bladder infections, chronic pain, deep vein thrombosis, pressure sores, and chest infections. Not only are they more susceptible to these problems but the consequences can be deadly. The development of a pressure area can lead to surgery as extensive as amputation while a bladder infection can result in the loss of kidney function.

Finally, after achieving and enjoying independence, a SCI can make an individual dependent on both equipment and other people. New ways of mobilizing must be used. A wheelchair will be necessary for many and physical assistance may be required with tasks previously completed independently. In other cases, independence can be maintained in the activities of daily life but in order to do so the individual must learn new skills and use adaptive equipment.

DeVivo and Stover (1995) point out that "during the last 50 years, both acute and long-term survival rates for persons with SCI have improved dramatically ...but for most individuals with SCI... life expectancy remains somewhat below normal" (p. 289). McColl, Walker, Stirling, Wilkins, and Corey (1997) elucidate the

differences in life expectancies when they comment that it was “ found in a 20 year study (between 1968 and 1988) that spinal cord injured veterans had a mean life expectancy of 39 years post injury, whereas non-disabled veterans could expect 48 more years and members of the general population could expect 46 more years” (p. 818-819). In their own study of life expectancy after SCI between 1945 and 1990, McColl et al. “ found a median survival time of 38 years post – injury with 43% [of their sample] surviving at least 40 years” (p.818).

Whiteneck (1993) points out that “as life expectancies increase through the control of classic causes of death in SCI like renal failure, the full range of mortality causes emerge as reflected in the general population” (p. 36). Current causes of death for paraplegics include “septicemia, suicide..., heart disease , and cancer” (DeVivo & Stover, 1995, p. 290) while respiratory problems are the leading cause of death in those with quadriplegia (DeVivo & Stover). As life expectancy increases and mortality decreases, we must turn our attention to the process of aging with SCI.

Aging with a Disability

SCI is not the only disability for which mortality has decreased and life expectancy has increased. Aging with a disability has also become an issue for those with polio, cerebral palsy, young adult onset of stroke, and muscular dystrophy. In a summary of the results of current research into aging with a disability, Kemp (1998) points out that as individuals with disabilities grow older, new problems develop in terms of health, function, support, and quality of life. The new problems in health are co-morbidities and secondary conditions. Functional changes include weakness, pain and fatigue as well as increased disability and reduced employment. New problems with regard to support are the prevention of health care problems, the use of personal caregivers, and the access to technology and personal care. Changes in quality of life

are the development of psychological distress and a lower level of satisfaction with life in general.

The development of new problems supports the idea, proposed by both Campbell (1996) and Kemp (1998), that disability is not static. Aging with a disability is a dynamic process that involves the individual and the environment. Campbell describes the relationship between the individual with the disability and his or her environment during the aging process as an interaction.

The best known research concerning the dynamics of aging with a disability is that of Treischmann (1987) who developed a description of this process from numerous interviews with longterm survivors of disability. Treischmann refers to this description as "how life actually is, in reality, not in theory" (personal communication, October 5, 1998). Treischmann spoke to survivors of polio, SCI, multiple sclerosis and congenital disabilities and described their experiences of aging with a disability as an interaction between biological- organic, environmental, and psychosocial variables in life during which changes in the biological- organic variables often result in changes in the other two types of variables. Interventions to manage aging with a disability involve restoring the balance between the three types of variables.

In 1987 Menter developed a three part linear model of aging with a disability from work with individuals with SCI. Menter's (1992) model can be used to understand aging in SCI, brain injury and polio. Congenital disabilities are not mentioned in the model.

Menter's (1992) model is based on functional change. Stage one is *acute restoration*, "the process by which an individual moves from having virtually no function immediately after a spinal injury to regaining the maximal amount of function consistent with his or her level of neurological injury" (p. 881). In stage two,

maintenance, the individual sustains this level of function for a specific period of time. Finally, *decline*, or stage three, involves a decrease in function and “occurs with the gradual onset of the physiologic aging process” (Menter, p. 882).

This three stage model can be considered interactive because it can be combined with the “physiological changes of the body,...changing social roles,...[and] issues of self-realization” (p. 880) in order to understand individual examples of aging with a disability. However, it is not clear if the subjective experience of aging with a disability is included in the model. Furthermore, the model does not provide direction for intervention.

The most recently developed and most comprehensive model of aging with a disability was adapted by Campbell in 1993, from earlier work done by Scheer and Luborsky (1991). Scheer and Luborsky studied the histories of polio survivors and developed an interactive model of the process of aging in this population stressing the importance of the subjective experience of aging with polio. They explain that “data from in-depth multiple interview case studies ...illustrate how adults present their polio-related experiences within the context of their biographies” (p. 1173). For example, they found that as declines in function occurred for their participants aged 60 and older, these declines were conceptualized as being part of normal aging rather than as being part of the effects of polio. Thus, “by metaphorically describing the polio-related disabilities as ‘normal aging’ changes of the body and decreased energy levels,...[the survivor] bridges the social gap between the disabled and the nondisabled” (p. 1177).

The “use of ‘aging’ as an explanation for new losses” (Scheer & Luborsky, 1991, p.1177) is an example of normalization although Scheer and Luborsky do not label it as such. Normal and normalization are frequently mentioned in the literature

concerning disability in general. Marks (1999) reminds us that

our sense of normality and difference does not arise naturally from physical or mental differences between individuals, but rather is an effect of the way in which these differences are framed through an interaction between people in the context of work and society. (p. 82)

Historically three factors have influenced the social construction of what is normal and what is not during the last six hundred years. These factors were economics, religion, and science (Finkelstein, 1981) and their influence has been explored in detail by disability researchers in England (Barnes, 1996; Barnes, Mercer, & Shakespeare, 1999; Marks, 1999; Oliver & Barnes, 1998; Thomas, 1999). Briefly, as long as those who were different could contribute to the economy in some way, they were part of the community. This was possible when the economy was based on agriculture. However, as the industrial revolution developed and spread, agriculture gave way to industry and individuals with a disability were no longer able to contribute as part of the work force. Generally, machines could do things better and faster than normal people and certainly better and faster than the disabled. Therefore, people with disabilities became dependent on others for the necessities of life. This led to the development of special places in which to house them and special organizations to care for them. Meanwhile, under the influence of the church, disabilities were often seen as the work of the devil or as evidence of sin. With the advent of scientific knowledge, however, the role of the church in society was diminished and disabilities began to be understood as biological instead of demonic.

Nowadays in the disability literature normalization usually refers to mainstreaming those with disabilities into society from institutions or other protected environments thus allowing them to take risks so as to prevent their devaluation by

the rest of society. The idea is that this will allow those with disabilities to participate fully in life. Normalization in disability, however, can also refer to trying to achieve normal standards after the onset of acquired disability. Wright (1983) describes this as “idolizing normal standards” (p.121) and differentiates it from mainstreaming by explaining that

the person with a disability clings to the standards of the normal majority...In an ...effort to forget and conceal the disability, the person tries to act ‘as if’ the disability did not exist...[and] the standards of behavior relevant to the nondisabled state become enshrined as the ideal, as the preeminent guide for the person’s own behavior and relationships with others. (p. 123).

Olson (1985), on the other hand, sees normalization or mainstreaming as it refers to disability as a positive and useful process. The author believes that normalization involves the individual’s significant others and that interaction with these people determines the meaning and outcome of normalization for the person with the disability. Olsen believes normalization is a good thing because

what normalization implies is that through ‘normal’ or valued interaction and positive interpretation, both structures of the individual’s environment, the devalued individual becomes more valued in terms of cultural norms. The individual does not become ‘normal’, physically and mentally capable of all aspects of activity, or merely placed into the ‘normal’ environment. The words as normal as possible are important; they allow for individual consideration. Means may not be the same for every individual. (p.23)

Olsen has taken normalization and combined it with a symbolic interactionism approach thus expanding it to mean an active process occurring between people rather than simply the movement of those with disabilities into the mainstream of society.

Olsen’s (1985) ideas are similar to Oliver’s (1981) who takes a symbolic interactionism approach to acceptance when he states that “the meaning that disability has for individual[s] is created and negotiated in interaction with both significant and

generalised others" (p.53). It is interesting to note that although Oliver acknowledges the role of interaction with others in the acceptance of disability, he later supports the idea that disability itself is created by the environment.

Further discussion of disability and normalization can be found in the work of Phillips (1985, 1990) concerning the perception of disability by those who are not disabled. Phillips (1985) used qualitative methodology to investigate the definition of successful rehabilitation. The participants in this study reported that despite a professed focus on the individual, rehabilitation professionals promoted the idea of a return to normality as a successful outcome. Phillips (1985) found that for those that adopted this strategy, normalization was "marked by affiliation with 'normals', distinctiveness as a handicapped person ... and disaffiliation from those perceived to *acquiesce* to the 'crippled role' " (p. 50). In 1990, Phillips explored the interactions between those with disabilities and those without disabilities and described normalization as a "concept...better located in socially-constructed realities" (p. 851). Participants in this qualitative research study often found that they were treated as or considered damaged goods in their interactions with others. Phillips concluded that "my informants' narratives reveal the existence, and perhaps even the preponderance in American society, of patterned interactions between disabled and nondisabled persons" (p. 855).

Campbell (1993) expanded Scheer and Luborsky's (1991) model so that it can be used to understand aging with any disability. The result is a conceptual model that Campbell refers to as Aging with Disability-A Life Course Perspective. It does not include normalization. This model builds on the work of both Menter and

Treischmann as it incorporates the interactive element from Treischmann's (1987) work and the element of stages from Menter's (1987,1992) model.

Campbell (1996) believes that "the longterm effects of disability are seen as a complex process involving the intersection of individual or chronological aging, social aging, and historical time, all of which are superimposed upon the unique features of the 'disability timeline' " (p. 2). This illustrates the interactive element of the model. The disability timeline corresponds to Menter's three stages, *onset*, *maintenance*, and *decline*, but also includes the development of secondary conditions which occur as a result of either aging with a disability or of simply aging (Campbell,1993). Secondary conditions include the changes that were normalized by older participants in Scheer and Luborsky's (1991) work with polio survivors. Campbell's model, however, does not provide direction for intervention.

With regard to the current state of research into aging with disability, Campbell (1996) concludes that " we need more knowledge of the dynamics of the disability experience, the changing needs of persons with disability and the role of the social environment in the disablement process" (p .2). Research that focuses on the experience of growing older with a disability can contribute to our knowledge in each of these areas.

Aging With Spinal Cord Injury

Most of the research done so far on aging with a SCI has focused on the effects of independent variables such as age at injury, chronological age, duration of injury, neurological outcome of injury, and environmental change on health, function, support, and quality of life. For example, studies using a variety of measurement tools, some developed specifically for SCI and others adapted for use with this population, have investigated life expectancies, changes in functional abilities, changes in support needs,

subjects' ratings of their quality of life, and causes of death (DeVivo, Shewchuk, Stover, Black, & Go, 1992; DeVivo & Stover, 1995; Frankel et al., 1998; Gerhart, Bergstrom, Charlifue, Menter, & Whiteneck, 1993; Whiteneck et al., 1992)

Investigators have attempted to identify and to quantify the changes that occur in health, function, quality of life, and support using cross sectional, longitudinal, or time lagged designs. However, each of these three research designs has limitations. Krause and Crewe (1991) point out that longitudinal designs cannot control for societal changes, medical advances, and cultural factors, and cannot separate the effects of duration of injury from those of chronological age. Cross-sectional designs cannot control for changes in the dependent variable that occur over time and time-lagged designs cannot control for the effect of duration of injury and chronological age. Therefore, it has been difficult to separate and to identify the effects of the independent variables.

Another problem encountered in the research done on aging with a SCI is the grouping together of several functionally distinct neurological outcomes such that their influence, subtle or otherwise, on the dependent variables is lost (Treischmann, 1987). Investigators also combine various durations of injury in the same sample thereby losing the impact of long durations of injury (Treischmann). Finally, the use of incentives to encourage participation and self reported data as well as the lack of power analyses also impinges on the value of much of the research done so far on aging with a SCI (Fuhrer, Rintala, Hart, Clearman, & Young, 1992; Krause, 1998; Treischmann).

Following the outline of health, function, support, and quality of life developed by Kemp (1998) to summarize the changes typically associated with aging with a disability, I will now review the results of the current research into aging with a SCI. I will redefine the changes in health, function, support, and quality of life, as necessary,

based on these findings.

Health. The earliest and most fundamental hypotheses concerning health and aging with SCI was developed by Ohry, Shemesh, and Rozin (1983). Their experience in SCI rehabilitation led them to state

that chronic spinal cord injured patients are prone to premature aging. Physical and mental disabilities and prolonged immobilization change the entire homeostatic mechanisms [sic] into a new state. Thus, we feel that this lead [sic] to accelerated aging among these chronic handicapped persons. (p. 467)

Recent research has provided some evidence to support this hypothesis.

Whiteneck et al. (1992) found that “the illnesses which are problematic for SCI survivors mirror those of the general population ...however, ...deaths among these SCI survivors—and the illnesses that lead to those deaths—are occurring at younger ages than one would expect within the nondisabled population” (p. 628). Whiteneck et al. commented that “there is a clear interplay between the normal aging process and the consequences of spinal cord injury” (p. 627).

Menter and Hudson (1995) speculate that aging with a SCI is the result of the interaction of chronological age, duration of injury, and the neurological outcome of the injury. They believe that these factors “must be merged and examined in terms of their impact on one another and their interrelationships” (Menter & Hudson, p. 279). Krause (1998) points out that environmental change also has an impact on aging with a SCI. He defines this as legislative or practice changes, such as the introduction of the Americans with Disabilities Act or the use of new assistive devices, that occur over time. It is generally accepted that as chronological age and duration of injury increase, health declines (McColl, Walker, Stirling, Wilkins, & Corey, 1997), and that specific health outcomes are determined by the neurological impairment caused by the SCI (Menter & Hudson). Environmental change appears to impact health in that the

longterm health outcomes are influenced in part by the rehabilitation goals of the decade in which the SCI occurred (Rodgers & Marini, 1994). For example, according to Rodgers and Marini, rehabilitation in the 1950s promoted a sedentary life style after SCI. Therefore, longterm health outcomes for those injured in the 1950s can include “obesity, increased cardiovascular disease, and increased smoking” (p. 98). Those injured in later decades may develop “entirely different patterns of aging” (p. 98).

Menter and Hudson (1995) expand the idea of accelerated aging by including overuse syndromes as a second cause of this phenomenon. They state that “the years following the SCI may be associated with an acceleration of the aging process... because of the increased demands made on still –functioning body systems” (Menter & Hudson, p. 273). However, the overuse of body components such as shoulder joints from pushing a manual wheelchair following SCI is better described as a physical change which leads to a functional change than as a cause of premature aging. In this example the functional change is the decreased ability to use a manual wheelchair.

Based on these ideas, in the context of aging with a SCI the changes in health are the development of premature aging and overuse syndromes.

