

**“Subjective quality of life of persons with spinal cord injury, ages fifty and over: views
of persons with short and long durations of injury”**

by

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Abstract

Technology and increasingly sophisticated rehabilitation techniques have advanced to the point that life expectancy of persons who have had spinal cord injuries for long durations is approaching that of the general population. As such, a paucity of research exists on such 'aging' persons with spinal cord injury. This qualitative study compared subjective perceptions of quality of life among four persons, aged fifty, with durations of injury of twenty-five years or more, to those of four persons, aged fifty, with durations of injury of five years or less. Participants with long durations of injury were observed to emphasize maintenance of independence in establishing indicators of quality of life. In turn, participants with short durations of injury emphasized adjustment to living with a disability as an important indicator of quality of life. Participants with long durations of injury also rated their quality of life higher than their short-duration counterparts.

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For SM and MW, the ship

For EJ, the sail

For MK, the wheel

For AA, the wind

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Introduction

Subjective quality of life (QOL) can have several definitions. For example, it may be seen as a person's expectations and corresponding perceptions of whether or not those expectations were met (Duggan & Dijkers, 2001; Dijkers, 1997). More broadly put, subjective QOL may be seen as a person's own conception of whatever (s)he finds important (Kemp & Ettelson, 2001). However one may choose to define it, understanding the interpretations of QOL of aging persons with spinal cord injury (SCI) has increased in salience as their life expectancies approach those of the nondisabled population (Frankel *et al*, 1998).

The question for study was "what are perceptions of quality of life among persons with SCI aged 50 years and over, having injury for a short duration (5 years or less) or a long duration (25 years or more)?" This study's objectives were twofold: it first investigated definitions and subjective indicators that persons over the age of 50 with SCI used in understanding QOL. Secondly, persons over 50 with SCI were asked to evaluate their QOL using the indicators that they had each constructed. It then compared the findings between participants who had had a SCI for short- and long-term durations. A short-term duration was classified as having had a SCI for five years or less. Participants with SCI for twenty-five years or more were considered to be long-duration survivors. Four short-duration and four long-duration participants were chosen for the study. The aim was to understand how duration of injury interplayed with participants' experiences of an 'aging process.' Grounded theory methodology was used to analyze the corresponding social processes that occurred between the participants and others in their lives, and the environment around them. All participants were current or former

outpatients of the Spinal Cord Rehab Program at Lyndhurst Centre in the Toronto Rehabilitation Institute.

Importance of the study

This study on subjective QOL while aging with SCI challenged professional medical dominance by privileging people with SCI with the power to discuss issues that they find important (Boschen et al., 2003). Few qualitative studies investigating subjective QOL among persons with SCI exist (Duggan & Dijkers, 2001; Boswell et al., 1998); the number of qualitative studies involving persons with SCI over 50 years of age remains low as well (Zarb et al., 1990; Morris, 1989). Thus, this investigation attempted to bridge a gap between subjective QOL indicators and aging with SCI. It was hoped that data from two cohorts with different durations of injury would shed light on their respective daily experiences.

Rehabilitation research and objective QOL

Issues in aging with SCI have become more important in recent years because of increased life expectancies of persons with SCI. While life expectancy after SCI in the 1940s and 1950s was one to ten years, it has now increased to approximately 85%-90% of that enjoyed by a person without SCI (Kemp & Ettelson, 2001: 116). Improved emergency medical services (Frankel et al., 1998; Menter, 1993) and advancements in rehabilitation technology have brought about a decline in premature mortality rates, specifically from respiratory and renal ailments (Zarb et al., 1990; Oliver et al., 1989; McColl et al., 1997). While this medical achievement is laudable, a concern arises as to

how information about aging issues for persons with SCI is presented. The medical model of disability that much of the rehabilitation literature adopts is inadequate in explaining all aspects of SCI; and rightly so, for the rehabilitative element of SCI is only one aspect of a person's disability.

The medical model of disability posits a person with impairment as the recipient of an abnormality or deficiency. All too often, the impairment then becomes his/her singular representation to others (Barnes et al., 1999). In addition, emphasis on the medical model transforms an impaired person's life into a victimized 'personal tragedy' that iterates the need for pity (Barnes et al., 1999). A person with SCI, in this case, is portrayed as ill. His/her actions are circumscribed within a dynamic of care and dependence on others. The corresponding societal disadvantage through impairment, then, is considered surmountable only through the fortitude to surpass one's limitations, or by the removal or rehabilitation of the bodily complication (Crow, 1996).

The state of their health, however, is only one facet within the lives of persons with SCI. Other variables may include educational or employment status, material possessions obtained, spiritual development, or positive value changes over time (Duggan & Dijkers, 2001; Tate et al, 2002). Clearly, the rehabilitation literature revolving around aging with SCI has important uses. It informs lay people and health practitioners of the various biophysical conditions that manifest themselves as people age, and it brings research advances and theories together in proposing new ways to treat SCI. More often than not, however, many health professionals who work with current SCI clientele are most interested in immediate physiological problems as opposed to longer-term issues

(Adkins, 2001). This would indicate why rehabilitation research on intervention of physiological complications associated with SCI often gains priority over aging issues.

Medicalization has become the dominant construct of disability, with health professionals privileged as experts. Professionals may indeed be proficient at stabilizing the health of people's bodies upon impairment or prescribing appropriate treatments. Yet they are not equipped to make judgments regarding the societal impacts of disability upon persons with SCI (Oliver, 1996; Oliver *et al.*, 1989). Until recently (e.g., see Fougereyrollas *et al.*, 2002; Boschen *et al.*, 2003), SCI rehabilitation literature had primarily used clinical quantitative research models (Chenail & Maione, 1997), employing the medical approach to disability as a means of investigating aging persons with SCI.

The most extensive clinical literature on QOL with SCI addressed psychological and emotional impacts, including coping, depression, and disability acceptance (e.g., see Craig *et al.*, 1999; Krause, 1998; Tate *et al.*, 1993). These studies largely investigated QOL with SCI based on objective indicators. As opposed to subjective, participant-driven notions of QOL, objective QOL indicators were supposedly constructed from values that were deemed to have 'universal' societal significance (Dijkers, 1997). These include income, employment, education, and social relationships. Such objective QOL indicators, however, tended to ignore the wealth of human experience that exists (Clayton & Chubon, 1994) outside of 'achievements' such as a good job, post-secondary education, or meaningful friendships.

Short- and long-term durations of SCI among aging persons

This study's importance may also be seen in its analysis of two groups of persons with SCI: those who have had a SCI for twenty-five years or longer, and those with a SCI for five years or less. Importantly, these participants were not considered to be 'aging' per se for the purposes of this study; this was because a sample of young participants was not used to support that those who were over 50 years of age were indeed aging.

Nevertheless, several studies had suggested that persons 50 years of age and over with SCI were considered to be aging. These studies had attempted to measure QOL of persons with SCI in relation to their age and duration of injury. For example, Whiteneck et al. (1992) observed that QOL and life satisfaction of the participants with SCI in their study decreased as they reached fifty years of age and had their injury longer than thirty years. In another investigation, life satisfaction and QOL issues such as economic and marital wellbeing were found to increase for participants fifteen years after the onset of their SCI (Krause, 1992). Their average age of forty-five at the time of the study, however, was below that of the participants of Whiteneck et al. Also, Eisenberg and Saltz (1991) concluded that persons who had had a SCI from the ages of forty-five to fifty-four for longer than twenty years expressed the lowest life satisfaction. Finally, Pentland et al. (1995) classified persons with SCI over fifty as 'old' in a cross-sectional QOL study. For participants with a long duration of injury, then, it was estimated that an age requirement of fifty years and SCI duration of twenty-five years would have provided a sufficient window of time in which participants would have commenced the aging process. That is, they would have begun experiencing the physiological and social effects of aging.

Concomitantly, the selection of participants with short durations of SCI was predicated on a number of studies. Krause (1998) found a negative correlation between age at time of injury and life adjustment, quality of health and activity levels. Persons over 40 (the oldest group) experienced the lowest degrees of adjustment. Another study investigating persons forty-five years or older and with a SCI for at least fifteen years concurred with the previous findings: decreased life satisfaction was found to be related to both increased age and shorter duration of SCI (McColl & Rosenthal, 1994). As a result, older participants with SCI for a short duration were probably experiencing a lower QOL than those with a long-term injury.

Based on these reports, criteria for selection of participants for this study indicated an expectation that they would be experiencing decreased QOL. Those with long-term SCI may have reached a plateau in their QOL. Participants with short durations of SCI, on the other hand, may have still been trying to adjust to their environment, relationships with others, and their injuries. The justification was that one expressed aim of this study was to comprehend how age and SCI interplayed in causing lowered perceptions of QOL.

Literature review

Introduction

This literature review will first address the ways in which QOL can be observed, specifically within studies that investigate objective and subjective QOL. Adjustment to disability and SCI is next discussed. This is crucial in understanding how a person's QOL with SCI is impacted. Addressing the topic of aging with SCI illuminates various ambiguities that manifest themselves in trying to establish how chronological age, duration of injury and age at time of injury interact to produce aging with SCI. The review concludes with an investigation of the various socioeconomic resources that persons with SCI utilize in pursuing satisfactory QOL and the implications of SCI for aging women.

Quality of life: frameworks of measurement for persons with SCI

Quality of life is a vague concept and difficult to define, with its meaning hinging on the research context in which it is used (Veenhoven, 2000; Dijkers, 2005). For example, Rejeski and Mihalko (2001: 24) differentiate between the use of QOL as a psychological conception of wellbeing and as an "umbrella term" for preferred medical outcomes. Dijkers (1997) iterates that QOL can be related to wellbeing in terms of materiel, functioning of the body, quality/quantity of interpersonal relations, or life satisfaction.

Uses of QOL studies include estimating rehabilitation progress and program efficacy, measuring the life quality of various disability groups to set priorities for resource allocation within organizations, and understanding how perceptions quality of

life differ among persons with disability (Clayton & Chubon, 1994). QOL studies may generally be divided into two groups: those using objective and subjective measures. Consensus among SCI research suggests that objective measures are more suitable for examining QOL on a societal scale, while subjective measures are best for investigating QOL on an individual level (Kemp & Ettelson, 2001).

Objective indicators include physical and psychological functioning, income, and employment (Clayton & Chubon, 1994). Participants who score high in these indicators are assumed to have a better QOL than those who score lower. This assumption, however, can lead to erroneous conclusions. For example, a high income is not necessarily an indicator of a high QOL (Flanagan, 1978). As well, individuals' perceptions of their behaviour may indeed be more powerful than the actual behaviour when appraising their health status (Anson et al., 1993). For example, in Anson et al.'s study (1993), some participants who had assigned themselves the highest possible score in terms of giving support to the community had, in turn, indicated that they were not currently participating very much, but had the desire to do much more. This subtle difference between action and intention as expressed in an individual's self-rating may prove difficult to discern within an objective QOL study; it would appear easier in a qualitative investigation that examined both a person's actions and the reasons behind them.

Subjective QOL studies, however, investigate people's perceptions of how well they are progressing with regard to various life indicators. Their perceptions are often measured using rating systems. Subjective QOL studies are important in that a person's

situational meaning is ascribed to their results (Clayton & Chubon, 1994; Duggan & Dijkers, 2001). In one of the first subjective QOL studies, Flanagan (1978) attempted to establish what most American's considered QOL to be by examining 6,500 critical incidents from across the United States. Criteria such as physical and material wellbeing, relationships, and personal development were constructed, along with more specific sub-categories (Flanagan, 1978). Next, a survey involving the ranking of these criteria using Likert scales was administered. Flanagan's approach employed to understand subjective QOL is reflected in studies at the Rehabilitation Research and Training Centre (RRTC) on Aging with a Disability. Researchers use a seven-point Likert scale, asking respondents to rank their QOL from 1 to 7. One is a negative rating and implies distress, while 7 implies satisfaction (Kemp, 2004). From this, questions from a range of topics relating to QOL with SCI can be asked; for example, "How do people with disabilities compare to able-bodied people? Which factors best describe people having low QOL versus high QOL? How do objective factors, such as severity of disability, relate to this subjective measure?" (Kemp, 2004: 52).

Recent research has further segmented the study of QOL according to desired outcomes of data usage; that is, what exactly are objective and subjective measures looking for? Subjective QOL is seen as the midpoint in connecting individuals' expectations and priorities, or goals and values, with achievements such as accomplishments, health, relationships, status, and acquired possessions (Duggan & Dijkers, 2001; Dijkers, 2005). The views of the 'insider,' or participant, are paramount. Subjective QOL can be measured as life satisfaction, self-esteem, or negative-positive

affect (Duggan & Dijkers, 2001; Dijkers, 2005). Taken together, these aspects of measurement constitute QOL as subjective wellbeing, or “the sum total of cognitive and emotional reactions that people experience when they compare what they have and do in life with their aspirations, needs, and other expectations” (Dijkers, 2005: Conceptualizations section). Objective evaluations, on the other hand, attempt to validate the views of the ‘outsider,’ or researcher, through empirical use of data. Objective QOL is the midpoint between ‘societal’ standards as determined by the researcher and the aforementioned achievements (Dijkers, 2005).

In positing some of the weaknesses of subjective QOL investigation, Flanagan (1978) expressed that large-scale studies usually cannot employ the resources necessary to establish the importance of each criterion to a participant. For example, while a participant may rank her involvement in community organizations as high, a survey such as the one employed by Flanagan cannot determine why she gravitated toward involvement in organizations, or even investigate her past for any clues. Furthermore, a participant is more apt to notice the salience of a criterion if it is not present in her/his life; on the other hand, it is easy to overlook it if it is present (Flanagan, 1978). Flanagan (1978) did suggest that further subjective quality of life studies could employ participants as their own researchers in order to understand the importance of criteria in their lives. Using daily logs, they could be trained to examine themselves for critical events that would indicate the saliency of each criterion. While the present study does not involve such a participatory research element, it asks the participant what criteria are important in establishing QOL as well as ranking how the participant’s needs are being met. The

study asks participants to recount specific experiences in their own lives that lend weight to their rankings.

Dijkers' (2005) criticism of research on QOL of subjective wellbeing of persons with SCI is that predictors of QOL have not been directed by theory. Researchers generally believe that people's expectations and priorities remain static after SCI, with the result that their QOL decreases with impairment and raises only with regained function (Dijkers, 2005).

How, then, to account for individuals who may have a high QOL even with SCI? Stensman, in a 1994 study, investigated QOL of a group of persons with SCI for five years starting with the initial rehabilitation process. Four groups were found: those whose QOL stayed at a high level throughout the study; those whose QOL dropped substantially as rehabilitation and the rest of their lives progressed; those whose QOL first dropped and steadily rose again, and those whose QOL continually went up and down. The variations in QOL among those within the latter two groups may be attributable to "shifting parameters of expectations and achievements" (Duggan & Dijkers, 2001: 23). That is, people's adjustment to a new 'way of life,' whatever that life may be, may be based on certain intrinsic characteristics and attributes that they possessed in the past. In turn, these intrinsic features may or may not have been influenced by environmental inputs. Dijkers (2005) reflects that indicators of subjective wellbeing may indeed be unique among each individual, and not cut across such stratifications as age, culture, gender, and ability. They may possibly only be realized according to goals and requisites that a person has recently established.

Duggan and Dijkers' 2001 study most closely resembles the present research in its endeavour to qualitatively investigate perceptions of QOL among persons with SCI who are fifty years and older, with two prominent differences being that their study does not investigate age or duration of injury as variables. Subjective QOL was investigated with a sample of 40 participants with a mean age at time of study of 42.6 years and an average of 5.4 years since injury. Most participants in this study had difficulties defining QOL because of the concept's vagueness, although QOL was seen to be fluid, subjective and unique (Duggan & Dijkers, 2001).

Participants who rated themselves to possess a high QOL used such indicators as having good relationships with adequate social support, financial independence, opportunity to pursue leisurely activities, and "meaningful social roles in the family, at work, and within the larger community" (Duggan & Dijkers, 2001: 15). Regrets included not finding a life partner and inability to participate in activities that they had pursued before SCI. Respondents with a 'medium' QOL generally said that their QOL was as indicated because of the quality of their relationships and social support as well as personal development and changes in values (Duggan & Dijkers, 2001). Those who were posited to be in the low QOL group mentioned fewer satisfactory aspects of their lives; while they generally felt grateful for support from their friends, families and support providers, and sometimes positively remarked on their health and independence, other QOL outcomes as given by those in the other groups were not cited (Duggan & Dijkers, 2001). One unexpected finding from Duggan & Dijkers' 2001 study was that among persons in the high QOL group, several indicated that "nothing" would improve their

QOL. It is surmised that high QOL is at least partly attributable to having a positive outlook toward aspects of life that cannot be changed, including SCI. Further qualitative research, it is stated, is needed to substantiate that people with a high QOL accentuate the good parts of their lives rather than grieving what has been lost.

Adjustment to disability and SCI

The implications of adjustment to traumatic onset disability are important for the purposes of this study. The way in which a person adjusts to a sudden, chronic injury such as SCI influences his/her long-term outcomes (Craig et al., 1999). Adjustment to disability is defined as an emotional and behavioural acquiescence and integration of disability into an individual's life (Livneh, 2001; Livneh & Antonak, 1997). It is seen in such ways as reaching psychosocial equilibrium or a state of reintegration; trying to achieve one's long-term goals; and a positive regard toward oneself, others, and the disability (Livneh & Antonak, 1997). Before the 1990s, coping with disability was only addressed in a descriptive fashion. Use of this term was colloquial, not scientifically well defined (McColl & Skinner, 1995). While the significance of psychological variables in effective adjustment to disability and rehabilitation has been recognized (Trieschmann, 1980), empirically formulated treatments for coping with SCI have been slow to develop.

Research in recent years, however, has focused on constructing taxonomies of behaviour for coping with disability. Formulation of taxonomies allows service providers to create models for psychological and emotional support of persons who have sustained traumatic injury. In one of the first of such studies, Bracken & Bernstein (1980)

investigated coping behaviours of 96 persons with SCI immediately after discharge following injury and one year after injury. Although participants had started to cope with their disabilities one year after injury, the coping process had not come to its conclusion. Bracken & Bernstein (1980) found that defense/denial of disability was found to be effective almost exclusively immediately post-injury. These strategies became maladaptive in participants who continued to deny their disability at one year. Emotional release, defined as anger, anxiety and depression for that study, had continued to the one-year mark and was determined to have no positive value for participants' future coping.

While certain disability scholars (Oliver, 1990; Barnes et al., 1999) may decry the use of stage theory in adjustment, it must be noted that different individuals adjust to new disabilities in different ways. Some, for example, may appear to be in denial of impairment for much longer than others. Other individuals, in contrast, may appear to have adapted to their disability only to become depressed at a later time at the thought of incurring impairment. The pain and disappointment of impairment may indeed be felt on an individual level, independent of structural and cultural considerations that constitute the social model's outlook (Morris, 1991). Thus, the theorization of stages of adjustment may be used to explain that though a person with a disability has adequate resources, (s)he may still be maladjusted to living with impairment. Livneh and Antonak (1997: 136) iterate phases of adjustment that typically follow SCI. These include (1) shock, (2) anxiety, (3) denial, (4) depression, (5) anger, and (6) adaptation. These phases may indeed overlap, and are not all evident from individual to individual. Furthermore, individuals' coping styles may not run linear with this mode. The process is not entirely

determined by internal psychological factors; indeed, adaptation to SCI is also influenced by preinjury personality attributes including optimism, independence and motivation, organic variables such as the individual's physiological condition, and situational/environmental conditions, including socioeconomic status, social support, and available medical care (Trieschmann, 1988; Livneh & Antonak, 1997).

One noted ambiguity in the adaptation process, however, is found in the opinion that depression following SCI is a universal reaction. This is not necessarily so. Personal, organic and environmental variables (Trieschmann, 1988) may interact in such a way as to render moot the positing of an automatic period of depression following injury. Nevertheless, in a two-year longitudinal investigation of 41 individuals who had sustained SCI two years before, Craig et al. (1994) found that SCI resulted in significant negative psychological impact. Depression and anxiety were found in all participants up to two years following injury, with up to 30% of participants severely anxious or depressed (Craig et al., 1994: 678). Contrary to a theory of stage adjustment with gradual reduction of depression, Craig et al. (1994) did not detect any decrease in depression or anxiety over the course of their study. Depression may be related to frustration that persons with SCI feel knowing that this is a permanent neurological condition that will never be fully resolved. Yet newly injured individuals may also be anxious or depressed due to economic and vocational constraints, inaccessible physical environments, or poor relationships with friends and family who may not be able to accept their disability.

Lazarus and Folkman (1984) articulate one of the most widely used models for

stress and coping. They suggest that five factors influence how much stress a person experiences when relating to their life challenges: (1) the number and kind of life events, particularly negative ones, that a person copes with; (2) the ways in which the person interprets these events; (3) the social support that the person receives in coping with these events; (4) the way in which the person copes with these events; and (5) the undergirding of personality traits that inform a person's outlook on life. The implication is that persons who have optimistic outlooks will find it easier to gain support from others when approaching challenges, than those who have negative outlooks.

Martz (2004) suggests that an individual's experience with trauma may result in a diminished future time orientation. Future time orientation is an individual's "degree of general concern, engagement, and involvement in the future" (Martz, 2004: 86). Future time orientation is essential in providing motivation to pursue present goals. This is especially salient for persons who have recently experienced SCI, for Martz proposes that recent exposure to physical trauma such as SCI may impact a person's impetus to rehabilitate. Without a positive outlook toward the future, intermediate and long-term goals may possibly be nonexistent, with short-term expectations lacking (Martz, 2004).

Aging with SCI

One may surmise a number of definitions when determining what 'aging with SCI' is. For example, Menter et al. (1991) suggest that aging with SCI is a combined factor of age and duration of injury. The age component can account for various physiological and psychological aging processes that similarly occur within persons with and without SCI.

The duration component specifically accounts for processes associated with aging with SCI, for example, wear and tear of upper extremities. From a health care perspective, the reasons for aging research include the effect that time has on impairment and disability (Adkins, 2001). A further purpose is to understand whether the causes of changes that occur to persons with SCI over time are a result of “genetic traits, behavioral factors, environmental events, or personal conditions” (Adkins, 2001: 128).

A commonly cited problem in aging with SCI research is the small samples of persons over the age of fifty-five in long-term SCI studies (Adkins, 2001). Before the early 1980s, little interest in aging-with-SCI research existed, as technological advances in acute and follow-up care had not yet precipitated greatly increased SCI life spans compared to the rest of the population (Adkins, 2001). Concomitant with more primitive technology and rehabilitation practices in previous decades was less emphasis on perceptions of quality of life among persons with SCI, with more placed on medical management, survival and life expectancy (Boschen et al., 2003; Kemp & Ettelson, 2001). Increasingly successful efforts in SCI rehabilitation led to a growing emphasis on functional independence and adjustment to SCI (Kemp & Ettelson, 2001). QOL issues, focusing less on the individual’s physiological attributes and more on the environment than previous efforts, came much later as an area of SCI research.

The question exists as to whether a negative QOL is related more to chronological age or duration of SCI. If chronological age is more critical, there may be little that can be done in terms of rehabilitative intervention in order to improve QOL (Adkins, 2001). The implication is that a negative QOL is inevitable for all persons with SCI after

reaching a certain age. Duration of injury, resulting in “wear and tear” from living with SCI for a long time, however, should also be considered. If this factor is found to be more important than chronological age in assessing QOL, the implication is that interventions exist in improving QOL among persons with SCI who are 50 years of age or older.

In a cross-sectional study involving 435 participants who had been injured for 30 or more years, Krause (1998) sought to identify the relationship between aging and life adjustment after SCI. Here, it was found that age at time of study was negatively correlated with life adjustment, while time since injury was positively correlated with adjustment. Also, age at onset of injury was more highly correlated with life adjustment than was chronologic age at time of study, while time since injury was more highly correlated with positive adjustment than was chronologic age at time of study (Krause, 1998). This suggests that any negative impacts of an aging process upon health and activity levels of participants are less critical than the age at which a person is injured. A corollary is that while advanced chronologic age may negatively influence the life adjustment of every person with SCI, existing rehabilitative interventions or personal resources may have assisted those who sustained SCI at a young age and are now older in attaining positive adjustment.

A number of studies (Cushman & Hassett, 1992; Fuhrer, 1996; Dijkers, 1997) conclude that level and completeness of SCI do not significantly affect adjustment to injury or a person’s perceived QOL. This is in addition to Frankel et al. (1998) who posit that no difference exists in mortality rates between persons with quadraplegia, or

paralysis of both arms and both legs, and paraplegia, or paralysis of the lower half of the body, provided that individuals survive one year post-injury. Of note is Cushman and Hassett's (1992) observation that the only factor that seemed to be related to the life satisfaction of the people with SCI in their study was their ability to live in their preferred setting; i.e., whether by themselves, or with family or friends. Furthermore, the perceived satisfaction that the participants' had of their living situation took precedence over their actual social circumstances (Cushman & Hassett, 1992). That is, although some participants may have admitted that their living situation was not ideal, it may indeed have been 'good enough,' thus not greatly affecting their life satisfaction.