Function. Cross-sectional studies of function and aging with SCI typically show that dependence increases with age and that this increase begins earlier than in the able-bodied population (DeVivo, et al., 1992; Gerhart et al., 1993; Menter et al, 1997). Gerhart et al. also found that dependence increases more quickly for those with quadriplegia than for those with paraplegia. Since cross-sectional studies can only measure differences at a single point in time, they cannot capture the impact of environmental change or duration of injury on function. Nor can they elucidate how function changes with time.

Longitudinal studies of function and aging with SCI are done less frequently

and are also unable to capture the effect of environmental changes on function.

Functional changes detected in longitudinal studies can be related to increased age or duration or to both. However, Charlifue, Gerhart, and Whiteneck (1998) found no link between age or duration and decreased function. This could be because their sample was skewed towards older subjects or because their analysis was not powerful enough to detect differences.

Earlier work found that the reasons for declines in function included weakness, shoulder pain, weight gain, and postural changes (Gerhart et al, 1993). A decline in function was also found to be linked to a decrease in perceived quality of life. Charlifue, et al. (1998) expanded on these findings. They found that the use of a foley catheter as well as certain types of pain and fatigue were predictors of decreased function. As well, they also found that participants with higher perceived quality of life were physically and functionally more independent, younger, weighed less, had less fatigue and had a more active social life.

Functional changes caused by overuse syndromes or “ increased demands on still-functioning body systems” (Menter & Hudson, 1995, p.273) are not specifically addressed in studies of aging with SCI. However, Maynard (1993) compares post-polio syndrome functional outcomes to those of aging with a SCI and comments that

the problems of chronic muscle overuse and progressive muscle weakening probably are not unique to individuals with a history of polio...[as] people with chronic SCI are likely to experience progressive weakening of those muscles with partial innervation, such as those which recovered strength slowly after the acute injury and which were used strenuously.(p. 192-193)

Maynard points out that not only systems with preserved function but also those with partially preserved function will be affected by overuse.

Declines in function that occur for those aging with SCI often result in the need

for new or modified equipment or assistance with activities of daily life (DeVivo, et al., 1992). Sometimes both are required. Maynard (1993) includes the learning of new skills and describes these three as “ options for responding to changes” (p. 195). Reassessment of quality of life and alterations in work, social, and family roles may also be necessary as function declines (Maynard). Charlifue et al. (1998) note that “ the issues...become those of adaptation and maintenance-adapting to changes that might diminish one’s quality of life and health and maintaining a satisfying level of function” (p. 46).

After reviewing what is currently known about function in the context of aging with a SCI, it is clear that increased dependence is the change that occurs most frequently.

Support. It seems reasonable that as new problems develop in health and in function as a result of aging with a SCI, support needs will change as well. As mentioned earlier, assistance with personal care may be required for the first time and equipment changes may be necessary (Maynard, 1993). Treischmann (1987) adds community support services, access to health resources, financial security, and role models to the list of necessary supports. Canupp, Waites, DeVivo, and Richards (1997) also found that appropriate local health resources are an important source of support for those aging with a SCI.

Ivie and DeVivo (1994) published an interesting study related to support and aging with SCI. These investigators attempted to develop a model that could predict those with SCI who are most at risk for unplanned rehospitalizations. Despite a cross-sectional design and subjects with durations of injury of only one to seven years, Ivie and DeVivo found evidence to suggest that ventilator use, foley catheter use and being dependent for mobility were risk factors for rehospitalization. They state that “our

results indicate the strongest measures of the risk of hospital readmission are measures of functional assessment as opposed to measures of neurological impairment” (p.1187). This is an important link to function and may indicate that individuals with these risk factors need additional support (Ivie & DeVivo).

McColl and Rosenthal (1994) studied the details of the “resource needs of aging spinal cord injured men” (p. 261). They found that emotional support, financial security, and health were important to their subjects. Those at risk for depression, decreased life satisfaction, and decreased adjustment to disability were concerned about their health, were less financially secure, and had less emotional support. In a later study, Pentland, McColl, and Rosenthal (1995) found that “as subjects lived longer with their SCI, they felt less financially secure” (p. 367).

Often a spouse is the primary source of support during aging with a SCI (Weitzenkamp, Gerhart, Charlifue, Whiteneck, and Savic, 1997). Parents can also fill this role (Treischmann, 1987). Unfortunately, as the spinal cord injured person ages so does his or her spouse or parents. Therefore, as time passes these informal caregivers are less and less able to provide the needed physical, emotional, or financial support to their loved ones. As a result it may become necessary to seek assistance from other individuals (Eisenberg & Saltz, 1991). Also, the toll of providing care may cause burnout (Weitzenkamp et al.). Therefore, family members may not be perpetual sources of support.

Based on the above review, in the context of aging with a SCI, the changes in support are the identification and the use of new resources.

Quality of Life. There is a popular misconception even today among both the general public and health professionals that life after SCI is not worth living

(Gerhart, 1997). This is unfortunate given that life expectancies and survival rates are increasing and a substantial number of people are aging with a SCI. Quality of life is an elusive concept and it must always be assessed from the point of view of the individual with the SCI (Gerhart). The consequence of doing otherwise is the “perpetuation of the message that death is better than life with SCI” (Gerhart, p. 82).

Quality of life after SCI has been researched for a number of years. Numerous quantitative studies have been done and several address quality of life and aging with SCI. However, as Dijkers (1997) points out, many quality of life studies of spinal cord injured individuals are seriously flawed. In a meta analysis of these studies, Dijkers found subjective measurements of the quality of life lacking as well as a number of methodological errors related to sampling and measurement. Despite these problems, the findings from these studies should be noted. Dijkers found that “the average person with a spinal cord injury experiences a lower quality of life than the average person without such injury” (p. 837). Krause (1997) provides a more detailed summary of results based on the study design used and states that:

cross-sectional studies suggest that chronological age is negatively correlated with post-SCI adjustment and time since injury is positively correlated with adjustment. Although the impacts of chronological age and time since injury tend to balance or neutralize each other, the only study to utilize time-lagged data suggested that broader environmental change will tip the scales toward more favorable adjustment over time, if environmental change is positive. Longitudinal studies have identified mostly positive changes in life adjustment over 11-year, 15-year, and 20-year periods...likely the result of cumulative influences of these three facets of aging. (p. 652)

Of more relevance and interest, given Gerhart's comments, are qualitative studies of quality of life after SCI. Boswell, Dawson, and Heining (1998) used focus groups to “examine the meaning of quality of life as defined by adults with paraplegia.

or quadriplegia” (p. 27). Analysis of their data revealed that for these subjects, “quality of life was characterized as a subjective construct that changes as people progress through the lifespan ... The experience of disability was...a catalyst for changing their perceptions of quality of life” (p. 29). Quality of life was influenced by resources available, employment, and attitude.

A qualitative study of quality of life done by Bach and McDaniel (1993) identified the components of quality of life for adults with quadriplegia. These subjects considered the components to be assertiveness, health, relationships, inner strength/survival, job/productivity, dependence/independence, level of activity, and finances. Based on their findings, Bach and McDaniel speculated that adjustment to SCI is continuous rather than finite and that dependence/independence as well as assertiveness were specifically connected to quality of life for those with a SCI. The same is likely true for those aging without SCI.

A review of the results of studies concerning quality of life and aging with a SCI, suggests that in the context of aging with a SCI, the changes in quality of life can be both increased adjustment and decreased adjustment to SCI.

While all this information is useful, it only addresses a narrow part of aging with a SCI. In fact when this body of knowledge is considered in its entirety, it becomes obvious that actually we know very little about this process. Few investigators have studied the experience of aging with a SCI. In order to understand aging with a SCI, we must use a holistic approach that includes this key component. In other words, the client’s perspective must be included in the study of aging with a SCI.

The Experience of Spinal Cord Injury

Little is known about the client's perspective or the experience of aging with a SCI, though some researchers have explored the experience of SCI. Oliver, Zarb, Silver, Moore, and Salsibury (1988) combined interviews and statistics to study the experience of SCI in the United Kingdom (U. K.). They set out "to describe the lives of people with spinal cord injury: to look at what happened to them at the time of their injury, on discharge from the spinal unit and at the time of the interview" (p. x). Oliver et al. point out that it is important to understand that "the consequences of SCI involves a complex relationship between the impaired individual, the social context within which the impairment occurs and the meanings available to individuals to enable them to make sense of what is happening" (p. 11). According to this group, "the central issue for the late twentieth century is not whether people with a spinal injury can be kept alive, but what kind of life they can expect" (p. 127).

Oliver et al. (1988) used a sample of 77 male patients aged 20 to 77 years from Stoke Mandeville with durations of injury of 2 to 15 years. The sample was almost equally divided into paraplegics and quadriplegics and interviews were used to capture the subjective experience of SCI. In order to capture the temporal nature of the experience of SCI, they chose to use the concept of *disability career* as their conceptual framework. This allowed them to not only consider SCI as more than a single isolated event but also to include what the SCI means to the individual. Such definitions were included in the framework because Oliver et al. believed that experience is a process which is managed by the attribution of meaning, via interactions with others, to events that occur. They state that "the meaning of SCI was an intervening variable between the extent of the individual's physical impairment and his or her social and material

circumstances" (p.13).

The outcome of this study was a consideration of what it is like to have a SCI in the U.K. and a critique of the services available and the rehabilitation approach used in the U.K. The interview excerpts presented in the discussion of the physical, social, financial, employment, leisure, and housing outcomes illuminate the experience of SCI. Individuals with a SCI talked about what happened to them and how they felt about it. Oliver et al.'s work put a human face on SCI.

For most of those interviewed in Oliver et al.'s (1988) study, change occurred in the areas of physical condition, relationships, independence, and self-image. They concluded that improvements in services were needed in order to assist individuals in the management of these changes. The four areas identified by Oliver et al. as those in which change occurs post SCI are similar to those later identified by Kemp (1998) as the areas in which change occurs during aging with a disability. Kemp's areas of change are health, support, function, and quality of life. Support encompasses relationships as does quality of life. Quality of life also involves self-image. Independence is part of function and physical condition is part of health.

Although Oliver et al. (1988) did not address aging in their study, the durations of injury they chose to use are similar to those used in many studies of aging with SCI. This highlights the need to focus specifically on the experience of aging and supports my earlier comment that duration of injury and aging with injury are difficult to separate. Future studies of the experience of aging with a SCI must clearly differentiate between duration and aging or include discussion of this issue as a limitation of the study.

Our lack of understanding of the experience of SCI was acknowledged by

Carpenter (1994) who developed a qualitative study to investigate this area. Carpenter interviewed ten subjects to collect information about the experience of SCI. The sample included six individuals with quadriplegia and four with paraplegia. These subjects were three to five years post injury at the time of the study.

Analysis of the data collected in the study, showed three “categories of descriptions or conceptions – rediscovering self, redefining self, and establishment of a new identity – by which meaning was made of the injury” (Carpenter, 1994, p. 619). Carpenter (1997) comments that “the continuity of ‘self’ was of primary importance to the ongoing experience of disability” (p. 551) and concludes that the results “provide strong evidence that, for individuals experiencing sudden onset of physical disability, the injury event is assimilated into a lifelong process and that within this continuum disability becomes integrated with the other demands of adult life” (Carpenter, 1994, p. 626).

Crewe (1997) explored the life stories of individuals with longterm SCI from a “personological” point of view and categorized them as ironic, tragic romantic, or comic. The personological approach was developed to “conduct personality research by constructing scientific biographies that could be analyzed and compared across people” (p. 27). Crewe collected qualitative and quantitative data using interviews and self rating tools. Crewe’s goal was to understand “the *experience* [italics added] of individuals who have lived with severe disability for many years” (p. 28). Crewe states

the contrasts between the four prototypic life storiesseem to demonstrate the validity of the hypothesis that the way in which a person adjusts to spinal cord injury reflects his or her long-standing, global perspective on life. The significant correlations between the psychometric inventories and the life story narrative form lend further support to the assertion that life stories can be [sic] studied and analyzed to provide a deeper understanding of adjustment to a disability such as SCI. (p.40)

Also in 1997, Scott examined the experience of SCI from the point of view of

adjustment using the qualitative research method of phenomenology. The experience of SCI was defined as beginning with injury and continuing until death and the durations of injury involved ranged from 5 to 25 years. All the individuals in this study had developed quadriplegia as a result of their spinal cord injuries. Scott acknowledges that the results of the study might have been different if those with paraplegia had participated.

Scott (1997), a proponent of the importance of both context and individuality in the experience of disability, found that a process of transition occurred during which the SCI became only one part of the whole person after an individual was injured. SCI was conceptualized as an unexpected transition. The transition included the phases of disorientation, rehabilitation, entering the community, and coasting and the final phase was a critical turning point. During the period of coasting there was limited activity until the individual made a conscious decision to turn his or her life around. Scott calls this the critical turning point and states that "the presence of a conscious decision to take action to reverse the negative situation is what distinguishes the critical turning point from other low points participants also experienced as very distressing" (p. 74). It is a point of change of attitude concerning life. It is noteworthy that Scott was careful to clarify that the phases "describe certain points in the experience that participants progressed through... They do not relate to passing through stages defined by emotional states and responses, although participants did speak about the emotions they experienced at these points of passage" (p.64).

When examining adjustment, Scott (1997) found that the participants had difficulty defining it. Most indicated that it was an ongoing individualized process that involved change and learning. The change was both external and internal in that it

included pursuing options, using positive thinking, and redeveloping self-esteem. Making changes was seen as moving forward and as the person moved forward or adjusted, “eventually adjustment has little or nothing to do with learning how to live as a person who has a disability, and simply becomes a part of the life of a person who happens to have a disability” (p.138).

Acceptance was considered a step towards adjustment but some participants adjusted without accepting what had happened to them. Scott discussed both adjustment and acceptance and explained the difference between the two as “adjustment was associated with movement, change, and learning. Accepting SCI was found to mean being fully cognizant of one’s situation” (p. ii). Scott also found that adjustment and acceptance did not occur in the rehabilitation setting. Participants commented that the rehabilitation setting was safe and that their real learning started when they returned to the community.

Crewe (1997), Scott (1997), Carpenter (1994), and Oliver et al.’s (1988) work is an exciting departure from the prevailing approach to research concerning SCI. As mentioned earlier, most studies done so far have focused on quantifying the changes in health, function, support, and quality of life that occur as the individual ages. The experience of aging has been investigated less because of the tradition of quantitative research in the field of rehabilitation and the lack of explicit subjective experience in models of disability. Both the medical and psychological models of disability locate disability within the individual (Marks, 1997) while “the social model locates disability ...in an excluding and oppressive social environment” (Marks, p. 88).

None of these models captures the subjective experience of disability. In fact there is debate among disability activists, some disabled themselves, as to whether the

subjective experience of disability is an appropriate topic for disability research (Thomas, 1999). While feminist disability researchers believe it is, others think that this experience is too personal to be explored and that a knowledge of the details of this experience would degrade rather than enlighten (Thomas).