Furthermore, Krause (1998: 321) indicates that studies focusing on age have not "adequately differentiated between the effects of age at time of SCI and chronological age". As a result, it is unknown as to whether the differences among people's life experiences are a result of their age at injury or from the aging process that occurs after SCI. Also, most studies have only involved participants who have been injured ten years or less (Krause, 1998). The result is that it has been difficult to determine whether or not a plateau exists upon which such outcomes as QOL or life adjustment decrease after a certain number of decades.

According to Cushman and Hassett (1992), one theme in aging with SCI research that has emerged in recent years is that of changes in physical function to non-impaired limbs of persons with SCI. For example, person with paraplegia who use a wheelchair without the assistance of a motor may be experiencing the euphemistic 'aging' of their upper extremity joints. In reality, this specific conception of aging should not be

confused with 'wear and tear' that can occur with overuse of the body at any age. As a further note, participants in Cushman and Hassett's study (1992) who had paraplegia reported more negative changes in their lives ten and fifteen years post-injury than those with quadriplegia. One possibility for this result was the former group's increased daily physical activity over the latter, and the possibility of overuse of non-impaired limbs (Cushman & Hassett, 1992).

Aging as a deterioration of the body occurs over a span of several years, beginning at approximately twenty-five years and rapidly accelerating between forty and fifty years (Adkins, 2001). As such, a study that only takes one group of aging people into account, e.g. those over fifty years, is limited in its scope of truly analyzing the aging process per se (Adkins, 2001). Hence, one of the limitations of this project is its restriction to the sampling only of persons fifty years or older. Even in this instance where all participants are 'aged,' it might have been beneficial to compare them against a younger sample whose bodies might have only started undergoing the aging process. Thus, this study reduces both samples of participants as ascribing to a social construction of 'aged' without actually determining how 'aged' differs from 'youth.' A number of studies (Crewe, 1996; Dijkers, 1997; Krause & Crewe, 1991; Pentland et al., 1995) suggest that the maximum subjective QOL of persons with SCI is attained between the ages of 45 and 50. At the same time, when examining duration of SCI, subjective QOL seems to increase until approximately 20-25 years after injury. As a result, the focus of the current study is necessarily located at the age of 50 or older, when the literature suggests that the QOL of persons with SCI may be decreasing. Variation in duration of

SCI is to be observed in order to understand how short and long durations may influence life experiences.

Resources employed in living with SCI

The experience of living with a SCI may indeed require persons with SCI to possess a set of resources different from people without SCI. There exists, however, uncertainty as to what those particular resources are, and how they influence different facets of people's coping strategies. Health, independence, spousal support, and employment have been addressed in this literature review based on the resource needs of persons with SCI. For example, McColl and Rosenthal, in a 1994 study, sought to understand the resource needs of men with SCI who were 45 years of age or older and had had a SCI for at least 15 years. Data were analyzed to construct a model of resources (independent variables) empirically associated with positive aging outcomes (dependent variables). These outcomes included lack of depressive symptoms, adjustment to disability and life satisfaction; they were chosen due to their long-term importance.

McColl and Rosenthal (1994) found that emotional support and health, which included perceived health, actual illnesses/symptoms and utilization of health services, were positively related to the aforementioned outcomes. Life satisfaction was most heavily influenced by tangible factors such as financial security and perceptions of health and social support. Interestingly, participants' evaluation of their life satisfaction was considered to provide a general assessment of their quality of life (McColl & Rosenthal, 1994). Finally, adjustment to disability was negatively affected by instrumental support.

This last relationship is noteworthy, suggesting that the more a person feels that (s)he must rely on others for tangible help, the more (s)he will negatively perceive his/her SCI. McColl and Rosenthal (1994) write of several participants' anecdotes that explain the importance of independence and the fear of losing even a small part of it. Importantly, this study does not address the resource needs of women with SCI.

Health

Information on life expectancy and mortality is of significant value for persons with SCI, clinicians and care providers, as well as policy makers who determine health care funding. Changes in causes of mortality among persons with SCI have occurred over recent decades (DeVivo et al., 1999). Frankel et al.'s (1998) fifty-year study of 3179 individuals determined that urinary problems, heart disease, and respiratory problems ranked as the leading causes of death for persons with SCI in the 1950s, 60s and 70s. In the 1980s and 90s, however, the leading causes of death had changed with respiratory diseases, especially pneumonia (DeVivo et al., 1999), ranked first, followed by heart disease, injury-related deaths and urinary deaths (Frankel et al., 1998). This shift in trends is due to improved emergency medical services at the scene of accidents and improved rehabilitation techniques.

Optimistic projections suggest that as persons with SCI survive to increasingly older ages, morbidity will be "compressed" into the last few years of their lives (McColl et al., 1997). Thus, people would have longer phases of healthy life. In a study designed to derive estimates for expectations of mortality and long-term health following SCI,

McColl et al. (1997) investigated a cohort of individuals who had sustained injury while relatively young, between 25 and 34 years of age. Injuries had been acquired between 1945 and 1990. Participants had been chosen primarily on the basis of supporting literature that suggested that age at injury was the most consistent predictor of long-term survival. Results showed that seven years of poor health could be expected at time of injury; this number decreased to 5 years of expected poor health 40 years post-injury (McColl et al., 1997). These figures represent an optimistic perception of healthy life expectancy, where poor health is generally found at the end of life and for a reduced period of time.

Finally, exercise can most clearly be seen as determinant of health; on the other hand, a consistent exercise regiment can alleviate such physical stressors as fatigue, which can in turn have an impact on QOL. Cushman and Hassett (1992) report that participants in their study who exercised regularly did not have significantly fewer problems with weight gain or needing further physical assistance. Those who exercised regularly, however, reported less need to make changes in their daily routines due to fatigue (Cushman & Hassett, 1992). While fatigue may be construed as a both a physical or mental phenomenon, increased emphasis on physical activity may indeed reduce stress on the body and mind in aging persons with SCI.

Independence

Perceived independence can be as significant a factor as the state of one's health when determining QOL. Independent living includes fulfilling various social roles such as

family and employment participation; having control over one's life; and relying as little as possible on others for accomplishing daily activities (Frieden et al., 1979; in Fox Harker et al., 2002). Importantly, however, independent living does not only entail participation in any sort of activity, but the perception that one has a stake in that pursuit with others (Oliver, 1990; Fox Harker et al., 2002). Thus, both an instrumental and perceptual aspect exists in articulating 'involvement' in activity.

In a study comparing 440 individuals who were at least 1-year post SCI and of working age to another sample of participants who had sustained traumatic brain injury, researchers attempted to find a relationship between involvement in paid productive labour and perceived community integration. Community integration within this study meant having similar levels of independence in relation to others within the community as well as having a productive role (Fox Harker et al., 2002). While this relationship was indeed found significant, results also inferred that more than 70% of SCI participants were in the moderately or least productive categories (Fox Harker et al., 2002: 98). One consideration is that "environmental barriers" in employment settings, such as inadequate access to buildings, may present challenges for persons with SCI. From their results, the authors were led to question whether participation in paid employment led to perceived community integration, or vice versa (Fox Harker et al., 2002).

Spousal support

The presence of a life partner may be one of the most important aspects in ensuring a high QOL among aging people with SCI. The quality of the relationship may be crucial

for young people in the period directly after injury, as married individuals with SCI who are thirty-five years or younger are more likely to get divorced within two years of injury than older patients (DeVivo et al., 1990). Opportunities for people to develop intimate relationships after SCI may be hindered by a lack of acceptance among peers as well as a lack of confidence (Kreuter, 2000).

As well, a correlation may exist between marital status and spousal support, and a higher perceived QOL as compared to unmarried individuals with SCI (Holicky & Charlifue, 1999). This claim is somewhat mitigated by a perceived decrease in physical independence among the spouses with SCI as well as higher levels of stress experienced by certain married individuals (Holicky & Charlifue, 1999). A perceived decrease in physical independence may be a function of the partner without SCI completing more physical tasks out of affection, convenience or observance of a role as opposed to the purpose of personal support (Holicky & Charlifue, 1999). Holicky and Charlifue (1999) also found that persons with SCI who received no personal support from their spouses had the lowest stress scores of the various subgroups tested, while married persons who received personal support had higher scores. This suggests that giving and receiving personal support may be a greater indicator of stress than that encountered by being in a marriage. Furthermore, non-married individuals receiving no personal assistance had the highest stress scores, which may imply that lack of close social contact of any kind is the overriding indicator of stress when investigating spousal support (Holicky & Charlifue, 1999).

Having a spouse does not necessarily guarantee successful coping with disability,

as Grand et al. (1993) suggest. Rather, the type of relationship that the couple has is paramount. The authors argue against the positing of aging as two distinct phases—the younger phase typified by rampant consumerism, followed by a phase of decline in all areas (Grand et al., 1993). Instead, analysis of an aging couple's internal cohesion and role and task distribution prior to the onset of disability is important in determining how the relationship may be influenced. Thus, the rules that the two have followed within the relationship will influence caregiver and receiver roles, the kind of care given and the outcomes experienced (Grand et al, 1993).

The experiences of care providers for persons with SCI have largely been under-researched. Most studies involving caregiving issues for persons with chronic conditions have focused on the stress and burden of caring for a person with a late-onset chronic disease such as Alzheimer's dementia (Shewchuk et al., 1998). The concerns that these providers face are far different than those of caregivers of persons with permanent impairments, such as SCI, in which a long life can often be expected if an individual sustains injury at a young age. Family care providers of persons with SCI may assist in such activities of daily living as toileting, feeding, dressing, and transferring. This issue is of especial importance in the current health services climate, as increased cuts in Ontario health care funding and shorter hospital stays may result in greater involvement among informal care providers (Boschen & Tonack, 2001). In the qualitative phase of a 2001 mixed-methods study, Boschen and Tonack endeavoured to document various caregiver responsibilities as persons with SCI were reintegrating into their communities. In particular, the researchers sought to understand how support

providers' experiences affected their general QOL. Lifestyles had changed, often for the worse, because of lack of readiness for adaptation. For a few participants, this had been somewhat mitigated by a long passing of time between the injury (Boschen & Tonack, 2001).

Adjustment to living with a person with SCI had possibly been influenced by a number of factors, including the nature of the provider's relationship with the person with SCI (e.g., partner; parent), and the "character" of the relationship (e.g., supportive or dysfunctional) (Boschen & Tonack, 2001). Providers also cited a need for greater emotional support, as few mental health services specialize in working with their population. This comment finds credence with Weitzenkamp et al. (1997), who report that spouses in a caregiving role show more symptoms of stress, depression and fatigue than their partners with SCI and other spouses who are not care providers. Also, Decker and Schulz (1989) suggest that a large part of rehabilitation practitioners' roles should be helping to develop support networks for primary care providers. On a positive note, providers in Boschen and Tonack's (2001) study noted a positive change in their attitudes toward advocacy against barriers to social inclusion for persons with disabilities.

The literature on caregivers within aging families indicates that they often encounter similar issues as families of persons with disabilities. One question, for example, concerns what exactly 'caregiving' is and how it differs from routine acts of altruism between family members. Arber and Ginn (1990) establish distinctions between 'caring' and 'normal' family care in describing the activities of helpers among family. This is partly accomplished by typifying instances of concentrated, instrumental co-

resident care, compared with extra-resident care that is observed to be weak and diffuse (Arber and Ginn, 1990). Gerontology and disability rehabilitation researchers often fail, then, to conceptualize family relationships as systems in which care ebbs and flows as various members depend upon each other for support at different times.

Connidis (2001) suggests a more nuanced view in approaching family support for aging persons. She proposes four models of social support among families: (1) the hierarchical-compensatory model, (2) the task-specificity model, (3) the functional-specificity model, and (4) the convoy model. The hierarchical-compensatory model identifies a person's favourite children as the loci for investigating support patterns, while the task-specificity model examines a person's most pressing tasks for delegation to other members of the family (Connidis, 2001). In contrast, the functional-specificity model offers a more varied outlook by examining different ways that relationships between people can be negotiated. The convoy model traces a circular intergenerational path in positing that families are transient groupings with ever-changing support needs. New members such as children and spouses will continually enter; others, including persons of advanced age, will leave (Connidis, 2001). This model's nonlinearity is held in stark contrast to family support models that typify caring as a one-way relationship from caregiver to aging person with SCI (e.g. see Weitzenkamp et al., 1997; Kreuter, 2000).