The ICIDH framework was developed by the WHO “to contribute to the systematic organization of information about disablement to help narrow the gap between what health care systems can do and what they might do” (Peters, 1995, p. 135). This framework is purported to include subjective experience because disabled individuals contributed to the development of the framework and the definitions in the framework include the phrase, *in the context of health experience* (Badley, 1995; Peters, 1995). Peters (1995) believes that “implicit within the relational logic of the ICIDH ...is the domain of human experience” (p. 138). However, in order to ensure the inclusion of the experience of disability, Peters (1996) suggests a framework based on the ICIDH but expanded to explicitly include interactions, contexts and, perspectives. Peters describes this framework as “a novel integration of...perspectives on disablement;...the contexts within which disablement occurs; and...interaction among these perspectives and contexts” (p.593). Peters perspectives include the observer, the interventionist, and the individual experiencing the disability. His contexts are the person, the mind-body, and the society.

The ICIDH framework has recently been revised but has not yet been tested in the field (WHO, 1999). In this new version, the *disability* dimension has been removed and replaced by *activities* in order to better capture what a person is able to do and the phrase *in the context of health experience* has been replaced with the phrase *in the context of a health condition* (WHO). The basic use of the revised ICIDH will be to continue to quantify and to document the impact of illness on individuals. It still lacks

the component of the subjective experience of illness.

Peters (1996) proposed framework illustrates what Spencer (1993) believes is lacking in rehabilitation research. Spencer suggests that rehabilitation research must expand to include meaning, change, and context and that these three concepts cannot be captured via quantitative methods. In order to understand disablement, we must stop measuring and start observing and interviewing. Peters (1995) agrees and describes phenomenology, a qualitative research method, as an appropriate approach.

Clearly we must expand to use both a quantitative and a qualitative research approach if we are to add to our understanding of aging with SCI. Those living with SCI are growing older with their injuries. Only those aging with a SCI know what this entails. They want “a partnership between the professional and the person with the disability, one which acknowledges the expertise of the SCI [sic] in managing his or her own body for all these years” (Treischmann, 1992, p .60). Healthcare professionals must collaborate with and learn from individuals with SCI in order to provide them with the best possible care (Carpenter, 1994; Corbet, 1990). Paternalism and compliance have no place in this partnership (Carpenter; Corbet). Crewe (1993) describes this partnership when she states that it is

very important to these individuals that health and service providers respect and enhance their strengths rather than force them into molds that may better fit other situations...[as] their special characteristics include psychological adaptation to disability and change, development of expertise with respect to their own conditions, and accumulation of knowledge about systems and services. (p. 358)

Since the number of individuals aging with SCI is going to increase and these individuals will have continued interaction with the healthcare system, nurses will have increasing professional contact with these people. Consequently, nurses must

develop this partnership and in order to do so we must understand how individuals with SCI manage the process of aging. An even more compelling reason to develop this partnership is the fact that individuals with SCI are themselves worried about aging. Zejdlik and Forwell (1993) discovered in their survey of the concerns of those living with SCI in British Columbia that aging is a priority concern.

While information concerning new problems in health, function, support, and quality of life can provide direction for nursing care, this information is not enough to help nurses establish this partnership. Nurses must also understand how individuals with SCI manage the process of aging. Nurses must recognize that aging with a SCI is an interactive process (Campbell, 1996) that occurs in a context which includes individuals, society, and the environment (Campbell, 1996; Lauer & Handel, 1977). In other words aging with SCI occurs in the real world (Spencer, 1993). Lauer and Handel comment that

people live their lives in the presence of others influence and are influenced by them, understand their problems in terms of the others who are involved, and so on. All of this occurs in interaction, from the time of infancy until death. (p. 7)

They go on to point out that “interaction is not simply the *expression* of behavior, it is the *creator* of behavior” (Lauer & Handel, 1977, p. 305). To fully understand the process of aging with a SCI, it is necessary to examine it from this point of view.

Therefore, the most important research question becomes ‘What is it like to grow older with a SCI?’ and the individuals that can best answer this question are the longterm survivors of SCI (Treischmann, 1992). We must immerse ourselves in their world and ask them what changes have occurred in their health, function, support, and quality of life as they have aged with their SCI. We must find out how they have managed those changes as well as what new needs developed and how they were met.

Summary

Ironically at the very time that the population of those aging with a SCI is increasing, we are just beginning to realize how little we know about this process. The knowledge we have only serves to highlight what we do not know. We can identify four areas in which change occurs, but we cannot describe the process by which the change takes place. Furthermore, we have little insight into the experience of aging with a SCI and so we are also unable to understand what it is like to grow older with a SCI. At the very time that these individuals are living longer than ever before, healthcare providers have little to offer them.

Chapter Three: Methods

The review of the literature presented in Chapter Two suggests that aging with a SCI involves the following:

- 1) Change occurs in the areas of health, function, support, and quality of life,
- 2) Change in one areas triggers change in one or more of the other areas, and
- 3) Change results in the development of new needs.

The literature review also suggests that the meaning of the experience of aging with SCI for the individual will be revealed through interaction and the exploration of the context in which the experience occurs. Interaction and context must be the focus of further research in this area. In this chapter I will present the research plan I used to explore the experience of aging with a SCI from the perspective of interaction and context.

Methodology

It is through interactions with other people that we create the meaning by which we interpret our world, including how we think about ourselves and what we believe about ourselves. In fact, Lauer and Handel (1977) contend that these interactions actually determine our behavior. Oliver (1981) applies this idea to disability and comments that "the meaning that disability has for particular individuals will be created in interaction with both significant and generalised others" (p.53). Based on these ideas and the results of my literature review, I chose to use the qualitative research paradigm of social constructionism.

Qualitative research is well suited for explorations of meaning as it seeks to understand individual experience. It is interpretative in nature and qualitative

researchers acknowledge that they themselves are factors in their own studies. As a consequence, they seek to detail their thoughts, reactions, beliefs, and decisions during their work and recognize how these can influence the outcomes (Beck, 1993; Padgett, 1998; Sandelowski, 1986). Quantitative research focuses on causal models and seeks to explain the world around us.

So far much of the research done on aging with SCI and, in fact, on aging with a disability in general has been quantitative. Researchers have focused on quantifying the changes that occur during aging. While this has provided some interesting information, it has given us only a partial understanding of what happens. In order to expand our understanding of aging with SCI, we need an in-depth exploration of what happens. The literature review provides evidence that interaction and context will be important components of the experience of aging with a SCI. Therefore, a qualitative research approach that focuses on both is appropriate and social constructionism meets this criterion.

Social constructionism has its roots in the same ideas that led to the development of symbolic interactionism (Burr, 1994). It focuses on "the... intersubjectively shared, social constructions of meaning and knowledge" (Schwandt, 1994, p. 127) and does not support the existence of an objective reality so that "within social constructionism there can be no such thing as an objective fact" (Burr, p. 6). Symbolic interactionism, on the other hand, proposes that individuals "confront a[n] [objective] world that they must interpret in order to act" (Schwandt, p. 124). I chose to use social constructionism rather than symbolic interactionism because it supports the development of subjective contextual meaning and knowledge.

Social constructionism links the three key concepts of behavior, thinking, and interaction. In social constructionism, our behavior “is critically dependent on the cognitive processing of information, the world as it is cognized rather than the world as it is” (Gergen, 1985, p. 8). What we think and believe determine our behavior and both our thoughts and beliefs are created and maintained through interactions with others (Burr, 1994). Therefore, “the question of ‘why’ is answered not with a psychological state or process but with consideration of persons in relationships” (Gergen, p.12).

Social constructionism compels us to look at the individual and the meanings a person makes of his or her experiences within the context of the setting or situation. As a result, in order to fully capture both the relationships in an individual’s life and the meanings that develop from them, a research design that focuses on the individual and the context in which that individual exists must be used.

Method

A “case study is not a methodological choice, but a choice of object to be studied. We choose to study the case” (Stake, 1994, p. 236). I chose to use a case study design to answer the research question ‘What is it like to grow older with a SCI?’. A case study was an ideal venue to do this as it allowed me to describe the individual’s experience of growing older with a SCI both in depth and in context. This approach not only gave me access to the intimate details of the life of someone aging with a SCI but it also gave me an opportunity to ask questions and to explore those details.

According to Mariano (1993), a single case study design is best when the case is revelatory, critical, unique, or typical. The situation that I wanted to explore was both a typical case and a revelatory case. I wanted to study a typical person aging with

SCI to learn what the usual experience is like. A typical case offers the optimal way to explore a little known area. This meant that my participant had to meet certain selection criteria derived from my literature review. I will identify these criteria when I discuss the participant and his recruitment. The case study would also be revelatory since the experience of aging with a SCI has not been addressed. Qualitative studies have explored the experience of SCI and quantitative studies have listed the types and frequencies of the changes in health, function, support, and quality of life associated with aging with a SCI, but the experience of aging with a SCI has so far been unexplored.

Research Design

Recruitment. I worked with an individual and his network of significant others in this study. This individual was recruited through the Outpatient Program at the G. F. Strong Rehabilitation Center in Vancouver as G. F. Strong is the most likely source of comprehensive assistance available to those aging with a SCI in the Vancouver area. I asked the Outpatient Nurse to identify potential participants. This pool included individuals who have dealt with or are dealing with as many of the changes identified in the literature review as possible and were willing to discuss this experience. Based on my review of the literature, a typical individual aging with a SCI is one who must deal with some or all of the following:

- premature aging
- overuse syndromes
- increased dependence
- the identification and use of new resources,

- increased or decreased adjustment to injury.

The Outpatient Nurse was able to identify potential participants based on her clinical experience with outpatients.

The Outpatient Nurse contacted each potential participant via phone and asked if he or she would like more information concerning the study. I contacted the first individual who expressed an interest via phone to explain my study and to offer the opportunity to participate. I discussed my study with three potential participants. Two chose not to participate due to time constraints and I chose not to interview the third as she was awaiting surgery for a medical problem. Furthermore, based on my review of the literature, I determined that she was not a typical case. The Outpatient Nurse actually spoke to the eventual participant about my study in person after an assessment session. I contacted him by phone and then met with him and his wife to explain the study in further detail and to answer questions concerning ethical issues such as confidentiality. At that time he agreed to participate.

Participant. The participant in my case study is an individual who has lived 28 years with a SCI. At the time of the study he was 65 years old, paraplegic, and dependent on a wheelchair for mobility. He could communicate verbally in English without difficulty and did not have a brain injury or concurrently suffer from an illness such as, for example, depression or schizophrenia. This excluded any major diagnoses that may have confounded the data. These are also characteristics of the subjects in the studies discussed in the review of the literature.

Since the participant was 65 years old, the usual changes associated with aging had begun to occur for him. This was important in my study because I wanted to make

sure that the participant had actually experienced what we consider to be aging so that his interpretation of these changes could be explored. Some of the physical changes commonly associated with aging are a decreased ability to cope with physical exertion, the development of osteoarthritis, or changes in bowel and bladder function (Newman & Smith, 1991). Psychosocial changes can include loss, retirement, and changes in body image (Springhouse, 1997).

Data Collection. Data collection occurred via open ended and focused interviews in the participant's house, field notes, observation and the review of the participant's outpatient medical chart (Yin, 1994). A review of this chart provided further information concerning the management of changes that had occurred as the participant aged. In total seven interviews, each approximately one hour in length, were done with the participant and his wife and two were done with their sons. I had hoped to be able to review other sources of data as well as the study progressed including cards, letters, and personal tapes (Mariano, 1993; Stake, 1995; Yin), but these did not exist. Therefore, my data sources were the participant and his wife, their two sons and, my journal. I will discuss this journal shortly. "Multiple sources of evidence essentially provide multiple measures of the same phenomenon" (Yin, 1994, p. 92) which increases the accuracy of the findings, therefore, I chose to use more than one source of data.

Participant observation would have provided both a further source of data as well as a means to validate interview data. However, participant observation was not possible due to a skin problem that developed for the participant. This problem required prolonged bedrest so that opportunities for observation were significantly

curtailed. Therefore, I had to use observations made during our interviews and recorded in detail in my journal after each interview.

I first met with the participant and his wife on April 4, 2000, to explain the study and offer him the opportunity to participate. He decided to do so and he and his wife both read and signed the letters of consent. He was eager to begin so the first interview took place that evening. Please refer to Appendix A for the interview guide. I invited his wife to participate in this interview and she subsequently took part in each interview with her husband. During the study the participant relied on me to ask him questions. Only once did he volunteer information without being asked. He and his wife explained that they would have to rely on me to ask the questions because everything had happened so long ago and they had put it behind them.

I interviewed the participant and his wife seven times between April 4 to July 10, 2000. The interviewing continued until no new information was revealed. The three of us sat at the kitchen table in their home and talked. I was also able to interview his two sons twice. These interviews were organized for me by the participant's wife. She was the gatekeeper through whom I organized all contact with the family. One interview with the sons took place in the family room in the basement of the house. That interview lasted approximately one hour. The second interview took place over the telephone and lasted approximately half an hour. Please refer to Appendix A for the interview guide for other informants.

Initially the participant and his wife were reluctant to let me talk to their sons, saying that they did not want to inconvenience them. However, after the three of us were unable to find another data source, they agreed to the interviews. I met with the

sons to explain the study and at that time they each signed a consent form. The sons told me that they were very comfortable being interviewed. And during these interviews, the answers one gave often triggered further discussion from the other so that the interviews provided detailed information.

All interviews were tape recorded and transcribed except for the second interview with the participant's sons. Since this interview was conducted over the phone, I interviewed the sons one after the other rather than together and I recorded the interview in written notes. I also took detailed written notes during the chart review. The two interviews with the sons, the information supplied by the participant's wife, the review of his chart at G. F. Strong, and my observations of the interactions between the participant and his family provided the data from additional sources about his experience necessary to increase credibility. Credibility will be discussed in detail shortly.

All observations, expectations and assumptions concerning my findings, and my decisions and reactions during the data collection were recorded in my journal. The dependability of my study was thus increased. The transferability of my study was established by the collection of data from April to July. Again, detailed discussion of dependability and transferability will occur later in this chapter.

Data Analysis. Since this was an exploratory study the data collected was analyzed using the method of content analysis to identify themes, ideas, and concepts. Content analysis is a qualitative data analysis technique that allowed me to make "replicative and valid inferences from data to their context" (Krippendorff, 1980, p.21). In this case study the data included the transcriptions of the interviews as well as notes from

observations, and the document review while the context was the participant's experience of aging with a SCI. Rather than quantifying the specific components of the data, I analyzed the data to identify concepts, themes and ideas. Burns and Grove (1993) describe this as looking for latent meaning in search of "relationships among ideas, reality, and language" (p.597).

The data analysis followed the general procedures for qualitative data analysis outlined by Miles and Huberman (1994). Specifically, my data analysis included

- Affixing codes to a set of field notes drawn from observations or interviews
- Noting reflections or other remarks in the margin
- Sorting and shifting through these materials to identify similar phrases, relationships between variables, patterns, themes, distinct differences between subgroups, and common sequences
- Isolating these patterns and processes, commonalities, and differences, and taking them out to the field in the next wave of data collection
- Gradually elaborating a small set of generalizations that cover the consistencies discerned in the data base. (p. 9)

Data collection and analysis occurred concurrently. This began April 4, 2000 and continued through July 18, 2000. This time frame included the time necessary for the participant to review my conclusions.

I documented all my decision making during the data collection and analysis as well as my assumptions since my experience in SCI rehabilitation as well as my work experiences at G.F. Strong influenced these procedures (Mariano, 1993; Stake, 1995; Yin, 1994). For instance, my clinical experience led me to expect certain themes or ideas to appear in the data which could have tainted my analysis. Furthermore, the participant reviewed my interpretation of the data to ensure that it accurately captured

his experience of aging with a SCI (Yin, 1994). The result of my study is a written case study report which includes my interpretation of the subjective experience of aging with a SCI and implications for future research, education, and practice (Stake, 1995; Yin).

To address the issue of rigor in this case study, I included procedures to ensure that I conducted a trustworthy study as outlined by Padgett (1998). Specifically, I ensured that the study was credible, transferable, and dependable (Beck, 1993; Denzin, 1994; Sandelowski, 1986). Credibility can be defined as “how vivid and faithful the description of the phenomenon is” (Beck, 1993, p. 264). In order to increase credibility, I chose to collect data in three different ways-interview, observation, and document review. I also chose to increase credibility by having the participant review the results of my study and by recording my thoughts, behaviors, and reactions in a separate journal during the study. Sandelowski comments that

since a major threat to the truth value of a qualitative study lies in the closeness of the investigator-subject relationship, the credibility of qualitative research is enhanced when investigators describe and interpret their own behavior and experiences as researchers in relation to the behavior and experiences of subjects.(p.30)

Keeping these field notes allowed me to do this. Finally, I included detailed excerpts of data in my case study report to increase credibility.

Sandelowski (1986) and Beck (1993) suggest establishing the typicality of the data and making sure that “the findings of the study, whether in the form of description, explanation, or theory, ‘fit’ the data from which they are derived” (Sandelowski, p.32) in order to ensure the transferability of a qualitative study. I accomplished both by collecting data over an extended period of time. Data collection occurred over a period of seven weeks. In order to ensure that my case study met the

criterion of dependability, I documented all my decision making during data analysis so that another researcher could follow my analysis. For example, I recorded how I decide to code the data. I saved all my data and its analysis so that it could be reviewed by others as recommended by Beck (1993) and Sandelowski (1986).

The interviews with the participant were coded in the following manner. Each interview was read and reread to identify concepts and themes (Rubin & Rubin, 1995) as well as the concerns of the study participant (Stake, 1995). Rubin and Rubin suggest looking for frequently used terms and the opposites of these terms, vocabulary specific to the interviewee, and stories within the data. Following a strategy outlined by Rubin and Rubin, each theme, concept, or concern was given a label. It usually took four codings of each interview to ensure that all the codes were identified correctly and consistently as I found that I often went back to the interview and made changes in the coding.

As interviewing continued, each time a new code appeared, previous interviews were recoded. In this manner codes that appeared only once were eliminated, unless they were significant, and each interview was checked for each new code. This involved comparisons between interviews.

When the codes were finalized and the comparisons completed, all material with the same code was put into one group. Each group was identified as a concept. Then the content of each concept was checked to ensure consistency. Next each concept was compared to every other concept to make sure that each one was in fact a separate concept. A concept is "a term that abstractly describes and names an object or phenomenon, thus providing it with a separate identity or meaning" (Burns & Grove, 1993, p. 172). Several of the concepts were related to acceptance in that they

concerned coping, change, responses to SCI, and managing the wheelchair. These were grouped together as acceptance. Health included three concepts, health, chronic pain, and aches and pains. All of the support concepts were grouped together to become family as the participant felt his family had been his major source of support. The concepts concerning independence, life-style, self responsibility, and self reliance were put together as independence and everything related to aging became view of aging. Therefore, the finalized concepts in the data collected were acceptance, independence, health, family, and view of aging.

After the participant verified my identification of the concepts, I went back to the concepts to look for relationships between them. I returned to a theme, normalization, that I had seen early in the data but had put aside to avoid tainting the data collection with premature conclusions. I asked myself, what evidence is there that normalization occurred ? The concept of view of aging then became evidence of normalization as this concept included the participant's definition of aging and few references to the wheelchair. Further evidence included the participant's accomplishments and beliefs about himself. Normalization was identified as an outcome because it seemed to be what he was trying to achieve. The processes of minimizing the differences and redefining normal were identified in the data after asking, if normalization is an outcome, how does it occur ?

Acceptance was mentioned several times by the participant during our interviews. He described it as a process. A re-examination of the data revealed five reactions and a trigger that led to acceptance. The reactions took place in hospital and at home and the trigger occurred at home. Acceptance allows you to stop thinking

about your SCI. Given that the outcome of acceptance is the removal of SCI from your thoughts, I concluded that acceptance must occur before normalization can be achieved. Therefore, I defined acceptance as *the incorporation of SCI into life* and redefinition and minimization as *the reconstruction of the self*.

Independence and health appeared throughout the data as two things that are important to the participant. Therefore, I labeled them values and considered what if any role they might have, because of their importance to him, in acceptance, redefining normal, and minimizing the differences. He had clearly stated the role of health in acceptance. The role of independence was also clear. When considering the independence and health, I asked myself would a change in either or both health and independence have an effect on redefining normal or minimizing the differences ? This revealed their potential as sources of threats to these processes. The idea of a threat led me to consider how threats might be managed which in turn resulted in my conclusion that while acceptance is a finite process, redefinition and minimization are continuous.

Next I thought about where acceptance, redefinition, and minimization may have occurred. I considered that the participant and his family had only recently arrived in B.C. when he was injured. I combined this with his frequent referral to his wife and sons as supporting him. Then I realized that the three processes had occurred within the context of his family.

I kept a record of each coding of each interview. Questions that arose during coding were set aside for investigation during the next interview as were ideas that were generated during coding. These were both recorded on the interview transcripts. The interview data from the wife and sons as well as the data from the chart review were not coded as the experience in question is that of the participant not his wife or

sons or the interpretation of individuals documenting in his chart. Instead these data sources were read and used to provide more detail concerning his data. According to Stake (1995), document reviews are frequently used in this manner. I chose to treat the interview data in the same fashion.

During the data analysis I also kept a record in my journal of my reactions and decisions as well as an account of my coding procedures to increase dependability. I increased credibility by having the participant review the results of my identification of the concepts in the data for accuracy and confirm my interpretation of his experience. I included detailed excerpts of data to support my interpretation.

Ethical Issues. This section is a description of the procedures used to ensure informed consent and associated documentation as well as a protocol describing how confidentiality was maintained. The content was developed from Locke, Spirduso, and Silverman (1993).

An ethical review at the university, Vancouver Hospital and Health Sciences Center, and G.F. Strong was completed before any potential participants were approached. Each institution reviewed my case study proposal and granted me permission to conduct my study.

The participant was given a letter that introduced me, explained the study, detailed the expectations of the participant, discussed how confidentiality would be maintained, and described the presentation of results. This letter also contained the name and contact phone numbers of my advisor. In the letter I offered the participant an opportunity to meet a second time to discuss the study further and to answer questions. Informed consent was indicated by the participant's signature and my

signature on this letter. Each of us kept a copy of the letter. Please refer to Appendix B for a copy of this letter. Please refer to Appendix C for a copy of a similar letter that I used with the participant's wife and sons.

In order to provide confidentiality for both the participant and for his wife and sons, I did several things. First, I coded the information that I collected so that only my advisor and I know the identity of the parties involved. Next, I ensured that any notes or tape recordings were seen only by myself and my advisor and were kept in my home under lock and key. All data collected was destroyed at the end of the study. Finally, I removed all identifying information from the tapes before they were transcribed. The transcription was done by an independent typing service.

Summary

After reviewing what is known and what is not known about the experience of aging with a SCI, I chose a case study approach to increase our knowledge in this area. This research approach allowed me to explore the experience of aging with a SCI both in detail and in context and was supported by my research paradigm of social constructionism. I found my participant through the outpatient program for SCI clients at G.F. Strong. Using analysis of the interview and observational data I collected as well as the review of the chart, I have produced an interpretive description of the experience that has been verified by the participant. This description will provide direction for further research in aging with a disability.

Chapter Four: Findings

In this chapter I will describe the participant in detail and discuss my findings. These will include five reactions to the SCI, three processes and their outcomes, and two values. I will also discuss the contexts involved. Excerpts from the data collected will be included both to illuminate and to substantiate my findings.

My review of the participant's outpatient chart revealed that he was dealing with the recent onset of pain in his hands, arms, and shoulders. These had caused a decrease in his ability to transfer effectively in and out of his car and, consequently, a shear injury to his thigh. He contacted the Seating Clinic and the Outpatient Program at G. F. Strong for assistance with these issues. According to the professional documentation in his chart, the participant was dealing with the result of overuse of his hands, arms, and shoulders, an increase in dependence, and the identification and use of new resources. Based on the information in his chart and my review of the literature concerning aging with SCI, I expected to find someone enduring the physical and psychological changes of aging. However, I found a man who believes that he is aging just like everyone else. He believes that his SCI has made no difference in his experience of aging.

The Participant

The participant was a 65 year old man injured in a work related accident 28 years prior. I have given him the pseudonym John. John was treated in a Lower Mainland hospital and diagnosed as having paraplegia in 1972. The accident left him with a T 12 (12th thoracic vertebrae) paraplegia. He lost all function from the waist down. He is married with two sons. John and his wife are originally from the South

Pacific. At the time of the accident his sons were 10 and 12 years old. They are now in their thirties. The oldest son, his wife and their two young daughters live in the lower portion of the house. The other son and his wife live a short distance away in a home purchased for them by John and his wife. Both sons are professionally employed and John's wife is retired from a job in retail sales.

John was initially a carpenter but he had also worked in construction and driven trucks for a living. He felt that his opportunities and those of his children were limited in his native country so he decided that his children would have a university education and he and his family emigrated first to England and then to Canada to make this possible. He has always valued hard work and independence. John has saved for everything that he and his family needed. He does not like to have debts.

My interviews with John and his wife took place in the kitchen of their home. The room was always neat and tidy as was the rest of their home and the yard surrounding it. John was always well dressed and well groomed. He is a large man with gray hair and moustache. He is soft spoken and deferential.

John was located with the assistance of the Outpatient Nurse at G. F. Strong Rehabilitation Center as described in Chapter Three. He told me that he and his family had put his SCI behind them and that he was reluctant to talk about it. However, he chose to participate in my study because he wanted to give something back and he believed that the research was important. John's wife was also reluctant to talk about what had happened to John. But as our interviews progressed, she and John told me that they were very comfortable speaking to me. They also wanted me to know that they were giving thoughtful consideration to all my questions.

An Overview of John's Experience

John was treated for his SCI in an acute care setting and when medically stable and ready for rehabilitation he was transferred to G. F. Strong. There he learned how to look after himself. As well, he continued the friendships he had established with other patients in the acute care hospital. John worked hard and participated in all his therapy at G.F. Strong. His wife and two sons visited frequently and he enjoyed trips out of G.F. Strong accompanying them to places like the nearby shopping mall.

Before returning home from G. F. Strong when his rehabilitation was complete, John and his family purchased a new home that was more wheelchair accessible and this enabled John to go home for weekend passes. During these passes he practiced in the home setting what he had learned and began doing for himself at the rehabilitation center. This included bathing, dressing, and transferring himself as well emptying his bowel and bladder. As a result, John was physically independent when he left G. F. Strong.

Although John could have returned to school or to work or to both, for financial and physical reasons he chose not to do so. Instead, he stayed home and looked after his sons while his wife worked. He continued to provide for his family as he received payments from the Workers' Compensation Board.

Even with his SCI, John continued to do the things he had done around the house before his accident occurred. For example, he gardened, washed the car, did minor car repairs and painted the house. He also looked after his body and generally problem solved any issues that developed. Therefore, he had little contact with his doctor. John also traveled with his family to the South Pacific and to the United States.

Recently while seeking to improve his posture in his wheelchair John re-established contact with G. F. Strong and became an outpatient.

The Interpretation of the Experience of Aging With a Spinal Cord Injury

John's experience of aging with a SCI is a case of acceptance, redefining normal, and minimizing the differences between his pre and post injury self. Contrary to my expectation of finding suffering and change, I found a man who had made peace with what happened to him and continued on with his life. After his SCI occurred, John redefined normal and minimized the differences between his pre-injury self and his post-injury self to achieve normalization. John's accomplishments and his beliefs about himself and about aging are evidence of normalization. John's values of health and independence also provide evidence of normalization. Normalization happened because John accepted his SCI. Acceptance was connected to health and independence. Family was the context in which the three processes occurred. Please refer to figure 1 for the diagram of the reactions, processes, values, and outcomes.

Acceptance. Acceptance is the process which in some way allowed normalization to be achieved via redefining normal and minimizing the differences. For John, normalization could not occur without acceptance. First, he incorporated his SCI into his life and then normalization occurred. According to John, acceptance removed SCI from his thoughts.

Reacting to SCI. John came to acceptance by way of five reactions and a trigger. The first reaction, denial, occurred in the hospital shortly after his accident. John's initial concern was that half his body was not working. He thought he had at most five years to live. John says that during this time

we were reluctant to talk about anything because if anyone would talk about my injuries, and if I discussed it, that means I'm thinking that I'm not going to get well and walk again. And I was very definite that I'm going to walk again...just couldn't accept it.

During the second reaction, wanting to die, John found out that he would be in a wheelchair permanently. This reaction also occurred in hospital. John describes what happened as "when I first knew that I would ...be completely confined to wheelchair and wasn't too happy about it...was thinking remotely about kissing the world good-bye".

The third reaction, accepting responsibility, began when John came home from the hospital for a visit and saw his wife and sons. This was when he gave up the idea of killing himself. He explained that "the first weekend when they brought me home after six weeks in general hospital and when I looked at my children and my wife and everything and I said no I can't do that. I've got responsibilities".

When John came home after completing his rehabilitation, he says "everything didn't seem right. Everything seemed so gigantic. Nothing seemed manageable". He felt he was sitting in front of a big mountain. The big mountain was SCI and the changes associated with it. He sat in front of the mountain for two to three years. John explained that

you're traveling on a road and you come to a dead end and there's a big mountain there...of course you'll sit there and wonder how am I going to get around it and so some people will sit and wonder for a long time, some people will just say well I have to go back and find another way. I think I may be in the middle. I must have sat there for awhile, I think two- three years.

This was the fourth reaction. During this time John was in a cocoon. He felt totally lost. Everything he did was limited to being at home and only that time period was involved.

The fifth reaction, letting go, took place while John was sitting in front of the mountain. He decided that he had to take things as they came not as he wanted them to or expected them to. In others words, he gave up trying to control what was happening to him.