Employment

Many people with SCI feel that a return to their previous employment prior to injury is no longer feasible (Pentland et al., 1995). Often, new forms of work entailing less physical

exertion must be found. Once new work is found, however, re-introduction to employment can be a difficult process indeed. This is especially so for persons with SCI who are already older workers, as they are less active and more prone to experience fatigue, symptoms and illnesses related SCI than younger persons with SCI (Pentland et al., 1995). Accommodations must usually be made so that persons with SCI can feel comfortable as they adjust to the environment. These adaptations include modifying the physical environment, providing special equipment/aids, altering the job, giving additional training to the employee, and orientating other employees of the individual's needs so that they can give additional assistance if called upon (McNeal et al., 1999).

In a 1999 study of 46 people 30 years of age or older and with a work history of at least 5 years since sustaining SCI, McNeal et al. investigated whether or not employees with SCI who were considered to be aging had experienced new work problems due to functional decline, and whether or not their problems at work were being sufficiently accommodated. Results indicated that 84.2% of respondents' work problems would have been as much of a concern when they first resumed employment as when they were interviewed (McNeal et al., 1999: 145). Thus, few problems appeared to be attributable to aging and functional decline. Amongst problems encountered at work by participants in McNeal et al.'s study, 39.8% of problems were related to "using equipment/tools/furniture" (1999: 146), with accessible desks being the biggest problem in that category. Access, in the way of traveling short distances by manual wheelchair or finding suitable parking, was the second greatest concern (24.3% of reported problems) (McNeal et al., 1999: 146). Also, 37% of participants reported that pain or fatigue

impacted upon their ability to perform certain tasks within a full working day (McNeal et al., 1999: 146). Flexible working hours were suggested as a possible solution.

As for accommodation of work problems, 85.7% of participants in McNeal et al.'s study reported some sort of modification on employers' parts, but only 69.5% of accommodations had been deemed satisfactory (1999: 147). Participants most often indicated that a suitable solution had not been provided because it had not been identified in the first place. Interestingly, in 72.7% of cases, the lack of an accommodation was deemed to be the employee's fault, not the employer's. Participants often felt that the accommodation would be too costly, were waiting or did not intend to ask, or did not consider the problem significant enough to warrant accommodation (McNeal et al., 1999). This last statistic suggests of social barriers that may have negatively affected participants' desires to ask for accommodations from employers. Persons with SCI need more supports than those without SCI in order to be productive in the workplace, yet it appears that a lack of perceived entitlement to those resources also pervades. This is troubling, in the light of work by the North American disability rights movement to effect a more inclusive atmosphere.

Theoretical standpoint

Introduction

This chapter begins by explicating the theoretical bias toward disability within this study, namely a materialist account of the social model of disability (hence articulated as the social model). While the social model is an important component in understanding disability, it ignores a personal aspect of impairment, being the pain and disorientation that can result from incurring disability. Thus, the theoretical bias is composed of the social model and an understanding of disability on a personal level. Next, various age theories are introduced, followed by an investigation that links aging and disability theory together. As some sources (Liebig & Sheets, 1998; Kennedy & Minkler, 1999; Priestley, 2003) suggest, disability and aging research often do not cross paths despite several analogues that appear evident. Differences between representatives of these two groups may result from a lack of material and the perception that separate agendas must be pursued in order to maximize available resources.

The social model of disability

One tenet of the social model is the dichotomy between the notion of individual impairment and a disabling environment. An individual/medical model of disability generally links the organic impairment of a part of the body to a reduced ability, or disability, in performing tasks. This may possibly be accompanied by a social disadvantage, or handicap (Bury, 1996; Barnes et al., 1999). Proponents of the social model, however (Oliver, 1996b; Barnes et al., 1999), suggest that impairment is separate from the social disadvantage that may result. Hence, with impairment being experienced

strictly on an individual level, social oppression occurs because of a disabling environment that does not properly support persons with disabilities (Oliver, 1990).

A second tenet of the social model of disability is that disability is produced by socioeconomic forces of capitalism and can be traced as far back as the Industrial Revolution (Oliver, 1990; 1996b). These forces are responsible for three aspects of the individualization of disability: the construction of normative categories that conversely produce abnormality; the rise of the medical profession with its power to define and prescribe; and the subsequent social construction of disability (Terzi, 2004).

This study, however, does not wholeheartedly accept the premises of the social model of disability. Concerns come in response to the proposition that the social model represents truth in depicting a disabling environment in no way connected to impairment. The model's position that disability is a social construction is problematic in the sense that constructionism is a *sociological* issue, and does not necessarily describe *social* life, or people's experiences with disability (Clarke et al., 2004). Social workers, however, are not sociologists; the goal of identifying a social process as indicated by this study's GT methodology is not to produce theory as a means to its own end. Rather, this study endeavours to understand how participants view disabling elements in their lives, be they of a 'structural' or personal nature. Hopefully, service providers will get a better idea of how to assist these individuals in attaining an acceptable QOL. Insights on perceived structures that form participants' ideas of social disadvantage due to impairment and disability may be gained as well. Information for practice is preferred to further development of sociological theory.

Foremost, however, is the acknowledgment that the social model brings a political dimension that recognizes that everyone, whether paralyzed by SCI, having autism, or lacking disability; in palliative care today or eighty years from now, has the right to a certain level of respect. This idea is important in that it transcends persons with disabilities, including those who may acquire a disability later on in life, to encompass all. That is, it bridges the gap between disability as a social construction and other *-isms* such as discrimination on the basis of class, gender, age, and sexual preference.

Disability: an individual and social interpretation

An individual model of disability is built on the proposition that impairment, disability and handicap are connected. According to the World Health Organization's 1980 International Classification of Impairment, Disability and Handicaps (ICIDH), impairment is a physical or cognitive abnormality that affects the body's function, while disability is a "restriction in the ability to perform tasks" (Bury, 1996). Handicap results from either disability or impairment and is the resulting social disadvantage from having one of the other two conditions (Bury, 1996). Thus, this classification system begins by locating the issue within the individual—hence an individual model of disability.

Criticism of the ICIDH definition is that it is based primarily on medical definitions of impairment, employing a physiological definition of 'normality.' As a result, the issue of boundaries for defining normality emerges. For example, while the wearing of glasses signals vision impairment, their use for the corresponding impairment has become 'normal' in Western civilization. Implied here is the suggestion that 'able-bodied' is a desirable, or normal, state (Barnes et al., 1999). Secondly, as impairment, or

physiological abnormality, is the source of disability and corresponding handicap, trained medical professionals can cooperate to rehabilitate the individual from its effects.

Curiously, the environment is portrayed as neutral, or having little effect on the person's life as compared to his/her impairment (Barnes et al., 1999).

Disability and the capitalist state

According to a materialist conception of the social model, disability has been largely produced by socioeconomic structures and core values representative of the current capitalist mode of production. This point is exemplified in Oliver's work (1990; 1996b), in which the needs of capital led to the individual-medical outlook toward disability. For example, many persons with disabilities were excluded from paid work with the emphasis on strict timekeeping, efficient use of limbs over prolonged periods of time, and the need to memorize detailed instructions in order to produce large quantities of manufactured goods (Oliver, 1990). Disability had already been present in pre-capitalist times, but feudal production processes did not segregate people to the extent that industrialization did (Oliver, 1990).

Certain beliefs and values toward disability became prominent at the same time as the capitalist mode of production began to emerge. For example, liberalism entailed an understanding of the individual as autonomous from societal constraints, possessed with the freedom to pursue one's own socioeconomic ends (Horowitz & Horowitz, 1988). Translated to persons with disabilities, this also meant the freedom for a person to be held individually accountable for his/her economic failures. Thus, a welfare state emerged to

fulfill the needs of those who could not take care of themselves within a capitalist mode of production (Polanyi, 1944; Horowitz & Horowitz, 1988).

Concomitant with the proliferation of liberalism was a 'medicalization' of society. This was manifested in institutions for sick and disabled persons as well as the increased importance of the medical profession, with practitioners having the ability to formally label people's physical conditions (Stone, 1984). Eligibility for state support was premised on being labeled as 'disabled,' which specifically indicated that the individual was incapable of work. As a result, persons with disabilities often became the 'worthy poor,' or those who had a 'legitimate' reason for not working (Rioux & Bach, 1996). The tolerance of poverty while receiving state support was built upon the English Poor Laws that dictated that persons receiving welfare relief should receive as meagre a level of income as possible in order to encourage a return to work (Lightman, 2003). Thus, many persons with disabilities faced the dilemma of work conditions that did not offer them appropriate supports, or accessing welfare rates that were purposely kept low.

Separation of disability and impairment?

While Oliver's materialist proposition of the social model separates disability from impairment, it denies the subjective experience of impairment that a person with a disability may be feeling:

... there is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability - and do indeed disable us - to suggest that this is all there is to it is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying. (Morris, 1991, p.10)

It is not denied that society is partly responsible for conveying a sense of inadequacy amongst persons with disabilities; rather, the issue is that disability is as 'real' when felt by an individual as any attitude propounded as a social construction. Oliver, in another work (1996a), admits that pain and perceived dehumanization do indeed lie within the purview of individuals. While the disabled movement can do little about the physiological pain that an individual feels, it can serve to expose disabling attitudes that pervade the current socioeconomic system. Medical or other professional treatment (and social workers must be thrust into this category) that is commonly given to persons with disabilities is problematic, as 'helping experts' propagate the very norms that are said to cause disability in the first place (Oliver, 1996a).

At the same time, however, many persons with disabilities do indeed feel that removal of a personal element from a notion of disability, whether physical pain or depression at 'having less' than persons without disabilities, devalues the experience. Shakespeare suggests that many disability advocates' strict separation of disability from impairment has a political reason, for "to mention biology, to admit pain, to confront our impairments, has been to risk the oppressors seizing evidence that disability is "really" about physical limitation after all" (1992: 40). Thus, to admit that impairment and disability are linked is opined to relinquish theoretical ground to proponents of an individual/medical model.

A researcher, then, is left with the problem that, to over-emphasize impairments would remove the focus on the environmental oppression of persons with disabilities. On the other hand, denying the experience of pain and impairment dismisses its part in the everyday lives of persons with disabilities, despite structural barriers to inclusion.

Methodologically, a GT study such as this also runs the risk of focusing too much on participants' issues of 'coping' with, and adjusting to, their acquired impairments. The reason is that respondents are expressly asked to describe their experiences with SCI; it is unknown as to the extent to which persons will link their experiences to discriminatory structures in a disabling environment. Furthermore, as this study entails individuals' experiences with disability, it would appear difficult for participants to ground their experiences in any way other than to express how they have managed to deal with adversity since incurring SCI.

Aging theory

Theories on aging may be investigated according to two dimensions: macro- versus micro-theorizing, and normative versus interpretive theorizing. Normative perspectives assume that interaction is governed by social norms, and that sociological explanation is deductive, much akin to explanation in the natural sciences (Marshall, 1996). In contrast, the interpretive perspective asserts that while norms are constructed, they are not necessarily followed. Explanation can be both deductive and inductive. Furthermore, the expected analytical outcomes from an interpretive perspective do not necessarily have to be predictive; they can be descriptive (Marshall, 1996). McPherson (2004) identifies a third perspective along the normative-interpretive spectrum, that being a critical perspective. Proponents of this approach study the inherent inequities that are argued to exist within the current social structure. These inequities occur along such categories as age, ability, race, class, and gender.

Of the other dimension by which to classify aging theories, micro-level theories of aging represent an individual view of the world, while macro theories use a societal focus. Macro-level theories of aging differ from micro-level theories in that elderly persons are investigated in terms of structural impact on either individuals or cohorts. While recent scholarship (Marshall, 1996; McPherson, 2004) suggests that comprehensive understanding of the aging process requires subscription to both micro- and macro-level theories, it is beneficial for pedagogical purposes to observe how each separate theory impacts investigation.

Three older micro-level theories of special note are activity theory, disengagement theory and continuity theory. Activity theory was the first theory in North America to describe and provide prescriptions for 'successful' aging in an individual's later years. Proposed in the 1950s, activity theorists suggested that rather than simply accept that they were increasingly losing fulfilling roles as they grew older, elderly people should endeavour to create meaning and QOL by participating in new activities and tasks (McPherson, 2004). The hypothesis of this theory is that a favourable outlook on life, as can only be maintained by taking on new challenges, is positively related to adjustment and successful aging.