The Trigger. Acceptance was triggered by boredom. John needed to keep busy. He had always worked hard and been very active. With nothing to do and unable to concentrate on his former pastime of reading, he found himself worrying all day about being in a wheelchair. He looked around and noticed that housework needed to be done and his wife was at work. Therefore, he went against his upbringing and began to do household chores. John and his wife explained that in their culture men do not do housework. The men's role is to provide for the family. Women are responsible for the domestic work. However, when he did the laundry and the dishes, John found that the days flew by and he and his wife had more time together to talk.

At the same time John began to go out more. Initially he had found outings very uncomfortable. He had felt he was totally different and this had made him sweat and avoid eye contact with others. Then he said "I noticed that since I never used to notice anyone on wheelchair before, no one was noticing me, so that made me very comfortable". What happened next in his process of acceptance John described in the following manner.

It gradually takes about two-three months and then when you're reaching out...started going shopping...Then you find that oh, it's better than what you thought. And it's nice and now I...that so much time has been spent on staying at home. Then you reach out for more. I think then you gradually then picks up the momentum and then you're totally away from it.

He describes these results as coming out of the cocoon or finding a way around the big

mountain and says that “ it feels like a lot of weight has been taken off, your mind separates from it and you have other things to think about”. John has also considered the results of lack of acceptance. If you cannot accept SCI, then you are 100% disabled. It is very hard mentally as “anything you do is...no I can’t do that because I’m on wheelchair ...it clouds your thinking because you always keep on referring...to ...that...because of injury, because of injury”.

The Role of Health and Independence. John believes that his good physical health at the time of his SCI assisted him to accept his injury. He feels that physical health problems would have led to mental health problems and that these problems would have made acceptance difficult.

John did not directly refer to a role for independence in acceptance. However, he had considered what life would have been like if his hand and arm function had been lost or compromised by his SCI. He said that this would have meant the end of independence for him and he is grateful that he was able to maintain function in those areas of his body. He also explained his feelings about independence.

I’ve always been very independent...Like if something is out of my reach...a cup sitting there...I’d rather not ask somebody sitting there to pass it. I didn’t even want to ask somebody to hand me that cup. I am so independent that I would go and get it myself...that’s sort of heavy on me, if I have to ask my son to come and do this for me and all that...being on wheelchair for all 28, 29 years, it still bothers me if I have to ask them.

Therefore, although John does not specifically link acceptance and independence, given its importance to him it is likely that independence did have some role in acceptance.

Information from Sons. John’s sons also provided information concerning his

acceptance of his SCI. His younger son, Alan, a pseudonym, confirmed that acceptance began at home when his father was no longer under care. He describes a period of adjustment during which the family moved to a more accessible house. Alan feels that his father had a battle within himself during this period and he was hesitant to go out in public. Alan believes that his father reached a turning point when the family convinced him to get out of the car during a stop on a family vacation. It was here that John realized, according to Alan, that no one was staring at him or looking at him. From that point on, John became more confident and, as Alan explains it, he ventured out more. Alan also describes cycles of minor depression or asking "what if" at first. However, John denies that he spent time worrying or thinking about what might have been. He also says that he promised himself that he would never become depressed. The cycles Alan noticed could have taken place prior to acceptance when John was sitting at home with nothing to do.

John's older son, Chris, also a pseudonym, feels that John has always accepted his SCI. Chris also believes that John's feelings of responsibility for his wife and children led to his acceptance of his SCI and led to a better outcome. Chris also explained that it was important to his father that he never became a burden for his family and that he continue bringing money into the home. John's payments from Workers Compensation allowed him to do so.

Normalization. Normalization means "to make normal as by transformation, to make conform to or reduce to a norm or standard" (Webster's New Collegiate Dictionary, 1981, p. 776). For John normalization is the outcome of the reconstruction to normal of the self after a SCI. John believes aging with a SCI is no different than

aging in general. From the beginning of our time together, John felt that he might have little to tell me about aging with a SCI because he lives "almost like normal". His wife also believes this. She described the family as being just like everyone else.

John explains aging as moving from one branch of a tree to another.

you know, once I get the boys out of university, I think I've done my job...then I say no, I'll wait til they get married and after that I said, oh, I'd like to see grandchildren...and now I've looked at this grandchild. And I want to see him grow up a little more...so it's like a monkey swinging from branch to branch. You always have a lot of branch there to grab on to. The thing is before you leave that, there's something else there to grab onto.

SCI has no part in this description. Later in our discussions, John acknowledges his normalization by saying that he believes that if he can manage from the wheelchair, aging will be not be a problem.

Minimizing the Differences. For John, normalization occurred by minimizing the differences between his before SCI self and his after SCI self. Evidence of this is his referral to the wheelchair instead of to his SCI or to his injury, which are the most common ways of describing SCI noted in the literature. Instead he talks about the wheelchair which he views as just a way of getting around. This reinforces normality because the effects of SCI on his body are not acknowledged. John's adamant refusal to use an external urine collection device led to another example of minimizing the differences. His accomplishment of bladder emptying every few hours manages an alteration in the ability to void, one of the most significant outcomes of SCI, in a more normal manner.

John's accomplishments after his SCI are further evidence of normalization. John was very quick to list all of the things that he has accomplished when we began talking about his experience of aging with SCI. These included gardening, painting the

house, traveling, washing the car, building furniture, and making small repairs around the house. These are all things he would have done if his SCI had not occurred.

Therefore, the differences between his before and after self have again been minimized. His most important accomplishment was sending his two sons to university. This was a key accomplishment because it demonstrated to John that his

SCI made no difference in his ability to provide for his family. He explains that if I wasn't on wheelchair and I couldn't achieve that goal of sending them to university, it wouldn't have bothered me that much, but since I am on wheelchair now, if I can't achieve that, it becomes a defeat just because I'm on wheelchair...If I get defeated on this while I sit in that chair so much then I'll feel defeated. I did it more for myself, I think so.

Later, when checking my interpretation of his experience, John commented that achievement was important no matter what the difficulty involved. This confirms the importance of his accomplishments.

Normalization is also apparent in the fact that John does not believe that he became another type of person after his SCI occurred. He describes himself as being the same person only in a wheelchair now. He continues to use a previous behavior of comparing himself to other people and doing better than they are in order to feel good about himself. He uses this coping mechanism to prove to himself that the wheelchair makes no difference in his life as he gets older. Again he is minimizing the differences. John explains that

you look around and you say well I've done slightly better than people who are not on wheelchair. Like my friends and associates. So that gives you a lift...I always do slightly better...no matter what the effort it takes...because it makes me think that it doesn't matter that I'm on a wheelchair.

Minimizing the differences is also apparent in his belief that the aches and pains he has developed would have happened as he got older anyway and are not related to his SCI.

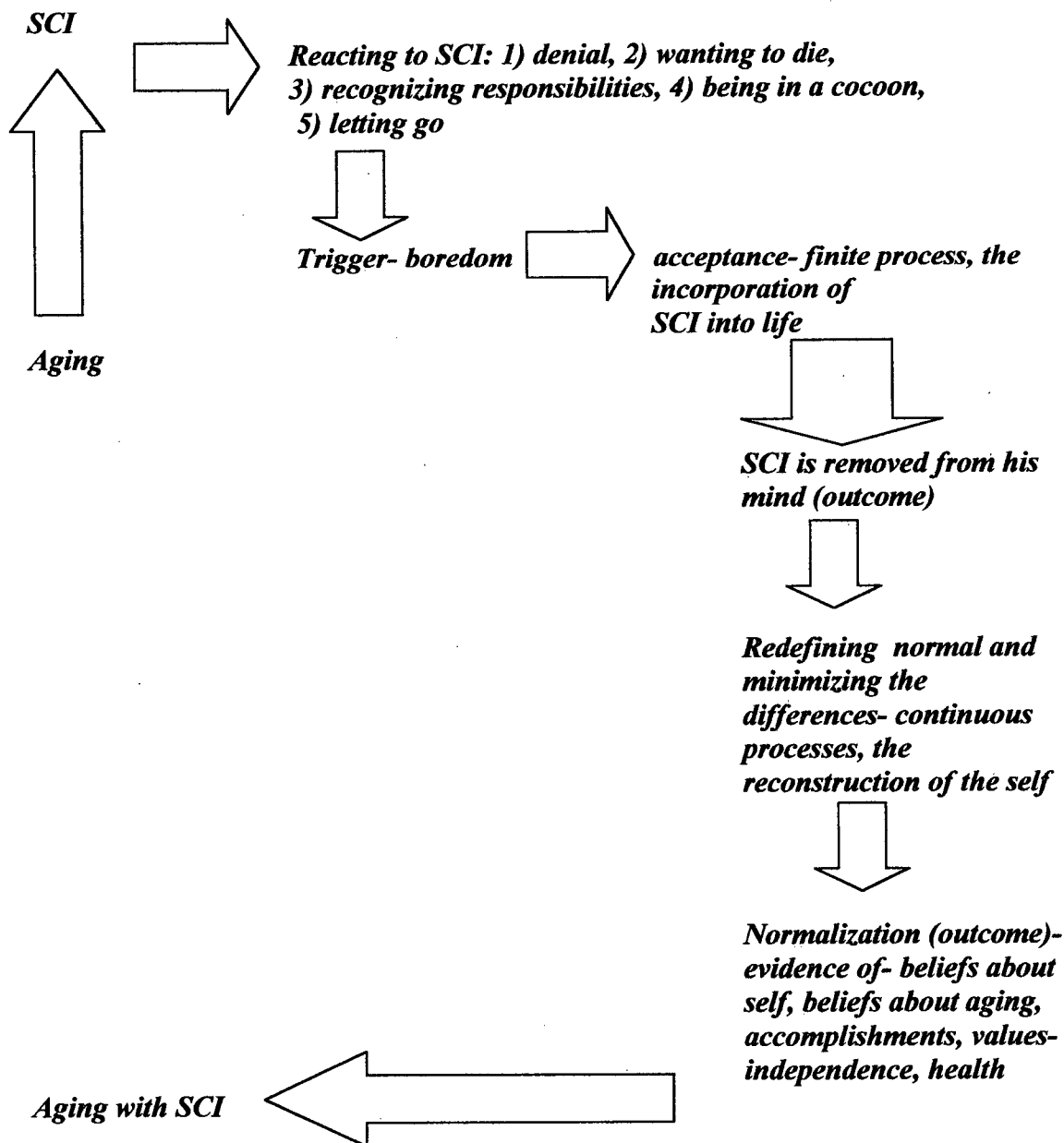


Figure 1: John's Experience of Aging With A Spinal Cord Injury

He says "I don't blame it for being paraplegic...this last Sunday I turned 65 and even if I was not on wheelchair, I'll still have aches and pains I think".

The fact that John has stayed away from G. F. Strong and has had little or no contact with others with SCI is also evidence of normalization. His peer group remained the same after his SCI and he minimized the difference between his pre – injury and post- injury self by avoiding contact with other people with SCI. He makes this clear in this comment.

my accident happened on March 5th. Before that I have other friends and associates and from the day I got injured...I didn't want to say that since March 5th I belong to this group now. So that used to bother me quite a bit and just being on wheelchair, I didn't want to accept that. I still liked my old friends and associates. ..I didn't want to categorize myself. Now, like, statistically I belong to their group now...I belong to general public and that's the way I think.

He has not maintained the friendships he made during his treatment and rehabilitation.

Redefining Normal. John also changed the standard for normalcy after his SCI occurred. He did this because although he minimized the differences between his pre injury and post injury self, he was not able to eliminate them. For instance, even though John was able to do things such as paint the house, wash the car, and travel after his SCI occurred, he had to develop new ways of accomplishing these things and he suffers from chronic back pain. As he was minimizing the differences he also redefined normal. He sees himself as a normal person in a wheelchair. He defines normalcy as getting back 70% of what you had before. Thirty per cent is the difference the wheelchair makes. For John the biggest impact of his SCI is not, as I suspected that he can no longer walk, but rather that travel is more complicated since more planning and preparation are now involved.

John's wife also provided information about the redefinition of normal. She

helped John to see their relationship after his SCI occurred as a partnership in which she is the legs and he is the brains. John comments on this partnership when he says "I always tease her my brain is all used up and she is still got a new brain because she never used it".

John's redefinition of normal also involves people other than his wife. Because he wanted to do everything himself, he said he felt very uncomfortable when he went out, when others tried to help by opening doors. However, he came to realize that if the roles were reversed, he would do the same for someone in a wheelchair. He was able to empathize with other people. Therefore, he included the acceptance of unsolicited help in his new definition of normal.

Threats to Redefining Normal and Minimizing the Differences. John values both health and independence. A value is defined as "an enduring belief that a specific mode of conduct or end-state of existence is personally or socially preferable to an opposite or converse mode of conduct or end-state of existence" (Rokeach, 1973, p. 5). John's main concerns about aging are the maintenance of his health and the maintenance of his independence. These are typical concerns of older adults. John is worried about developing cancer or diabetes or having a stroke as he ages. There is a history of cardiac problems in his family and he has already had two heart attacks. He has also seen his wife's health change as she has aged. In order to maintain his independence he has saved enough to ensure that he and his wife can remain in their own home as they get older. He is very clear that he and his wife will make their own decisions in this area. John explains that "we'd like to stay here...only we both can decide because I am quite secured. Like I own the property outright and we've got

sufficient amount RRSP and all that”.

However, the importance of health and independence also make these two areas a source of threats to his ability to redefine normal and minimize the differences. For example, John's current health problem with his skin has been difficult for him to manage both physically and emotionally. He developed a shear injury or scrape on the back of one thigh during a transfer out of his car and into his wheelchair. This is a common form of skin damage seen in those with SCI and if it is left untreated it can develop into a deep, open wound. John feels that his physician should have treated this area more quickly, but, he accepts some of the blame for postponing treatment. He allowed the treatment to be postponed, or in his words he “co-signed each delay”, because he knew that his recovery would involve some amount of bedrest to keep pressure off the site while it healed. This would have been a dramatic reminder of the physical affects of his SCI and threatened his vision of himself as being normal. John struggled to deal with the time he did have to stay in bed. It was so difficult that within the first few days he experienced a low level of depression.

The importance of being independent also made it an area of potential threats for redefining normal and minimizing the differences. After his SCI occurred John maintained his physical and financial independence. He had always saved for what he and his family needed. He paid cash and had no debts. He continued this after his injury and has saved enough so that he and his wife will be able to stay in their own home as they get older. Physically, John has been determined to use as few assistive devices as possible and has managed to do so. However, the recent onset of the aches and pains in his hands, arms, and shoulders has begun to affect his ability to be

physically independent. These aches and pains have limited his ability to garden, exercise, and transfer out of the car. In fact, when he goes out he plans his activities so that he only has to get out of the car once because of the pain and he has developed a sandbag device to assist him with that transfer.

As mentioned earlier, John believes that these aches and pains are the result of aging and are not related to the wheelchair. As long as he continues to attribute physical changes to aging rather than to his SCI, John will be able to see himself as normal. However, if changes develop that can not be conceptualized in this manner, John will have to use the mechanisms of minimizing the differences and redefining normal to manage them. If another change such as the increased dependence associated with his recent episode of bedrest arises that cannot be effectively managed by these two processes, John's vision of himself as normal will be threatened.

Information From Sons. John's sons also said that the SCI is not a factor in his life or in theirs. The younger son, Alan, commented that the family could care less about the wheelchair. They told me that as the years have gone by, they have noticed the wheelchair less and less and saw their dad more. They both think that John is as independent as possible. Chris, the older son, has noticed the onset of John's aches and pains. He says John has begun to ask for assistance more frequently. For instance, whenever possible Chris now helps John get out of the car and into his wheelchair.

Context. Although people outside his family had a role in redefining normal, in minimizing the differences, and in acceptance for the most part these processes occurred within his family. John described the rehabilitation center as a security zone and said "everybody else was on a wheelchair over there so there wasn't a challenge

there". At home he was confronted by the real world and he was also able to interact more consistently with his family. Thus the three processes had a context within which to occur.

According to Oliver (1981), significant others, in John's case these would be his wife and sons, have a fundamental role in creating the meaning of an individual's disability. John's wife's definition of their post SCI relationship as a combination of his brains and her legs is an example of this. Another example is how John's sons ignored his wheelchair. This led to the wheelchair becoming unimportant to John thereby contributing to his feelings of normalcy. During our interviews I had a chance to see that this message has been passed to the next generation, to John's grandchildren. I observed his granddaughter snuggling with him as she stood next to his wheelchair. Then she touched and played with the wheelchair as if it were a part of John. I also observed during my interviews and the few interactions between John and his family that I saw that little if any attention was paid to his wheelchair. John himself was always the focus of attention. Finally, I never saw anyone assisting John. He was always independent in his wheelchair.

John and his family also used their environment to create the meaning of his SCI. He had few modifications done to the house. He brought home only one or two items to use during his activities of daily living. He removes the handicap parking permit for his mirror when he drives. His sons say that John looks normal when he drives.

Part of John's family as the context for acceptance and normalization is due to the cultural importance of family to him. Family is a key part of an individual's life in

John's culture. Different generations often live together and the elderly are valued and respected. Geography also played a part in the creation of family as context however as John and his family were separated from extended family members and friends who lived in another country.

My interview with John's sons revealed many details concerning the creation of the meaning of John's SCI for him and for his family. In addition to the points already mentioned, his sons revealed that although John maintained his role as a father, he did so with the assistance of his sons because they took on some of the functions associated with that role that John was unable to do after his SCI occurred. Chris began checking the doors and windows in the house to ensure that they were locked each night before going to bed. This was something that John had always done. Both sons also took over some of the yard work that John had previously done. Both of them feel that John realized that they were doing things that typical teenagers did not do. As they got older John's sons also continued to seek his advice and to include him in as much as possible the activities they were doing around the house. In this way he never felt he was a burden. This was supported as mentioned earlier by his continued ability to bring an income into the house.

Chris and Alan also facilitate John's ability to travel. They do this by accompanying John and his wife on trips to help John deal with inaccessibility in other countries. John always pays for their travel expenses but does not ask them to go with him and his wife. The two of them also help John manage the environment at home. Both his sons modify the environment for John when they visit family or friends by removing small obstacles that could impede John's ability to move about in his

wheelchair. They do this automatically

In their interactions with others Chris and Alan also interpret their father's SCI. They describe him as retired because that is how they think of him. To his sons John is retired because he is not working any more. They do not think of him as disabled.

John and his family also used humor to create the meaning of his SCI. Alan and Chris believe that humor has been a major positive force in their family since John's accident. They have many stories of joking and laughing with their father about things that others might likely find upsetting. For example, John says that at least he'll never "kick the bucket". He was initially reluctant to travel home because there is a history of cannibalism in his country of origin and John jokes that he might have been mistaken for meals on wheels. Chris and Alan describe their home as an oasis for family and friends in the years following John's injury as there was always a barbecue or a party going on.

Finally, in regard to aging with his SCI, John's sons share his concern about aging in general. They, like John, are concerned about his getting older and staying healthy. His wheelchair and his SCI are not a part of this issue for Chris and Alan.

Overview of the Findings

One of the major findings of this study is that there may not be anything unusual or different about aging with a SCI. The literature review led me to believe that I would find an individual with special needs who was suffering through changes and problems as he or she got older. My experience as a rehabilitation nurse supported this belief. This was probably because my experience with people several years after the occurrence of their injuries has always involved health problems or changes in physical

abilities. Instead I found a person enjoying life who considers aging with a SCI to be nothing special. I suspect that only those having difficulties while aging make it into the literature because healthcare providers are too problem oriented and not interested enough in experience. Those doing well are overlooked since they often have little or no contact with the system.

A second finding arising from this study is that culture is an important factor in the experience of aging with a SCI as it is in the experience of aging in general. Since culture influences values and beliefs, it likely had a significant role in John's experience. He comes from a culture in which many generations of the family typically live together and in which elders are greatly respected. We know that family is culturally important to him. Further study is needed to determine how his values were shaped by his culture. A related area of interest is the role of family in general when dealing with SCI. How does culture influence the family's reactions ?

Finally, the individual's level of SCI may also be important in the experience of aging with a SCI. John has T 12 paraplegia. He has full use of his arms and hands and shoulders. Would the experience of aging be different for someone who did not have this function ? John believed it would have been different for him if he had had a higher level of SCI.

Summary

During a 13 week period of time I interviewed John in order to understand his experience of aging with a SCI. I also interviewed his wife and his two sons. I also completed a review of the documentation concerning his outpatient treatment at G.F. Strong. Unfortunately, I was unable to collect much observational data during this

time. Although John seemed, according to his outpatient chart, to be dealing with most of the complications associated with aging with a SCI found in the literature, I found him to be remarkably free of problems. In fact, he thinks of himself as a normal person growing older. John's family supports this belief.

After analyzing the data I collected, I found that John's experience of aging with a SCI was determined by three processes. The first was a finite process called acceptance during which his SCI was incorporated into his life. The second and third processes led to the outcome of normalization. These are the two continuous processes of minimizing the differences between John's pre-injury self and his post-injury self and redefining normal. They result in the reconstruction of the self. John's family was the context in which all three of these processes took place.

A precondition for the occurrence of acceptance was also found in John's experience of aging with a SCI. Before acceptance took place John went through five reactions to what had happened to him. These reactions were denial, wanting to die, recognizing responsibilities, being in a cocoon, and letting go.

Chapter Five: Discussion

After John's SCI occurred in 1972 he lost all function from the waist down. During his experience of aging with a SCI John incorporated this loss into his life removing SCI from his thoughts and allowing him to reconstruct himself. He calls the incorporation of SCI into his life acceptance. The reconstruction occurred via his minimization of the differences between his pre- and post- injury self and his redefinition of normal. The outcome of his reconstruction was normalization.

In this chapter I will examine the literature as it relates to John's experience. I will discuss the reactions that occurred prior to acceptance and the trigger for acceptance. I will also include a discussion of the minimization and redefinition that John did and the outcome of normalization. Finally, I will include the role of values and context.

What Happens Prior to Acceptance: Reacting to Spinal Cord Injury

John's five reactions are reminiscent of stages discussed in the literature concerning an individual's reaction to such things as disability, terminal illness, chronic illness, and loss. Examples of stages found in the literature usually include denial, shock, anger, depression, bargaining, and acceptance. Acceptance is considered to be the last stage.

Oliver (1981) labels the idea of stages as the psychological approach to the onset of disability and contends that the idea of stages was developed from the assumption that individuals undergo psychological changes in response to the physical changes that have happened to them when disability occurs. Oliver suggests that the stage theory of response to disability has been empirically validated in several studies

because the researchers expected to find the stages and because all of these studies begin from the perspective that disability is a problem. This is in fact the position from which I began my exploration of the experience of aging with a SCI. However, I soon found out that John and his family did not consider his SCI to be a problem. Yet I still found reactions similar to these stages in the data I collected. In fact, John's experience does reflect the general idea that acceptance is achieved last and only after the other stages have been completed.

Acceptance

For John, acceptance is a process in his experience of aging with a SCI. According to John, boredom was the trigger that caused acceptance to occur. He went through the reactions of denial, wanting to die, recognizing responsibilities, being in a cocoon, and letting go only to find himself sitting at home with nothing to do. Therefore, to keep busy and to stop worrying about his injury, John began to do housework while the children were at school and his wife was at work. As a result he started the process of acceptance. He described the process of acceptance as taking time, being difficult, and being very important. It was also finite.

As a result of acceptance, John felt that a great weight had been lifted from his shoulders and his SCI was removed from his thoughts. Everything improved for him after acceptance occurred including his relationship with his family and he was able to ignore his wheelchair.

Models of Acceptance

The literature concerning disability is complicated by the use of both adaptation and adjustment to refer to what John calls acceptance. In the following

discussion I will indicate which authors use adaptation and which use adjustment. I have defined acceptance, based on John's experience, as the incorporation of SCI into the life of the individual since the outcome is the removal of the SCI from his thoughts.

The Stage Model. The stage model of adjustment, adaptation, or acceptance is the predominant model concerning individual coping and the onset of disability (Livneh & Antonak, 1997). While the stages themselves have been determined, the order in which they occur is still uncertain (Livneh and Antonak 1990). Most researchers believe that the stages include anxiety, denial, depression, internalized anger, externalized anger, acknowledgement, and acceptance (Livneh, Antonak, & Gerhardt, 1999). The research is complicated, as mentioned previously, by the interchangeable use of terms, sometimes by the same individuals. For instance, Livneh and Antonak (1990) use the term adjustment and define it as "a reflective internalization (i.e., emotional acceptance) of the functional implications of an impairment into one's self-concept coupled with behavioral adaptation and social reintegration into the newly perceived life situation" (p.14). In later work, Livneh and Antonak (1991) use the term adaptation and state that "adaptation embodies assessing, coping with, and gradually assimilating various changes in body, self, and person-environment interactions necessitated by the disability" (p.299). Livneh and Antonak expanded the stage model to include individuality as they found that "people with disabilities may skip a particular adaptation phase, as well as regress to earlier phases, observations often associated with renewed life crises and unexpected medical relapses" (p. 316). This idea is expanded in the recurrent model of acceptance of disability.

The stage model has been criticized by a number of researchers on two crucial

points. The basic contentious issue is that the idea of stages implies a passive response on the part of the disabled person (Kendall & Buys, 1998). Despite the work of Linveh and Antonak (1991), the idea of stages seems predicated on the idea that individual or unique responses to disability do not occur. Everyone must go through the stages in order to successfully accept their disability. Hence, if you remain depressed or do not become depressed, for example, you are not coping effectively with what has happened to you. Secondly, the individual is the focus of this idea of stages and, as Oliver (1981) points out, the family, significant others, and society in general are not considered relevant. This suggests that disability occurs in a vacuum.

When considering acceptance of disability, Oliver (1981) is a strong proponent of the idea that individuals with disabilities create the meaning of their disabilities within the context of their families and significant others. Albrecht (1976) also believes this and takes it further by stating that

physical disability can be conceived of as an attribute of the entire family or of the society...Disability dramatically affects the interaction patterns of the family and its entire system of generation and allocation of resources...disability also influences the larger society. Whole industries, which not only provide health care, drugs, and prosthetics, and physical, speech, and occupational therapy, but also pay the bills, are built up around the problems of the disabled. (p. 26)

In order to address context and disability, Albrecht suggests expanding the unit of study from the individual to family and society. Certainly in my experience interviewing John and his family, I found that context was important not only as it related to the process of acceptance, but also as it pertained to the reactions that occurred for John before acceptance took place. John's first two reactions, denial and wanting to die, took place in the acute care hospital. Recognizing responsibilities and

being in a cocoon took place at home, as did the fifth reaction, letting go. Acceptance did not begin in the rehabilitation setting because it was safe there and he felt secure. Later, when he was discharged home to continuous exposure to the real world and to family, acceptance began. Linveh and Antonak (1990,1991) hint at a role for context in the stage model of the acceptance of disability and imply both context and interaction when they use the phrases social reintegration and person-environment interactions.

Commenting on passivity and acceptance, Olkin (1999) contends that “a belief in stage models of response to disability is a pernicious trap for clinicians” (p. 47). It can lead to the identification of individual responses as maladaptive and since in this model normal responses are thought to include such things as depression, the individual may not receive necessary treatment. Kendall and Buys (1998) suggest that the stage model may prompt some healthcare providers not only to expect but also to encourage responses such as depression. Others elaborate on the idea of passivity with their criticism that stage models of acceptance cannot account for the variety of experiences following the onset of acquired disability (Buckelew, Frank, Elliott, Chaney, & Hewett, 1991). However, stage models can be clinically useful as road maps to what might be seen in reaction to a disability. They are misleading when used to subordinate individual experience.

Vash (1981) suggests a somewhat different stage model concerned with adjustment to disability. According to Vash, the three phases or stages of recognition of the facts; acceptance of the limitations, and embracing the experience more adequately capture what happens for an individual with a disability. Vash describes the first two as levels of acknowledgment and the third as a “level that goes beyond the resumption of

normalcy to what might be construed as development into a higher consciousness-catalyzed in part, by the experience with disability” (p. 128). It is unclear whether Vash considers this model to be psychological in nature. Vash does however point out that few people achieve the final level of embracing the experience and that it is typically not seen in Western culture. Rather, embracing the experience is a component of Eastern beliefs. It is possible that John’s sons were referring to this when they told me that the occurrence of John’s SCI was actually a good thing for their family as they felt it was possible that without it they may have been different people.

The Value Model. The most notable model of the acceptance of acquired disability is that of Wright (1983). Wright acknowledges that reactions of shock, denial, anger, and others may occur in an initial crisis period and suggests that then the acceptance of loss, which is defined as seeing oneself as nondevalued, occurs via four value-related changes. Building on the work of earlier researchers in this area, Wright explores acceptance in detail through an analysis of each value change. These changes are “enlarging the scope of values,...subordinating physique relative to other values, ...containing disability effects, and...transforming comparative-status values into asset values” (p. 163).

Although Wright examines acceptance in detail, Keany and Glueckauf (1993) point out that this work lacks depth in several areas. For example, the concepts are not operationally defined, the value changes have not been tested, and the model is based on visible physical disabilities so that invisible disabilities are not considered. However, Wright’s model through the consideration of values does include reference to context. Wright discusses the individual’s desire to fit in, to achieve the norms or

standards set by society. In fact, the idea of devaluation is based on the fact that those with visible physical disabilities are different and different is not good.

Wright suggests that those with disabilities who “try to act as though the disability makes no difference, outdo himself or herself in maintaining normal standards, and in general appear as much as possible like a nonhandicapped person” (p.157) are actually feeling inferior to nondisabled individuals and have not accepted their disability. According to this idea, John has not accepted his SCI since he is concerned about being as normal as possible. However, I did not explore John’s values or how they developed in detail. I only know that he values health and independence and that his both helped him to accept his SCI. Therefore, any application of Wright’s model to John’s experience at this point would be premature.