Activity theory can also be viewed from a gender perspective. Reitzes et al. (1995) observe that leisure activities involving relatives and work friends had a positive effect on the self-esteem of women aged 58 to 64, but not on men in the same age group. Role commitment on the women participants' part was seen as instrumental in raising self-esteem. On the other hand, leisure activities that were accomplished while alone such as exercise and hobbies seemed to have a positive effect on the self-esteem of the

men in the study, but not the women. Reitzes et al. (1995) conclude that the quality of an activity, especially with the effect of drawing praise from friends, family and coworkers, is more important than the quantity of activities accomplished. As well, the prevalence of high self-esteem in older working-age men when accomplishing solitary activities suggests that the motivation to self-initiate activities as a vehicle for raising self-esteem in men should not be ignored (Reitzes et al., 1995).

Activity theory is still the basis on which much elderly social programming is structured. Elderly persons are often encouraged by different social elements such as family, friends and institutions where they may reside, to keep busy in order to maintain a healthy self-concept. The main criticism of activity theory is that activity levels can diminish without necessarily a loss of morale, and that many individuals may not have the economic means to maintain an active lifestyle yet do not exhibit diminishment of self-esteem (McPherson, 2004).

Disengagement theory was developed in the early 1960s and represented a contrast from activity theory. According to disengagement theorists, individual aging was accompanied by one's gradual withdrawal from certain social positions and responsibilities (Morgan & Kunkel, 1998). Disengagement is claimed to be necessary because of an older person's reduction in abilities as (s)he ages; because of his/her relative closeness to death in temporary terms; and because of the emphasis on tasks and roles being assumed by younger individuals (Morgan & Kunkel, 1998). As such, aging is supposed to involve older people's voluntary withdrawal from their stations. The withdrawal is voluntary, as elderly persons will then be free of pressures to fulfill the responsibilities that they are seemingly less and less capable of completing. They are

also given greater freedom to deviate from social norms without being sanctioned (McPherson, 2004). Successful aging in this context, then, is a gradual, dignified retreat from former responsibilities.

Bengtson et al. (1999), however, argue that disengagement theory is not universal among individuals. More recent theories posit that the directions of people's lives have a multitude of permutations that develop from both structural and intrinsic factors. Internal critique of disengagement theory suggests that older people do not necessarily withdraw from their tasks as completely as is suggested (Achenbaum & Bengtson, 1994). That is, elderly individuals seem to withdraw from activities in different ways. One may be formally attached to a certain task, such as belonging to a service organization, even though (s)he has already lost interest. Or, one may seemingly be unattached to a task, such as participating in public worship, but may be actively involved in completing the task privately. Finally, the theory has been criticized for ambiguity on whether the process of disengagement is initiated by the individual or society (McPherson, 2004). The individual may have been socialized to remove him/herself from responsibilities at a certain age. Alternatively, (s)he might have felt coerced into removal from tasks because of lack of power or interaction (McPherson, 2004).

In contrast to disengagement theory, which emphasizes elderly persons' gradual withdrawal from productive society, continuity theory, another micro-level perspective, proposes that middle-aged and older people challenge exclusion from productive activities by making "adaptive choices" that encourage stability in their current situations (Atchley, 1989: 183). According to continuity theory, people are considered to adapt successfully to aging if they can continue their lives in the same manner as was pursued

in earlier years. Thus, according to continuity theorists, a person who was often surrounded by friends and family and led an active social life in past years may adjust poorly to aging if left virtually alone in the house of a mature child who is often gone. One issue that continuity theory apparently fails to address, however, is whether it sheds light on aging processes as opposed to possibly describing a cultural effect of viewing time as a linear progression (Kenyon et al., 1999) that might actually reflect 'the good old days.' That is, people's life stories, based on 'inner time,' possibly manifest differently than 'real time.' People may not see their identities as advancing or changing with time, but only see themselves as static entities getting older.

Pedagogically located between a micro- and macro-level categorization of aging theories is age stratification theory. Age stratification theory focuses on aging comparative to all ages. Specifically, it investigates differences as opposed to conflict between age cohorts (McPherson, 2004). Though Weberian dimensions of social class include such factors as wealth, power and prestige (Quadagno & Reid, 1999), separation of people into divisions for the purpose of distributing socioeconomic goods can also be seen along age lines. While it takes the life course into account, this paradigm is noted for expounding upon the impact of social structures on aging people's lives. Critics of age stratification theory suggest that it depends too heavily on a monolithic conception of social structure and does not allow for individual autonomy or address political practices that spur on inequality (Dowd, 1987; Quadagno & Reid, 1999). That is, age stratification theorists tend to represent social structure as seemingly innocuous interactions between positions without addressing the power relationships that create inequality (Marshall, 1996).

Age stratification theory is thus seen to adopt an ecological perspective to aging. Ecological perspectives are those that present social phenomena as the culmination of interactions between individuals and their environments (Coates, 1992). Though institutions within age stratification theory may be seen to be inefficient in supporting the needs of aging persons, the belief in “the ultimate soundness of current socioeconomic arrangements” still prevails (Coates, 1992: 127). That is, institutions are not observed to be perpetuating conflict between age strata. An ecological approach in age stratification theory is seen in the representation of ‘cultural lag’, or the observation that institutions, norms and social structures are slow to maintain pace with micro or macro changes in individuals and technology (Caro et al., 1993; Riley et al., 1994). Specifically, society is sluggish in realizing that elderly persons do indeed have the personal resources to remain productive even when faced with psychological or physiological decline (Caro et al., 1993). This is due in no small part to the evolution of technology in making many kinds of work easier to perform. The current socioeconomic climate is seen as flawed, but ultimately worthy of preservation.

In contrast to an ecological approach in addressing structures, a political economy/conflict approach posits that social problems are directly related to a liberal, capitalist order (Coates, 1992). Adherents to this approach insist that the current welfare state be transformed in order to support humanitarianism, egalitarianism, and social justice. A political economy of aging perspective, then, incorporates analysis of financial and industrial capital, state functions, aging “enterprise”, the medical-industrial complex and public attitudes in investigating exploitation of elderly persons (Estes, 1999). Indeed,

resources and aging persons' health are interconnected and are determined by an individual's position in society, along such lines as production, ability and gender.

The political economy perspective assumes that elderly persons as an age group lack power and material and puts undue emphasis on the centrality of the state in influencing human interaction. This approach to aging, however, is does not lend sufficient explanation in regard to older persons whose needs have been met by the socioeconomic system. As with other macroeconomic perspectives, it is best used in tandem with micro theories in addressing the plethora of individual aging experiences as exists (Passuth and Bengston, 1988).

Caro et al. (1993) propose a macro-level aging perspective known as productive aging. This viewpoint opposes a generalization of elderly persons as frail and dependent, suggesting that such a group of people is a relatively small percentage of the aged population. The corollary is that chronological age is not a predictor for a great many activities. With that in mind, productive aging can be defined as "any activity by an older individual that produces goods or services, or develops the capacity to product them, whether they are to be paid for or not" (Caro et al., 1993: 6). Volunteer activities are especially noted as one productive outcome that elders can and do participate in. The term differs from other positive views toward aging such as successful aging, which emphasizes individual psychological and physiological ability (Rowe & Kahn, 1987; 1997), or normative aging, which examines an individual's development over the life-course as a whole. Specifically, the difference between productive aging and these other two conceptualizations is the relationship between an individual and society, as opposed to strictly one's personal attributes (Caro et al., 1993).

Productive aging as a concept is noteworthy in that it exhibits the influence of both ecological and conflict perspectives. In addition to containing the ecological element of structural lag, productive aging also takes a conflict approach to the study of aging. Not only are institutions seen as slow to evolve in accommodating emergent socioeconomic needs; present institutional arrangements may foster competition between elderly and non-elderly people. This competition is brought out in the labour market. Market pressure as well as reactions from trade unions and governments is assumed to result in the exclusion of elderly persons from jobs (Caro et al., 1993), if even on the rhetorical basis of frailty. 'Growing old' does not only suggest physiological or psychological decline, but implies that people 'show their age' through a retreat from labour, often involuntary. Age may be seen here as a social construction in which the means of production creates inequality amongst generations (Marshall, 1996; Quadagno & Reid, 1999).

Admittedly, the term 'successful aging' is a nebulous concept that lacks universal meaning. For disengagement, activity and continuity theory, successful aging is observed in individuals' pursuit of their personal goals as defined by each perspective. Within disengagement theory, the goal is to retreat comfortably into a life that is increasingly sedentary and devoid of social contact. Activity theory, on the other hand, proposes that persons age successfully by 'renewing' themselves and participation in new, enjoyable tasks. In turn, continuity theory marks successful aging as the further pursuit of activities that an individual found enjoyable prior to aging. For the macro theories described here, successful aging of individuals is secondary to analysis of distribution of

resources across various strata. The degree to which strata are in conflict with each other varies as well.

In positing one's theoretical bias on aging within this study, it is important to first acknowledge the interplay between micro and macro aging theories. No single theory carries full explanatory power in describing observed phenomena. That said, at the micro level, continuity theory with its emphasis on older individuals' freedom to pursue activities similar to those that they accomplished when they were younger is the theoretical stance taken in this study. Importantly, subscription to this theory alone does little to inform on how socioeconomic arrangements constrain and shape people's attitudes toward their current activities. As such, recognition of a political economy approach in fostering disparities between cohorts on such grounds as age, disability, gender and class is similarly important. In addition, how individuals view their QOL is dependent on their comparison of what is important to achieve in life, measured against their socioeconomic circumstances. These circumstances, however, are influential in shaping individuals' needs and preferences.

Intersection of age and disability

Just as the social model of disability posits that disability has at least partly been constructed by the current modernized mode of labour, so do macro-level theories of aging suggest that older people are castigated in socioeconomic terms by industrialized capitalism. Priestley (2003) uses an economic argument in linking disability with old age by suggesting that policy makers often associate the two phenomena as one. For example, from a political economy perspective, older people in Western countries usually

have some 'generational' component built into their employment. They enter retirement upon being replaced by younger persons who, presumably, can make production more efficient (Oliver, 1993). Persons with disabilities of working age who do not have gainful employment, however, are seen to age 'prematurely', because perceptions of their disabilities often preclude them from working. As a result, they enter 'early retirement', perhaps earning meagre pay in sheltered workplaces in nonprofit organizations, or else not working at all (Priestley, 2003). Thus, aging and disability seem to intersect, in that seniors have the highest rate of disability in Canada (42%) at almost four times the rate of the working-age population (11.5%) (Social Development Canada, 2004: 9).¹ But, more illustrative of their respective socioeconomic status is the fact that both groups suffer exclusion from the paid labour market.

At first, it would seem that a number of common resource needs would engender more cohesion between the disability rights movement and the aging persons' movement. These include the need for assistive technology and home modifications, as well as personal care (Liebig & Sheets, 1998). In North America, however, disability and elder groups have often pursued different agendas for a variety of reasons. For example, various disability groups have placed an emphasis on independence, dignity, education, job training, and their place as consumers first, in their philosophical stances. Aging groups, while also striving for dignity, tend to focus on establishing social wellbeing and managing physiological risks (Simon-Rusinowitz & Hofland, 1993; Priestley, 2003). To reiterate, it would seem that advocates of the elderly and persons with disabilities share a common cause in striving for greater access to socioeconomic benefits. This has not

¹ Social Development Canada considers working age to be from 15 to 64.

materialized, however, largely due to the conflicting aims prevalent between these groups.

Besides the pursuit of dissimilar agendas, differences between persons with disabilities and elders have been accentuated by the direction of much gerontological work over the past few decades. This is seen, for example, in proliferation of the term ‘successful aging.’ In one of the early studies of two proponents of successful aging (Rowe & Kahn, 1987), a crucial dichotomy espoused by previous gerontological research distinguishing pathological aging from non-pathological aging was eliminated. Pathological aging was encumbered with disease and disability. Such symptoms as increased blood pressure and blood glucose level as well as certain cognitive conditions such as lapses of memory, however, were seen to be ‘normal’, non-pathological and even intrinsic to an aging process (Rowe & Kahn, 1987;). These supposedly ‘non-pathological’ aging conditions were simply symptomatic of poor exercise and dieting habits, and could be preempted. As a result, successful aging was also held to include low-probability of disease and disability caused by disease, high cognitive and physical functioning, and an active engagement with life (Rowe & Kahn, 1997).