The Recurrent Model. The recurrent model is exemplified by Yoshida’s (1993) pendulum model of adjustment to disability (Kendall & Buys, 1998). This model, like Wright’s, explores acceptance in detail. The recurrent model of acceptance involves the idea of changing the way in which the individual views the world. Specifically, Kendall and Buys propose that a disabled person is able to give up his previous ways of interpreting the world and himself and to develop new ways of understanding life as time and experience accumulate. This new understanding involves finding meaning, control, and mastery as well as a new identity.

In designing a recurrent model of the acceptance of acquired disability, Yoshida (1993) has drawn from previous research concerning chronic illness. Yoshida believes that acceptance of chronic illness and disability is a continuous life long process, that identity reconstruction involves combining the pre and post illness or disability selves,

and that the actions of others are important in maintaining the self. The overall process that Yoshida has developed from these points and her own research is called identity reconstruction. In John's experience, the reconstruction of the self occurred during the processes of redefining normal and minimizing of the differences. These processes occur after acceptance takes place and, in fact, they cannot occur until acceptance is finished. They result in normalization.

Yoshida's (1993) model is considered recurrent because it demonstrates that "identity reconstruction is a continuous, evolving, dual-directional process" (p. 241) rather than a finite process. The model was developed from interviews with survivors of SCI with durations of injury ranging from 1 to 22 years. The participants therefore included individuals aging with their SCI. According to Yoshida, during the acceptance of their spinal cord injuries and within the context of various experiences, the study participants moved back and forth between their pre-injury selves and their post-injury selves in their search for a new identity. While Yoshida found that acceptance was continuous, I found it to be finite and I found minimizing the differences and redefining normal, the processes by which normalization occurs for John, to be continuous.

There are three similarities between my research results and those of Yoshida (1993). First, context is important. In both cases significant changes occurred in the way individuals saw themselves after they left the rehabilitation center. For John this was when acceptance began. In Yoshida's study integration was involved. Yoshida states that

integration consists of two components: a process of reclaiming the lost aspects of the nondisabled self and an initial process of inclusion of the disabled self.

The most frequent period of integration was upon discharge from the hospital or rehabilitation center. (p. 232)

Also, both Yoshida and I discovered that significant others provided an important context. For John this was his family. Yoshida found that "significant others ...sustained the nondisabled self of respondents by maintaining a link between the respondent and their nondisabled world" (p. 232). In John's situation his family reminded him of his responsibilities. Second, both Yoshida and I found that unsolicited offers of assistance were not appreciated by our participants. In Yoshida's study this was associated with the supernormal version of the self in which participants "engage[d] in activities of an extraordinary nature requiring increased time and energy and/or the person refuses *any* assistance from others" (p. 226). I found a similar situation in that John initially refused the help of others because to him accepting that help meant that he could not manage on his own. Third, Yoshida found examples of something similar to the trigger for acceptance that John mentioned to me. Yoshida describes this in the following manner, "for...the vast majority of the ...respondents the decision to 'get on with their lives' became a pivotal point in their movement along the pendulum" (p.225).

The Transition Model. This is the model developed by Scott (1997), another proponent of the importance of both context and individuality in the experience of disability, and discussed in detail in Chapter Two.

Scott (1997) found that adjustment and acceptance did not occur in the rehabilitation setting. This is similar to what John experienced because for him acceptance took place at home. However, John did not differentiate between adjustment and acceptance. He spoke only of acceptance. For John it was a difficult

process that took time. Apart from his description of the outcome of acceptance as the removal of SCI from his thoughts, John did not mention any internal changes associated with acceptance. On the other hand, he does include gradually going out more as part of the process. This could be similar to Scott's finding of pursuing options.

Other similarities can also be found between Scott's (1997) findings and John's experience. For instance, some of Scott's participants considered suicide as did John. Participants also commented that the rehabilitation setting was safe and that their real learning started when they returned to the community. John experienced the same thing. Also, the participants in Scott's study mention a period that Scott calls "coasting" that is remarkably similar to John's experience of being in a cocoon and John's reaction of letting go when he decided to take things as they came not as he wanted them to or expected them to sounds like Scott's critical turning point. Both are a point of change of attitude concerning life.

The Self and Acceptance

Yoshida's (1993) is not the only work concerning the self and disability. Another interesting example that includes acceptance is the examination of the responses of individuals to burns. Although acceptance is not specifically discussed, Morse and O'Brien (1995) found that people critically injured and burned in accidents go through a four stage process of maintaining the self during their experience of recovery. This process includes acceptance of what has happened to them. Values are not discussed but context is important as Morse and O'Brien found that significant others were the link to the real world for participants during their recovery.

The purpose of Morse and O'Brien's (1995) work was "to examine the experience of traumatic injury, to describe the transformation from person, to victim, to patient, to disabled person" (p.887). Using grounded theory methodology they found that the basic social psychological process was preserving the self and that this occurred in hospital, in rehabilitation, and after discharge home. The final stage of the process described by Morse and O'Brien is "striving to regain the self: merging the old and the new reality" (p. 888). In this stage

the individual must preserve self by redefining the self. This includes making sense of the experience, learning to know and to trust the altered body, viewing life beyond the self, and accepting the consequences of the experience. The person learns to redefine the self as a disabled person, and to reformulate expectations of the self and expectations of one's future. (p.895)

This final stage in Morse and O'Brien's process sounds similar to what happened for John during his acceptance of his SCI. For example, John found things to do around the house, he began to go out, and gradually his SCI faded from his thoughts as it was incorporated into his life. It even includes elements of redefining normal, one of the next two processes that occurred for John after acceptance and that resulted in normalization. This suggests the possibility of further similarities between the experience of aging with a SCI and recovering from a traumatic burn injury.

The Trigger for Acceptance

In John's experience boredom was the trigger for acceptance. In Yoshida's (1993) study of the recurrent nature of acceptance of disability, the participants identified their trigger as the decision to get on with their lives. When investigating the experience of SCI, Scott (1997) identified a similar point in the lives of the individuals with SCI. This was the critical turning point.

The Role of Health and Independence in Acceptance

Values are alluded to in some of the models of acceptance or adjustment that I have discussed and in Wright's (1983) model they are considered fundamental elements. Values are also implied in the literature discussing the correlates of acceptance of disability. For instance, Brillhart (1986) looked at predictors of self-acceptance and found that knowledge of disability and perceived physical reality were significantly correlated with self-acceptance. These two variables were defined as

awareness of the etiology and prognosis of the disability and the self-care required to maintain or improve the level of health...[and] an accurate concept of the condition or a state of the body that has been determined by reality testing, observation, and the opinions of reliable authorities. (p.9)

John's described his values of health and independence as being important in acceptance. Brillhart's definition of knowledge of disability includes health and presumes an understanding of the level of independence associated with the disability. The definition of perceived physical reality also infers an understanding of independence in that it must include an understanding of what the individual can do and how he can do it.

Severity of disability was investigated by Woodrich and Patterson (1983) and found not to be linked to acceptance. They defined severity of disability in terms of the level of the SCI the individual had., e.g., paraplegia versus quadriplegia. The level of the SCI determines to a large extent the individual's ability to be physically independent. John had considered that he would have been less independent if his SCI had occurred at a higher level. Health and independence could be components of the severity of the disability since both would have an influence on the perceived severity.

John suggested this when he commented that poor physical health after his SCI would have made acceptance even more difficult for him because it would have led to mental problems.

After reviewing the literature with regard to acceptance and disability, several similarities to my research results concerning the experience of aging with a SCI became apparent. For instance, I found reactions similar to the stages noted in the literature. I also found similarities between my results and the four models of acceptance listed above and that John's values of health and independence could be related to correlates of acceptance. I discovered similarities concerning context and self and acceptance. Now I will review the similarities between the literature and my results concerning normalization.

Normalization

For John normalization was the outcome of minimizing the differences between his pre and post injury selves and redefining normal. These two processes took place for him after acceptance occurred, and consequently, they occurred outside the rehabilitation hospital and within his family.

Minimizing the differences and redefining normal encompass the reconstruction of the self for John after his SCI occurred. Unlike acceptance, minimizing the differences and redefining normal are continuous processes for John which are always working to manage the changes in his health or independence or both that may threaten his view of himself as normal. For now John has redefined normal as getting back 70% of what he had before his SCI occurred. Thirty per cent is the difference the chair makes.

John's normalization does not mean mainstreaming in the traditional use of the term. Rather John's normalization is consist with Olsen's (1985) idea of normalization and it also encompasses Wright's (1983) idolization of normal standards. For John normalization was the outcome he achieved after his SCI occurred and he had accepted it. Normalization is also the outcome he works towards as he ages with his SCI. John accomplishes normalization by minimizing the differences and redefining normal. Now I will discuss these processes and the information concerning them in the literature.

The Process of Minimizing the Differences

After John had accepted his SCI, he accomplished normalization via the use of two processes. John minimized the differences between his pre- and post- injury self by continuing to do things he would have done had he not been injured. These included sending his sons to university, gardening, painting, making small repairs around the house, and washing the car. He refers to the wheelchair as just a means of getting around and has managed to maintain as normal an appearance as possible in the wheelchair. Also, John does not believe he became a different person after his SCI. He describes himself as the same person only in a wheelchair now. He also stayed away from G. F. Strong until recently, had little or no contact with others with SCI, and maintained the same peer group he had before his SCI. Finally, John compares himself to others and does better than other people to prove to himself that the wheelchair makes no difference in his life. In these ways he has minimized the differences between his pre- and post- injury self.

The process of minimizing the differences did not begin for John until he was at

home with his family. His sons and his wife contributed to the minimization of the differences by ignoring John's wheelchair. His sons also facilitate his ability to travel and his ability to continue being a father. The outcome of normalization has been extended to include the entire family as John's wife described the family as being just like normal and his sons confirmed this belief.

In the literature I found that John's process of minimizing the differences is similar to a coping behavior used by families dealing with chronic illness. Following diagnosis of a chronic illness, families will "minimiz[e] its personal and social significance" (Robinson, 1993, p. 10). This is normalization. For John normalization was the outcome of minimizing the differences and redefining normal. In the literature, normalization is a process which can include both minimization and redefinition.

Normalization involves behavioral and cognitive components (Knafl & Deatrick, 1986) in an "interplay of defining and managing processes" (Deatrick, Knafl, & Murphy-Moore, 1999, p. 212). John's behavior in minimizing the differences reflects the published findings that after the diagnosis of a chronically ill child, parents will avoid contact with others with similar diagnoses, focus on a normal appearance for the child, and continue with the usual family activities (Knafl & Deatrick, 1986). John did not allow his SCI to change the activities he undertook, he did not associate with other individuals with SCI, and he made sure that he appeared as normal as possible in his wheelchair. Cognitively, he continued to see himself as the same person and he considered the wheelchair simply a means of getting around. Robinson (1993) calls this cognitive strategy using a normalcy lens to consciously focus on the remaining normal aspects of life following the child's diagnosis.

John's cognitive strategy of seeing the wheelchair as only a means of getting around is also similar to a normalizing strategy described by Robinson (1993) as choosing "a narrowed or constricted focus in order to encapsulate the problem" (p. 13). John focused only on the wheelchair. He rarely speaks of his SCI. The wheelchair is something that both John and his family are able to ignore, thereby minimizing the differences by avoiding acknowledgement of the physical changes that his SCI caused.

Similarities between John's minimizing the differences and the experience documented in the literature also extend to the timing of this process. In their recent revision of the concept, Deatrick, Knafl, and Murphy- Moore (1999) point out that normalization usually begins "after the uncertainty of the prediagnostic period has been resolved and the shock of the diagnosis has subsided" (p. 211). For John, diagnosis, denial, wanting to die, recognizing responsibilities, letting go, and acceptance had to occur before minimizing the differences could occur.

In John's experience of aging with a SCI, minimizing the differences is not the only means by which he achieved normalization. John also redefined normal. This process will be discussed next.

The Process of Redefining Normal

John used the redefinition of normal because although he was able to minimize the differences between his pre- and post- injury self, he could not eliminate them. For instance, even though John continued to do things such as wash the car, paint the house and travel; he had to find new ways to accomplish them. He sees himself as a normal person in a wheelchair.

In the literature concerning coping with chronic illness, redefining normal is a

strategy that is used to when normalization is not possible (Deatrick, Knafl, & Murphy-Moore, 1999). John could eliminate his wheelchair after his SCI. It became a permanent part of his life so he redefined normal to include the chair.

Carpenter (1994) also found a redefinition in the qualitative exploration of the experience of SCI. Participants in Carpenter's study redefined their spinal cord injuries as a challenge rather than a disability in an effort to discover and to fulfill their potential after their injuries occurred. They wanted to show the rehabilitation staff who had set limits on their post injury abilities that they were wrong. Essentially these participants wanted to prove that they were more than their SCI. Redefinition in this case did not involve normalization.

A renegotiation of normal was one of the types of successful rehabilitation outcomes that Phillips (1985) discovered. Phillips, unfortunately, does not elaborate on this finding so what renegotiation entails is unknown. However, Phillips does comment that the renegotiation of normal is used for personal rather than social success.

John accomplished normalization by minimizing the differences and redefining normal after his SCI occurred. Similarities can be found between the literature concerning chronic illness and John's experience even though in the context of chronic illness, normalization is considered to be a process. This same literature also includes threats to normalization. Threats will be considered next as they relate to John's experience.

Threats to Minimizing the Differences and Redefining Normal

Health and independence are important to John. So far he has been able to continue to see himself as normal because he has been able to attribute changes in

health or independence to aging rather than to his SCI. However, if changes develop in either health or independence or both that he cannot attribute to aging, he will have to manage them by using one or both of the processes of minimizing the differences and redefining normal. If he cannot manage a change effectively by using these processes, John's vision of himself as normal will be threatened.

In the literature threats to normalization as a process are discussed by some authors. In their early work concerning the concept of normalization, Knafl and Deatrick (1986) suggest that treatment programs for chronic conditions will threaten a family's normalization since attending such a program involves acknowledgement of a need to be there. Later, Deatrick, Knafl and Murphy- Moore (1999) point out "that certain family processes such as parental conflict or developmental transitions may threaten normalization" (p. 212). A third type of threat to normalization is the development of visible evidence of difference for the first time or a sudden increase in visible difference as might occur with multiple sclerosis (Gordon, Feldman, & Crose, 1998). The first type of threat is the only one relevant to John's experience. In John's experience, he avoided both treatment programs and other individuals with SCI. Avoiding contact with others was one way in which he minimized the differences between his pre and post injury self. However, he has recently initiated contact with the Outpatient Program at G. F. Strong for assistance with seating which means that he will have some contact with other individuals with SCI. However, it may be such limited contact that it does not threaten his minimization of the differences. This was an aspect of his experience that we did not explore.

Summary

After analyzing the data I collected from John concerning his experience of aging with a SCI, I returned to the literature to look for similarities between my results and those of other researchers. First, I compared John's reactions of denial, wanting to die, recognizing responsibility, being in a cocoon, and letting go to the stage model of acceptance of disability. I found that some of John's reactions were similar and that the sequence of events for John was also similar to that discussed in the literature. Next I reviewed the information available concerning acceptance and found that John's experience held similarities to each of the stage, value, transition, and recurrent models of acceptance. I also reviewed the literature with regard to the self and acceptance and found that John's experience was similar to that of burn victims. Finally I looked for the role of health and independence in acceptance. In this case I found no direct similarities. However, I discussed John's experience with health and independence as it related to research concerning the correlates of acceptance of disability.

When I examined the literature about normalization I found that while normalization was an outcome for John, it was discussed in the literature as a process. I also found that as a process, normalization was considered both useful and inappropriate (Olsen, 1985, Wright, 1983). John's experience was closer to the concept of normalization as a useful process as described by Olsen. When I looked at the processes of minimizing the differences and redefining normal that John used, I found similarities between John's experience and that of families with a chronically ill child. There were few references to redefinition and none to minimization in the disability literature. Therefore, while John's experience of aging with a SCI held many

similarities to the disability literature concerning acceptance and normalization, it was the literature about chronic illness and families in which I found the references to processes he used to achieve normalization.

Chapter Six: Implications, Limitations, and Recommendations

As a significant number of individuals with disabilities in Canada are living longer and actually aging with their disabilities, it is apparent that health care providers are poorly prepared to assist them. This is due to a lack of understanding of the experience of aging with a disability. For nurses, this lack of understanding can undermine the establishment of a nurse- client partnership to address the issues of aging with a disability. In an effort to increase nursing knowledge of this experience, I have designed and conducted a case study to investigate the experience of aging with a SCI. The results of this study indicate that for the individual with whom I worked, aging with a SCI is a case of acceptance, minimizing the differences and redefining normal. In this chapter I will discuss my conclusions and the implications of this study. I will also review the limitations of the study and make recommendations for the future.

Implications

The results of my exploration of the experience of aging with a SCI imply the importance of context in this experience. John's wife and sons as well as the "real world" provided the context in which the process of acceptance took place and are the context in which minimizing the differences between his pre- and post-injury self and redefining normal continue to occur. In other words, John's family has helped him to determine the meaning of his SCI. The information that John and his family provided is evidence that aging with disability and disability in general cannot be considered issues of the individual.

The objective of this case study was to describe the experience of aging with a

SCI and in doing so, to obtain a greater understanding of the process of aging with a disability. I assumed that the core of nursing practice with individuals aging with a disability would be the management of the changes involved in aging for them. However, based on the results of this study it appears that the process of aging with a disability may be simply be the process of aging. Therefore, instead of having special issues to be addressed, people aging with a disability may have issues common to those aging without a disability.

The results of my study also imply that normalization should be added to the literature concerning aging with a disability. Scheer and Luborsky (1991) report similar findings in their research concerning individuals experiencing post polio syndrome when they note that participants over 60 years of age considered the effects of this syndrome to be normal changes associated with aging. However, Scheer and Luborsky do not refer to this as normalization. Instead they describe it as a means of "bridg[ing] the social gap between the nondisabled and the disabled" (p. 1177). My findings clearly demonstrate a role for normalization in the experience of disability as it concerns aging.

Limitations

The lack of detailed information concerning both the role of John's culture in his experience of aging with a disability and the trigger for acceptance is the first limitation of this study. Although we briefly talked about his cultural background, John and I did not explore it in depth due to time constraints. I believe that culture had a significant role in his experience. This belief was supported by comments made by John's sons about their reactions to his SCI which indicated the impact of their culture.

Further exploration of the role of culture in John's experience would have increased the credibility of my study. Further detail concerning what triggered acceptance for John would also have increased the credibility.

The second limitation of this study involves the fact that few observations and no participant observations were included. This decreased the credibility of my study. A greater use of observations would likely have given me more data and a better understanding of John's experience. My lack of observations is in part due to the bed rest that John required following the treatment of his skin wound but it is also the result of my lack of experience in conducting qualitative research.

Recommendations

The following recommendations have been drawn from the results of this study.

Research. As I stated in Chapter Four the level of John's SCI probably influenced his experience of aging with his SCI. He had considered what might have happened if he had lost function in his upper extremities. He thought that this would have been the end of his independence. The level of injury is already included in quantitative studies concerning aging with a SCI. It must also be included in future qualitative studies. Case studies involving individuals with quadriplegia would be interesting.

Further research into the experience should also include participants who feel that they are aging successfully. So far the research concerning aging and SCI has taken a problem oriented approach which suggests that it is an unpleasant or difficult experience.

Finally, I support any research approach that recognizes and includes the significant others of the individual with the SCI. My findings indicated how important

these people are for John. The role they play can be explored further in case studies in which they are included as part of the case rather than secondary data sources.

Practice. The results of this study have indicated that the experience of aging with a SCI may not be any different from the experience of aging in general and that it is not necessarily an experience filled with problems. This means that practicing nurses should not assume that the individuals they see that are aging with a SCI will be suffering from a multitude of unique problems or that they will have problems at all. The results of this study also serve to remind nurses of the importance of significant others in the experience of disability in general. In fact, John's experience that acceptance began at home reinforces the need for a shift in perspective in rehabilitation from that of the professionals to that of the consumer with a subsequent reorganization of services (Barnes, Mercer, & Shakespeare, 1999; Carpenter, 1994; Scott, 1997).

Education. After completing this study I reflected on my nursing education. I do not remember much content concerning disabilities and certainly none concerning aging with a disability. Given that individuals with disabilities are now aging this is a deficiency that must be addressed. If not in official nursing programs then at least in orientation to the specialty practice area of rehabilitation nursing there must now be significant content related to aging with a disability.

Summary

I undertook this case study of the experience of aging with a SCI because the literature has focused almost exclusively on the quantitative aspects of aging with a SCI and has done so from a problem oriented approach. Quantitative research has revealed that changes occur in health, function, support, and quality of life as

individuals age with SCI. For instance, in the area of health, the changes are the development of premature aging and overuse syndromes. In the area of function, increased dependence occurs. The most frequent changes in support are the identification and the use of new resources. The changes in quality of life include both increased and decreased adjustment to SCI.

While this is all useful information, it does not tell us how individuals experience aging with a SCI. Based on my review of the literature concerning aging with SCI, I expected to find an individual dealing with several of the changes listed above. This expectation was supported by the professional documentation I found in John's outpatient chart at G.F. Strong. This documentation reflected the idea that the experience of aging with a SCI is problematic. However, the qualitative study I conducted revealed that the experience of aging with a SCI can be both positive and rewarding just like the experience of aging itself. This approach uncovered the personal aspects of aging with a SCI. John and his family believe that aging with SCI is no different than aging in general. John felt he might have little to tell me about his experience because he lives "almost like normal". At the same time, I discovered that the issue of culture and what leads to acceptance should be explored in depth in future research concerning the experience of aging with SCI. I also believe that future research must include significantly more observational data than I was able to collect.

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Appendix A

Interview Guide for Participant

Tell me what it has been like to live with SCI for such a long time.

What changes have you noticed in your :

- a) Health- better, worse, new problems, when did these changes occur?
- b) Function- more dependent, need more help with activities?
- c) Support Needs- who helps you, has this changed, what kind of help is most useful?
- d) Quality of life- how do you feel about your life, what do you enjoy?

How have you managed these changes?

Do you think that aging for you is different than aging for those without SCI ? In what ways?

Which has been more important for you as you have aged-your chronological age or your

duration of injury? Why?

Appendix A

Interview Guide for Other Informants

What is your connection to -----?

How have you assisted----- as he/she has aged with a SCI?

What changes have you noticed as ----- has aged?

How has ----- managed these changes?

How is aging for ----- different than aging for people without SCI?
?

Which do you think has been more important for -----as he/she
has

aged, his/her chronological age or his/her duration of injury? Why?

Appendix B

Informed Consent Form for the Study Participant

The Experience of Aging With a Spinal Cord Injury

Principal Investigator: JoAnn Perry, RN, PhD.
Assistant Professor
University of British Columbia School of Nursing
2211 Wesbrook Mall
Vancouver, B.C.
Phone: 822-7496

Co- Investigator: Melanie Forseng, RN, BSN
University of British Columbia School of Nursing
2211 Wesbrook Mall
Vancouver, B. C.
Phone: xxx-xxxx

Purpose

I am currently working on my Master's thesis in Nursing at the University of British Columbia. I am interested in exploring the experience of aging with a spinal cord injury from the point of view of the person with the injury. I have worked in spinal cord injury rehabilitation for several years at the G.F.Strong Rehabilitation Center and now I am a staff nurse on the Acquired Brain Injury Program there. I became interested in aging with a spinal cord injury when I realized that people are growing older with their injuries and nurses are lacking knowledge in this area. In order to provide effective healthcare to those aging with spinal cord injury, nurses must develop an understanding of what this experience is like. Therefore, I decided to conduct a study to expand our understanding of this experience

Procedures

My study involves interviewing and observing a person with SCI over a six to eight week period. The interviews will initially be at least one hour in length and will occur in a convenient private location. The information I collect in each interview will determine the questions I ask in the next interview as well as the length of the next interview. No interview will be longer than two hours. It is difficult to specify exactly how long the interviews will continue but I estimate nine to eleven interviews between April 4, 2000 to June 4, 2000. The observation will occur during the same time period and will involve observing the person during day to day life.

It is likely that I will also want to review the medical records or other personal materials of the person such as cards, letters, tapes, or journals and possibly interview friends, family, or others such as health care providers to clarify my understanding of the person's experience of aging with a spinal cord injury. I may also wish to observe the person with family, friends, or others.

There is no penalty for deciding not to become involved in this study. The study participant and anyone else participating in the study may remove any data from the study at any time and are free in fact to drop out of the study at any time. If a participant does drop out, any information collected from that person will be destroyed and the individual will not be penalized in any way.

Interviews will be tape recorded. I will write out my observations. All tapes will be manually destroyed at the end of the study. All coded data will be kept.

Once I have analyzed the data and prepared the description of the experience of aging with a spinal cord injury, I will ask the person to review the description to

ensure it is accurate and to give me feedback. Changes will be made based on the feedback I am given.

Confidentiality

The information I collect during the study will be coded so that only I and my advisor know the identity of the study participant and any other others who provide information. Any notes and tape recordings will seen by only myself and my advisor and will be kept in my home under lock and key. Any tape recordings will be transcribed by an independent typing service only after all identifying data has been removed.

Risk, Stress, or Discomfort

The risk involved in participating in this study is the occurrence of painful memories or feelings. If this in fact occurs, I will refer the person to appropriate professional resources.

Benefits

The potential benefits of participating in this study are the identification of and referral to new professional resources for assistance with problems.

Contact

Please contact me at 420-1438 or my advisor Dr. JoAnn Perry at 822-7496 at any time if you have any questions or concerns. I will be happy to meet with a second time to answer further questions or address additional concerns.

If you have any concerns about your rights or treatment as a research subject, please contact Dr. R. Spratley at 822-8598. Dr. Spratley is the Director of the UBC office of Research Services and Administration.

Participant Consent

I understand the information and conditions and explained above and I consent to participate in this study. I understand that participation is voluntary, that I may withdraw from the study at any time, and that there are no consequences for withdrawal. I have received a copy of this consent form.

Participant..... Date.....

Researcher..... Date.....

Witness..... Date.....

**Participant Consent for Review of Medical Records and
Personal Materials Such as Tapes, Cards, Letters, and Journals**

I consent to the review of my medical records and personal materials such as tapes, cards, letters, and journals during this study. I have received a copy of this consent form.

Participant.....Date.....

Researcher.....Date.....

Witness.....Date.....

Appendix C

Informed Consent Form for Other Informants

The Experience of Aging With a Spinal Cord Injury

Principal Investigator: JoAnn Perry, RN, PhD.
Assistant Professor
University of British Columbia School of Nursing
2211 Wesbrook Mall
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Phone: 822-7496

Co-Investigator: Melanie Forseng, RN, BSN
University of British Columbia School of Nursing
2211 Wesbrook Mall
Vancouver, B. C.
Phone: xxx-xxxx

Purpose

I am currently working on my Masters thesis in Nursing at the University of British Columbia. I am interested in exploring the experience of aging with a spinal cord injury (SCI) from the point of view of the person with the injury. I have worked in SCI rehabilitation for several years at the G.F. Strong Rehabilitation Center and now I am a staff nurse on the Acquired Brain Injury Program there. I became interested in aging with a SCI when I realized that people are growing older with their injuries and nurses are lacking knowledge in this area. In order to provide effective healthcare to those aging with SCI, nurses must develop an understanding of what this experience is like. Therefore, I decided to conduct a study to expand our understanding of this experience.

Procedures

My study involves interviewing and observing a person with SCI for six to eight weeks. I would also like to interview the family, friends, and frequent contacts of this person. Observation of the person with these individuals may also be necessary.

The interviews will initially be at least one hour in length and will occur in a convenient private location. The information I collect in each interview will determine the questions I ask in the next interview as well as the length of the next interview. No interview will be longer two hours. It is difficult to specify exactly how long the interviews will continue but I estimate one to two interviews each week between April 4, 2000 to June 16, 2000. During the same time I may wish to observe the person with family, friends, and frequent contacts.

In order to interview or to observe or to do both, I must have the permission of the person in the study. I must also have the permission of the other people involved. There is no penalty for refusing to participate. If you do wish to participate in this study, please be aware that you and the study participant can withdraw at any time. Both of you can also remove any data involving yourselves from the study at any time. If you decide to drop out of the study, your data will be destroyed and you will not be penalized in any way.

Interviews will be tape recorded. I will write out my observations. All tapes will be manually destroyed at the end of the study. All coded data will be kept.

Once I have analyzed the data and prepared the description of the experience of aging with a SCI, I will ask the person to review the description to ensure it is accurate and to give me feedback. Changes will be made based on the feedback I am

given.

Confidentiality

The information I collect during the study will be coded so that only I and my advisor know the identity of the person with the SCI and of any other participants. Any notes and tape recordings will be reviewed by only myself and my advisor and will be kept at my home under lock and key. Any tape recordings will be transcribed by an independent typing service only after any identifying data has been removed.

Risk, Stress, or Discomfort

During this study painful feelings or memories may be triggered. If this should occur, referral will be made to the appropriate professional resources.

Benefits

Possible benefits of participation in this study include the identification of and referral to new professional resources.

Contacts

If you have any questions regarding the study, please contact me at 420-1438 or my advisor Dr. JoAnn Perry at 822- 7496. I would be pleased to meet with you a second time to discuss further questions or additional concerns.

If you have concerns about your rights or your treatment as a research subject, please contact Dr. Richard Spratley at 822-8598. Dr. Spratley is the Director of the UBC office of Research Services and Administration.

Informant Consent

I understand and accept the conditions explained above and I choose to participate in this study. I understand that I may withdraw at any time and that there will be no consequences for doing so. I have received a copy of this consent form.

Informant..... Date.....

Researcher..... Date.....

Witness..... Date.....