Successful aging and disability are thus linked: as advances in medical technology and health awareness have come about, people have generally reached older ages. With increased life spans has come the propensity to see successful aging as a lifestyle choice despite the increased prevalence of disability experienced by aging persons in Canada (Social Development Canada, 2004). This phenomenon holds for both persons who acquire disability later on in life and those who have a life-long disability or have had one at a young age. Most elderly persons who acquire disabilities have a

disability for a relatively short time span, as the disability most often occurs near the end of life (Verbrugge & Yang, 2002).

Successful aging may possibly be seen to adequately explain the outcomes of those who live a relatively long life, followed by swift decline and death. This term, however, introduces the notion that some people age *unsuccessfully*, characterized by acquired disabilities in advanced age. Thus, the definition of successful aging as represented by Rowe & Kahn, describing a lack of impairment and illness, is observed here. The fear of aging, however, may result from a fear of acquiring disability, which in turn originates from the fear of being dependent on others (Hevey, 1991; Priestley, 2003; Stone, 2003). Successful aging, she states, appears to be occurring: positive images of aging can be seen on television and in advertising. Becoming more prevalent, however, is a separation between chronological aging and physical ability. This is “bolstered by research suggesting that cognitive and/or physical decline is not an inevitable result of aging” (Stone, 1993: 62). More popular now is the view that ‘normal aging’ will be the outcome for most individuals, with disease processes possibly interfering with this normal aging. Minkler (1990) proposes that this view has caused regression of attitudes to the point that elderly persons with disabilities are deemed somewhat culpable for having become disabled. Proponents of successful aging, then, de-emphasize that every person declines and eventually dies at some point (Stone, 2003). Health is pursued to prevent death, as opposed to simply being one of many ways to live. This is not to suggest that a sedentary life style is to be pursued, but to understand that the popular promotion of healthy, active lifestyles is possibly marginalizing aging persons with disabilities to a greater extent than in times past.

Methodology

Introduction

This chapter has two objectives: it first describes the sampling methodology that has been chosen for this study. Next, in order to describe methodology for analysis, a review of the GT process is presented. This process includes such concepts as saturation, theoretical sampling and categories. Techniques including coding, categorization, and memoing and the use of literature are also addressed. The chapter concludes with the argument that GT is a methodology that can best be put forward as a non-positivistic, inductive hermeneutic form of inquiry. This approach is suggested by David Rennie, who finds Barney Glaser's conception of GT as solely inductive as being closer to the original formulation of GT as a 'discovery' methodology than is the inductive-deductive approach of Anselm Strauss¹ and Juliet Corbin. Yet, Glaser's method does not fully extend itself in resolving the realism-relativism duality that is a hallmark of GT. This is rectified by the application of C.S. Peirce's theory of inference to GT, along with the phenomenological idea of bracketing, the hermeneutic circle and the persuasive character

¹ Glaser and Strauss were the original proponents of GT. Mention of 'Glaser and Strauss' in this study refers to their 1967 publication, *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Glaser considered his *Theoretical Sensitivity* (1978) to be in keeping with the original tenets of GT, and criticized Strauss and Corbin's *Basics of Qualitative Research* (1990) in his 1992 work, *Emergence v Forcing: Basics of Grounded Theory Analysis*. Exploration of GT within this study leads to embrace of Glaser's interpretation. While certain aspects of Strauss and Corbin's work, such as open and axial coding are discussed, they are broached more with the intent to give a comprehensive review of the literature than to suggest subscription to them. As Melia (1996) suggests, the majority of researchers have gravitated toward the Strauss and Corbin interpretation because of its supposed virtues of verification. It would seem right to investigate Strauss and Corbin's approach out of the number of researchers who employ it at present.

of rhetoric. As a result, GT takes on an interpretive, descriptive élan, instead of an explanatory, positivistic one.

Sampling

An interview guide consisting of semi-structured questions revolving around the theme (Patton, 2002) of QOL was used in conversations with participants (see Appendix A). The emphasis on an interview guide as opposed to standardized questions allows for probes to be added as the need for clarification of responses arises. The interview guide “keeps the interactions focused while allowing individual perspectives and experiences to emerge” (Patton, 2002: 344).

Support providers, whether formal or informal, were not present, as they could have influenced participants’ responses. The interviews were conducted in places of the participants’ choosing. Participants had the option to continue at another time if necessary. Participants could stop the interview at any time and were not obliged to answer any questions. Participants were given a honourarium of \$30 for their time.

Participants were chosen using purposive sampling that focused on age and duration of injury. This ensured that participants from the two demographic categories would be chosen in equal numbers. Both duration cohorts consisted of four participants of fifty years of age or older, with those who had SCI for twenty-five years or more composing one cohort and those with SCI for five years or less composing the other one. While this study entails research with a small sample of individuals, an effort was made to select participants with as diverse a range of impairments as possible. A balance in participants’ genders was also attempted. Eisenberg and Saltz (1991: 515) state that the

incidence of SCI among women had increased to 20% of all persons with SCI as of 1991; that number was significantly lower in past decades. Nonetheless, with such a small qualitative study that cannot produce generalizations that extend to others with SCI, the sample was not chosen with gender taken into account. The long-duration cohort was composed of two men and two women; the short-duration cohort was composed of one woman and three men.

This study could not have been made possible without the generous help of Mark Tonack, Research Scientist, of Lyndhurst Hospital at the Toronto Rehabilitation Institute.

The researcher initially met with TRI outpatient staff and described the nature of the study as well as providing protocol. All questions posed by staff were answered. Following staff agreement to aid in obtaining a sample, posters calling for participants were put up in suitable areas of the Institute. Interested persons approached staff, at which time staff described the study in a general fashion. If the inquirers continued to maintain an interest in the study, they made this known to outpatient staff. Staff then provided the researcher's contact information. Interested persons then called or emailed the researcher for further explanation of the study. Subsequently, the researcher met with participants to give further information about the study. A letter of information was furnished and an appointment for the interview was made. The researcher obtained informed written consent (see Appendix B) before the interviews began. While no risks or discomforts were anticipated in participating in this study, participants understood that counseling services, provided by the Toronto Rehabilitation Institute, were available if they experienced distress during or after the interview.

Participants understood that their names were not to appear anywhere in the summary of findings and thesis report. Recorded interviews were kept anonymous in a database, and all hard copies of transcripts were kept in a locked filing cabinet. Only the researcher had access to the database and hard copies of transcripts. Recorded data are to be destroyed up to twenty-four months after the study's successful completion.

In-depth, one-to-one interviews between the researcher and the participant were conducted using GT methodology. Interviews were approximately one to one and a half hours long. Probing questions that produced richer descriptions from participants than the questionnaire were employed and were constructed during the interview. The questions were formulated in order to gain a context of how participants saw their lives as influenced by impairment and disability before inquiring as to what quality of life meant to them. The questionnaire was largely adapted from that of Duggan & Dijkers (2001) in their investigation of subjective QOL among persons with SCI. In their study, the mean age of participants was 42.6 years, with a mean duration of SCI of 5.5 years.

Two background questions on age and duration of injury were first posed, followed by questions that investigate the context in which participants view their lives. For example, participants were first asked to categorize segments from their lives as if they were chapters in a book. They were then asked to describe a moment in which they felt great happiness, followed by a question asking them to describe an unpleasant moment. These contextual questions were important in that they gauged the centrality of SCI to the participant's life. Next, questions investigated if and how SCI has influenced participants' lives. The second half of the interview asked questions related to participants' interpretations of the term 'quality of life' and asked them to rate their QOL.

As a form of pilot testing, questions within the interview guide were closely scrutinized after the first and second interviews to search for redundancies or gaps between questions.

The Carleton University Research Ethics Board and the Toronto Rehabilitation Ethics Board approved of the interview protocol on March 1st, 2005 and June 23rd, 2005 respectively.

A summary of the interview and analysis process is given:

- i) Pilot interviews were conducted with two participants;
- ii) Data within pilot interviews was coded and arranged according to themes and sub-themes observed;
- iii) Transcriptions were reviewed to examine suitability of questions; congruency between preliminary themes and sub-themes observed, and preconceived notions of those categories of analysis was reflected upon. Interview guide was altered as was deemed necessary;
- iv) Interviews commenced with the six other participants. Data was coding and categorized.

GT: basic definitions and roots

To quote Glaser and Strauss in their 1967 publication *The Discovery of Grounded Theory*, GT is “the discovery of theory from data systematically obtained from social research” (2). This is brought about by inductive reasoning, or allowing the theory to ‘emerge’ from the data instead of proposing a series of hypotheses with subsequent testing. Glaser and Strauss argue that the viability of a theory, including its “logical consistency, clarity, parsimony, density, scope, [and] integration,” is directly dependent on the processes by which it was brought about (1967: 5). Thus, it will appear ‘grounded,’ in contrast to theories derived from qualitative research that either lack strong methods for processing and analyzing them, or are advanced through logical

deduction (Patton, 2002); that is, squeezing the data to fit a hypothesis. Instrumentally, a GT study is considered 'grounded' in its use of a constant comparative analysis, or the coding of all relevant data followed by their consistent analysis (Glaser & Strauss, 1967). This process begins with the first participant's data and continues, back and forth across that of other participants, until theories begin to develop.

What exactly does GT look for? Unlike phenomenology², which investigates the experiences of certain participants in order to ascribe meaning to a given phenomenon (Baker *et al*, 1992), GT as sociological research examines the core and peripheral processes that operate within a certain situation (Baker *et al*, 1992; Goulding, 2001). These processes, as opposed to a person's experiences, are paramount in the study. The main philosophical roots for this outlook lie in symbolic interactionism as professed by George Herbert Mead in the 1930s and Herbert Blumer in the 1960s. Mead's primary tenet is that the self is essentially constituted of the social roles and perspectives projected upon it by society and the agents within (Annells, 1996). Blumer, in turn, adds that the self interprets the meanings that are laid in front of it by society in the form of symbols. Language would be considered to be the most influential system of symbols (Annells, 1996).

Critical to understanding GT, then, is symbolic interactionism's relation to ontology, or the nature of reality. According to Glaser and Strauss, GT adopts the Mead-Blumer pragmatist notion of 'critical realism:' that 'social' and separate 'natural' worlds exist with different realities, and that these realities can be gleaned through the interpretation of symbols, albeit in an incomplete manner (Annells, 1996). This is part

² ... to which GT is sometimes mistakenly ascribed.

and parcel of the ‘discovery’ element of GT: on the one hand, ‘reality’ can be observed; on the other hand, the reality that is beheld is only an interpretation, though a theoretically grounded one at that. Particularity is the byword; emphasis is also placed on the relativism, or perspectivism at work.

As a result, we see that the Mead-Blumer pragmatist approach does ignore two critical issues: the first is that symbolic interactionism, and GT by extension, only investigates the social processes that occur between individuals. Little emphasis is placed on the influence of social structures or class on people’s behaviour (Annells, 1996). Proponents of pragmatic symbolic interactionism take for granted that participants’ actions are agency-based and are not affected by social constraints around them. The second criticism is that not only does the researcher report an interpretation of ‘what is really going on,’ but the participant can only give his/her best description of what ‘reality’ is as well. Participants’ reports, no matter how well-intentioned, are still prone to the influence of “interests, beliefs and values” (Rennie, 2000: 483-484). The question then becomes a hermeneutical issue of how deeply the interpreter will interpret the informant’s story. But GT, as is argued later, can indeed be considered as ‘real’ as any other qualitative research study. This is contingent upon the elimination of the false Cartesian ‘subject-object’ inquiry that is predominant in inquiry today. Hence, it is possible to make propositions that extend past the sample in a GT study.

Categories and coding

A brief review of various concepts within the GT process is given.

Categories

Categories within GT serve as the links between transcribed data and theories of a more abstract nature. Constant comparisons among different participants' accounts inevitably present similarities and differences for the researcher. With time, lower level categories and their properties are constructed from early data analysis, giving way to broader categories that link concepts together (Glaser and Strauss, 1967). The process by which categories are formed, however, entails that the researcher first observe a 'thing's' properties and dimensions, or its attributes and their measurable extent. Categories do not 'have' properties and dimensions; rather, properties and dimensions can be categorized (Dey, 1999). Moreover, according to Glaser, categories do not entail the deconstruction of every distinct 'moment,' idea or sentence in the data. This would create a cumbersome theoretical apparatus to work with, as well as putting the methodology before the data. With Glaser's formulation of GT, data is to be as unfettered from over-conceptualization as possible. He proposes (1978; 1992) that an entire incident is compared to another until similar patterns, leading to categorization, emerge.

The subsequent naming of these categories and their properties can either be based upon prior sociological constructs or *in vivo* words (Glaser, 1978). Sociologically constructed categories are those that are based on theoretical writings; *in vivo* categories explicitly emerge from the conversations at hand. Glaser (1992) prescribes that most sociological writings will have fifteen *in vivo* categories to one or two constructs.

Coding

Coding in quantitative analysis (as well as some qualitative analyses) usually involves conceptual construction of protocols to handle various responses to questions before the study is administered. GT, however, entails coding at the same time; not before, initial analysis of a study is conducted. Thus, theorization should not be conducted independently of coding. The interplay of data through coding creates new categories and adds to the richness of those already present. In turn, however, the researcher's descriptions of the data become exhausted (Dey, 1999).³ As a result, the categories eventually become 'theoretically saturated,' leading to coding at higher levels. Although this explanation was the basic one put forward in the original GT text, Strauss' and Corbin's (1990) description of coding procedures is the most widely accepted interpretation in the literature and consists of more conceptualized measures, including open, axial and selective coding. Open coding is seen as "the part of analysis that pertains specifically to the naming and categorizing of phenomena through close examination of data" (Strauss & Corbin, 1990: 62). In turn, axial coding represents relationships between categories through the use of a coding paradigm (Goulding, 2001; Strauss & Corbin, 1990). The paradigm consists of basic questions including 'Who?' 'What?' 'Where?' 'When?' 'How?' 'How much?' and 'Why?' (Strauss & Corbin, 1990).

Unlike Glaser and Strauss and Glaser's later texts, this particular process breaks coding and linking of categories down into explicit phases. Glaser (1992) castigates Strauss and Corbin's coding, arguing that it 'forces' the data to do the researcher's bidding instead of allowing the data to 'emerge' like the old text and Glaser's 1978

³ Dey (1999) notes a common error made within GT studies: it is not the data itself that becomes saturated and bereft of further elucidations, but the interpretations of that data.

work.⁴ Even more issue is taken with Strauss and Corbin's coding paradigm to compare categories. Glaser (1992) claims that his 1978 text outlined eighteen 'theoretical' coding families, of which the coding paradigm is but one. Glaser's use of theoretical codes offers the researcher a much broader range of possibilities in terms of how categories are compared amongst one another. The researcher also avoids the pitfall of employing only one theoretical construct by paying heed to Glaser's approach. Another difference between theoretical coding and the coding paradigm is that the former is considered to emerge throughout the study, even as 'substantive' coding is taking place. The coding paradigm, on the other hand, is explicitly applied to categories after a number have been constructed.

Concerns do exist toward Glaser's interpretation of theoretical coding, however. For example, while categories seem to emerge from the data, it is odd that the theoretical codes that relate them to each other do not. Though he ascribes eighteen to Strauss and Corbin's one, they are preconceived nonetheless. In this case, emergence depends on which theoretical code(s) the researcher sees in the data, not the codes themselves (Dey, 1999). In addition, Dey (1999) questions whether the 'cues' that point toward certain relationships between categories emerge, or are conceptualized to be cues by the researcher. If they follow the latter course, the theoretical relation that ensues is inferred, not emergent. Such is the beauty of Strauss and Corbin's coding: while it is awkward in its focus on textual minutiae and appears to 'force' data analysis more than Glaser's approach, it is less mystical in assuming that a particular interpretation of data does not

⁴ As Glaser points out in his critique of Strauss' divergent GT, "If you torture the data enough, it will give up! ... Forcing by preconception constantly derails it from relevance" (1992: 123).

just fall into one's lap. Their coding paradigm has been chosen for the purposes of this study (see Appendix C).

Analysis: theoretical sampling, memoing and literature

GT analysis is a highly structured process; the researcher is dissuaded at all times from attaching theories to text that has not been specifically categorized according to the constant comparative method. How does this method play out in practice? Two important logistical aspects of GT analysis are theoretical sampling and memoing.

Theoretical sampling

Theoretical sampling is the process by which the researcher collects, codes and analyzes data. It is a key step in understanding underlying patterns, making future decisions on sample size, and understanding what data to pursue and where to find them. One critical question that the researcher must ask is what group(s) is going to be approached for study, and for what theoretical purpose. The GT researcher, for example, is not conducting an ethnographic study where the fullest account of a group is necessary; (s)he is looking for groups of people according to how the theory of a social process is developing (Glaser & Strauss, 1967).

Contrary to quantitative and many forms of qualitative research, GT advises against 'purposeful sampling;' that is, picking a certain number of participants based on a hunch or prior literature review (Goulding, 2001). Instead, theoretical sampling occurs according to the flow of data emergence and corresponding category construction. If no more categories are emerging and those present seem to be saturated, there is probably no

more need to recruit participants. The opposite will occur with inadequate data. In this way, the selection of participants is a “function of the emerging hypothesis/hypotheses and the sample size a function of the theoretical completeness” (Cutcliffe, 2001: 1477). Theoretical sampling also illustrates the lack of hypotheses present at the beginning of the study. As patterns emerge in the data, however, even Glaser (1992) admits that some minimal deduction occurs in postulating where to go next for information.

Students often only have limited control over their sample size. Also, exerting control over the numbers of possible participants indicates purposeful sampling, not theoretical sampling. For instance, in order to finish on time, a ‘realistic’ sample size for this thesis study appears to be approximately eight participants. It would be possible to search eight participants out, one at a time, based upon what patterns of behaviour that had been observed in the last interview, but this process would be painstakingly slow. GT would certainly seem more appropriate as a qualitative methodology for a researcher with a long timeframe, or for a quantitative researcher with access to large numbers of participants’ data at once. On the other hand, variation between samples is not contingent upon the number of participants in the study. Creswell (1998) suggests that the GT researcher first collect and analyze data from a homogeneous group of people before proceeding to collect data from a heterogeneous group of people, all of whom share some characteristic with the first group. As iterated, “comparison groups provide simultaneous maximization or minimization of both differences and the similarities of data that bear on the categories being studied” (Glaser & Strauss, 1967: 55). This is possible with two groups of four people each, albeit the probability for variation being lower with a smaller group.

Memoing

Memos are tangible records that are designated to hold all of the researcher's thoughts on a GT study. Memos are written to interpret *in vivo* material, articulate metaphors, examine the relationships among code categories, explain major code categories, explore methodological issues, and generate theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990; Eaves, 2001: 659; Goulding, 2001). Often written in the margins of data but best written on separate cue cards, Memos should be utilized whenever a thought related to the study enters the researcher's mind. Data analysis is to commence immediately after collection has started, and comprehensive memos will indeed affect the way that the researcher approaches the investigation with the next participant. Glaser (1992) cautions that while memos are useful for any aspect of the study, sooner or later they will have to be 'theoretically sorted' in order to form good analyses for future readers or listeners.

Literature

Glaser and Strauss (and later, only Glaser) advocate a bare minimum in bringing preconceived categories and their accompanying data from other theories into a GT study. Remembering that the crux of GT is theory development, the inclusion of old data and categories is apt to hinder the researcher from proposing new theories (Glaser & Strauss, 1967). Also, as GT is based on situational contexts, new categories are the best fit with fresh data. Glaser later reiterates

There is a need not to review any of the literature in the substantive area under study. ... It is hard enough to generate one's own concepts, without the added burden of contending with the 'rich' derailments provided by the related literature in the form of conscious or unrecognized assumptions of what ought to be found in the data (1992: 31).

This can present difficulties for a novice researcher, as the inclusion of older theories and data are necessary for a literature review, a critical piece of a Master's or Ph.D. thesis. In order to hinder 'forcing' of the data later on, Melia (1996) advocates proceeding into the field as soon as a phenomenon has been identified for study.

But the key is *when* to conduct the literature review: Glaser (1992) suggests that the researcher read the relevant literature during coding, as it will be faster and easier to digest because (s)he will only be looking for older data that is relevant to the emerging theory in his own study. Strauss and Corbin (1990), in contrast, suggest that a pointed literature review informs about the researcher's theoretical sensitivity toward the phenomenon. Such a review informs a priori assumptions (hence deduction and 'forcing' of the data, according to Glaser) toward a qualitative study. The student must keep both of these ideas in mind and make a pragmatic decision in creating a *successful* research design.

Moving GT away from positivism: hermeneutics and limits of deduction-induction

The final component of the methodology chapter links GT to hermeneutics in a move to address accusations that it is grounded as a positivist framework. This has important ramifications for its practical use, as GT would undoubtedly fail as an acclaimed positivist method with its lack of hypotheses and use of theoretical sampling, to name but a few concerns. In their original conception of GT, Glaser and Strauss (1967) claim that GT is an inherently generational theory, as opposed to a verifying one; a hallmark of positivist methods.

How do proponents of GT address concerns that it is too closely oriented to positivism? Glaser tends to avoid the question, answering that its generation of good, inductively driven theory is enough (Glaser, 1992). This claim often does not get far with skeptics of non-positivist qualitative research, who point out that Glaser and Strauss (1967) can only go so far (Rennie, 1998). Deductive reasoning suggests *a priori* assumptions, whereby a methodology would only be verificational. In conjunction, another problem is the view that GT has a perspectivist outlook. For example, Glaser and Strauss (1967) maintain that the results of a GT study may not be replicable with different participants or even researchers. This hearkens back to the stances taken by Mead and Blumer, the ancestors of GT. Thus, GT must also contend with existence as an unresolved realist-relativist duality (Rennie, 2000).

A solution to this conundrum may be found, however, if GT is posited as a form of phenomenology and hermeneutics. This is not difficult to conceive, as Glaser and Strauss adopt components from several methodologies without admission. Phenomenological bracketing entails the acknowledgment that the researcher's biases are inherent in the study. With this conscious affirmation, the investigator then examines the meaning of an experience with as faithful an adherence to 'objectivity' as possible (Zaner, 1970; Patton, 2002). This concept does not yet hold much currency against positivism, as a subject-object dichotomy in most research is still often espoused. Rectification comes by acknowledgment of a 'double hermeneutic,' or the understanding that not only are the researcher's observations interpretations at a fundamental level; interests and beliefs colour the participant's recollection of experience, transforming it into an interpretation as well (Rennie, 1998). Moreover, the qualitative researcher and

participant enter a ‘hermeneutic circle,’ in which the investigator learns about how (s)he perceives the world while actively observing the experiences of others (Addison, 1989; Moustakas, 1994; Rennie, 1998). This erodes the subject-object dynamic and moves GT farther away from pragmatism whose proponents, such as Mead and Blumer, posit a ‘real’ world apart from those experiencing it.

Successful negotiation of the Cartesian subject-object dualism, though, does not relieve Glaser’s GT of the burden that has affected it throughout this chapter: the suspicion that ‘emergence’ can never be fully inductive in that induction does not occur without *a priori* deductive assumptions; another Cartesian dualism. This is particularly problematic, as Glaser and Strauss (1967) herald GT as a methodology for understanding natural science. C. S. Peirce’s theory of inference reconciles induction as “sufficient unto itself,” obviating the deductive step and preventing GT from becoming part of the scientific method (Rennie, 1999: 482). Peirce holds deduction as redundant, for the meaning of its conclusions is found in its *a priori* premises. Knowledge, then, does not stem from deduction, but from the relationship between induction and abduction, an imagined hypothesis (Rennie, 2000). Peirce writes:

Abduction makes its start from the facts, without, at the outset, having any particular theory in view, though it is motivated by the feeling that a theory is needed to explain the surprising facts. Induction makes its start from a hypothesis which seems to recommend itself, without at the outset having any particular facts in view, though it feels the need of facts to support the theory. Abduction seeks a theory (1960, VII: para. 218).

The beginning of abductive inquiry, as opposed to being a statement of premises, is conceived to be a hypothesis of what is to come from examining a phenomenon. The hypothesis is then resolved through induction, letting the story reveal itself. In turn, the

new results may be postulated as hypotheses for the next round of inductive research. Induction becomes “self-correcting” (Rennie, 2000: 490). Deduction is hindered through bracketing of preconceived conceptualizations until the new data from the phenomenon have emerged. Thus, the relationship between abduction and induction is a symbiotic one. Bracketing is also made easier by the fact that the researcher has overcome the subject-object dichotomy as proposed by positivism (Rennie, 1999); (s)he can feel more comfortable in explicitly stating biases before interpreting the phenomenon. Another major implication for GT is that the realist/relativist duality is resolved; the abduction-induction symbiosis provides a vehicle for reality to be observed and interpreted, while perspectivism is upheld by the double hermeneutic, the hermeneutic circle and bracketing.

The role of rhetoric, or persuasive language in conveying a hermeneutic approach to GT must be emphasized. Rennie (1999) iterates Aristotle’s argument that rhetoric may be more powerfully conveyed to skeptics through *phronesis*, or an appeal to common sense, than *episteme*, or logical, rational arguments. Relating to GT, rhetoric must be used to defend a study on the grounds that it is sound and thorough. The theory must be grounded to the text and, above, all, *reflexive* in its observation of the subject-object duality, for that is the strength of qualitative research (Rennie, 1999). Rhetoric is such that some interpretations of reality will be considered more valid than others. With its realist-relativist orientation, GT is in a better position than many other interpretive approaches in articulating cogent theory to doubting readers.

This chapter has begun by iterating history and various conceptualizations are necessary for understanding GT. The second component consists of a defense of GT as a

form of methodological hermeneutics, primarily instigated by David Rennie. C. S. Peirce alters the conventional inductive-deductive duality with the introduction of abduction, or hypothesis (and not premise) at the 'moment' of beholding a phenomenon, thus obviating deduction and the positivist mode of inquiry. This can be implemented as long as the researcher agrees that the Cartesian subject-object duality is an illusion. The double hermeneutic and the hermeneutic circle teach reflexivity in interactional processes, while phenomenological bracketing and the acknowledgment of bias convinces the reader of the researcher's 'true' intent. The GT study is then objectified, or gains validity through rhetoric (Rennie, 1999).

GT has certainly taken its share of controversy, considering that it originated only 40 years ago. The Strauss and Corbin conceptualization of GT is a system that enforces rigorous rules for processing of data in order to draw theory out. Glaser (1978; 1992) argues that his colleagues have significantly deviated from the original GT premises of induction and discovery. Yet however much more one may support Glaser's message than Strauss and Corbin's, Glaser's emphasis on emergence ignores several a priori assumptions that crop up through the GT process. Many have been illustrated here. Rennie's approach protects Glaser from accusations of deduction and improves GT's validity over other hermeneutic methodologies that incorporate more relativistic elements.

Discussion of findings

Introduction

This chapter investigates the study's research question: what are perceptions of quality of life among persons with SCI aged 50 years and over, having injury for a short duration (5 years or less) or a long duration (25 years or more)? Grounded theory was employed to understand the basic social processes that were occurring in persons' experiences with SCI.

Participants were numbered in random sequence. Age, type of injury and duration of injury attributes was as follows:¹

Emma: 67 years of age. Complete paraplegia. Duration of SCI: 47 years.
Anthony: 72 years of age. Incomplete quadriplegia. Duration of SCI: 1.25 years
Sybil: 68 years of age. Incomplete paraplegia. Duration of SCI: 26 years.
Michael: 63 years of age. Complete paraplegia. Duration of SCI: 42 years.
Herman: 53 years of age. Complete paraplegia. Duration of SCI: 4 months.
William: 56 years of age. Complete paraplegia. Duration of SCI: 10 months.
Norman: 62 years of age. Incomplete quadriplegia. Duration of SCI: 44 years.
Jessica: 64 years of age. Incomplete paraplegia. Duration of SCI: 3.5 years.

A grounded theory approach

Analysis of the interviews of eight persons with SCI commenced in order to understand the basic social processes that occur in their lives. As previously iterated, this was accomplished according to an adaptation of grounded theory methodology. Initially, a set of 33 codes was derived from open coding, or a line-by-line analysis of interview transcriptions. With axial coding, these codes were collapsed and merged into 14 subcategories. These, in turn, were collapsed further until two extensive categories were constituted. A Level 1 designation constituted the most basic subcategories observed,

¹ Participants' ages and durations of SCI are at time of interview. Participants' names have been changed in order to maintain anonymity.

with Level 2 and Level 3 designations corresponding to broader, more abstract subcategories. The categories that emerged were “Regaining or maintaining independence” and “Social support and social relationships”. Subcategories received designations only in relation to more or less abstract phenomena that were observed above or below them. That is, a subcategory such as “Housing” was designated as Level 2, as there were no *more abstract* phenomena that would have entailed a more ‘basic’ designation of Level 1. Furthermore, subcategories of various levels were incommensurable *across* categories in terms of their ‘abstractness;’ ergo, neither of the two unconnected subcategories “Overuse of body due to SCI” and “Housing,” Level 1 and 2 subcategories respectively, were any more ‘abstract’ than the other.

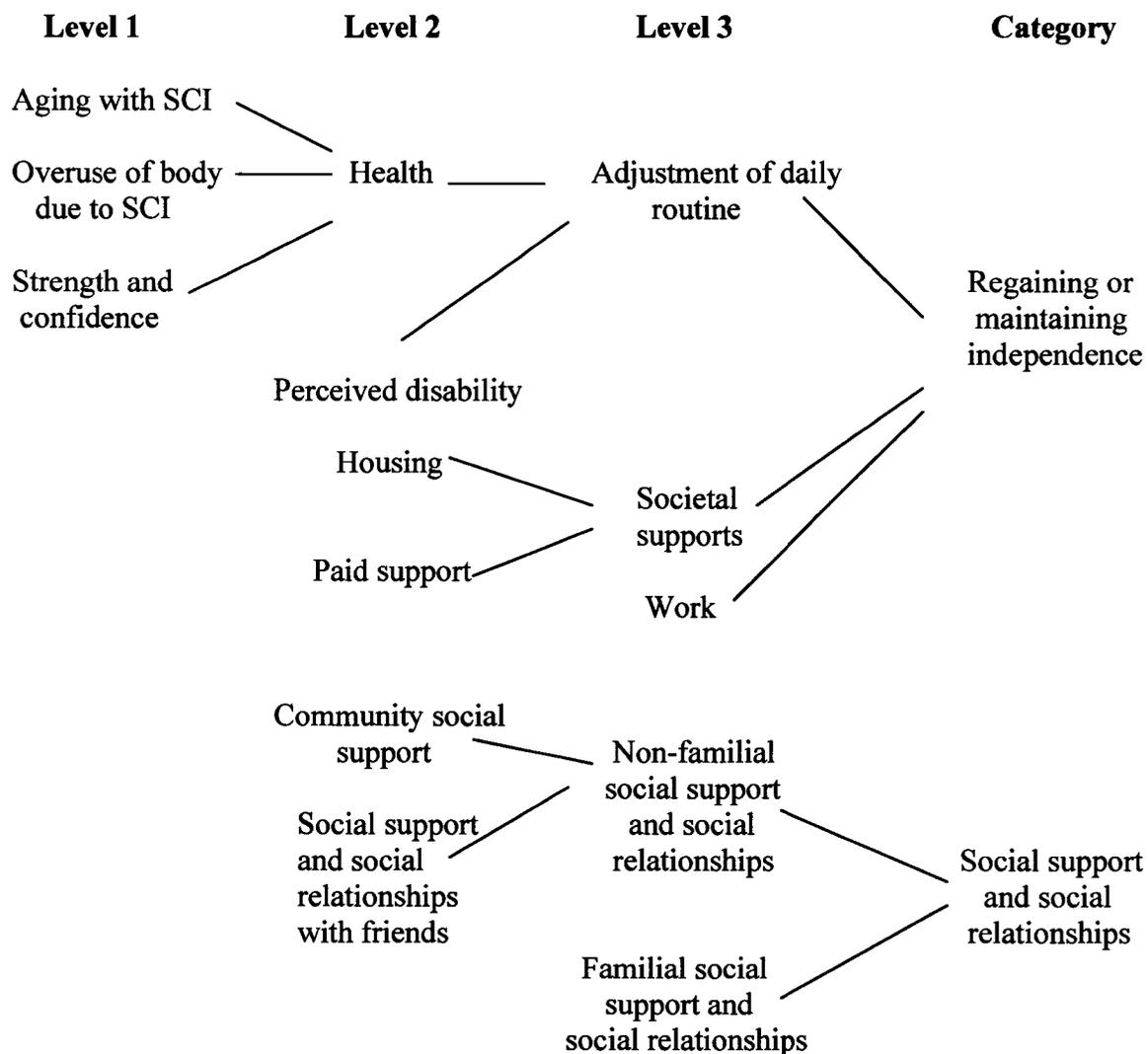
Constant comparison of each stage of coding and categorization with the interview transcripts ensured as accurate and rigorous a process as possible. The categories have been described with the basic social process, its causes, context, intervening variables, individual strategies, interaction among actors, and consequences taken into account. Figure 1 models the emerging categories with accompanying codes.

Explanation of each category will begin with description of its broadest, most abstract subcategories, followed by discussion of its most basic subcategories.

Category: Regaining or maintaining independence

Regaining or maintaining independence was one of the key branches in the lives of participants. Independence was affected by adjustment of daily routine with SCI, income and access to societal supports.

Figure 1: Emerging categories of interviews with persons with SCI, ages 50 and over, with short and long durations of injury



Definitions

Participants defined ‘independence’ in different ways and sometimes interchanged meanings in the interview. Herman, who had SCI for 4 months, defined it as being “able to do what you like in life.” Whether or not the accomplishment of the activity was aided by a care provider or assistive device was irrelevant; the individual had autonomy in deciding when the activity was pursued, and how the support, if one was present, was to be used.

Participants with long durations of injury were more inclined to define independence as not having to rely heavily on other people or assistive devices for help with any activities. For example, Michael, who had had SCI for 42 years, stated, “I don’t want anyone to take care of me; I want to be independent and look after myself. I think that’s the main thing with me.” In comparison, Emma, who had had SCI for 47 years, was hesitant to replace her manual wheelchair with a motorized one because she was afraid that she would not be able to learn how to use it effectively. Thus, employment of this particular definition of independence may have depended upon age at injury and duration of injury. For example, participants who were injured at younger ages and had long durations of injury would have been used to using such devices as manual wheelchairs for a significant portion of their lives; this would have made it more difficult to contemplate switching over to newer technology.

In contrast, some participants also gave a broader basis of meaning to the term, indirectly defining it as having control over the process by which desired activities were accomplished. Whether or not the accomplishment of the activity was aided by a care provider or assistive device was irrelevant; the individual had autonomy in deciding when

the activity was pursued, and how the support, if one was present, was to be used. A respectful attitude toward the individual on the part of care providers was considered crucial in maintaining independence.

Level 3 subcategory: Adjustment of daily routine

Participants spoke of a need to accept their SCI and ‘move on.’ This was important, as acceptance meant that SCI was no longer a central feature in their lives. ‘Moving on’ was interpreted to mean that processes by which activities of daily living (ADLs) and instrumental activities of daily living (IADLs) were now accomplished had been ingrained into their lives in the same way that they had been prior to SCI. That is, changes in daily activities due to SCI were internalized to the extent that they were not considered discreet phenomena known as ‘routines.’ They had become part of ‘life.’

Activities of daily living were orientated toward personal care and included such operations as toileting, dressing, feeding, repositioning of the body, and moving around (HD Links). Instrumental activities of daily living, however, encompassed operations that contribute toward “independent living” (National Center for Health Statistics, IADL section). These excluded personal care but involve such activities as buying groceries, opening mail, keeping a home clean, and social activities such as playing sports or watching a play.

Adjustment to daily routine was composed of the subcategories health and perceived disability.

Level 2 subcategory: Health

Health was observed to be one of the branches of adjustment of daily routine.

Maintaining a high level of health enabled a person to continue to pursue their desired outcomes to the fullest, as well as having to rely less on others for assistance.

Level 1 subcategory (Health): Aging with SCI

In regard to health, aging was observed as changing physiological processes that were consistent with what other aging persons without SCI were experiencing. These processes were either unrelated to SCI, or related to SCI but came as a result of diminishment of strength, flexibility and mobility. While it was difficult to observe if participants were experiencing adverse effects of SCI due to overuse or diminishment of strength, flexibility and mobility, some participants made the distinction.

Participants with long durations of disability were more affected by adverse aging concerns than their short-duration counterparts. Some physiological concerns seemed to be attributable to lack of movement of certain bodily extremities. Michael, who was 62 and had had SCI for 42 years, recounted

I don't have the strength [to accomplish certain activities]. Like when I played basketball, I used to get up and down the floor in this chair just like that. I can't do that. Don't have the strength and the mobility and flexibility. Now, I have to tie my feet in, because I'm so spastic.

Michael discerned that a gradual weakening of his body had occurred and was observed in his declining efficiency in ADLs and IADLs. This, despite the fact that his former home, a house, had been modified to accommodate his needs, and that he had used a number of supports to accomplish such tasks as snow clearance, gardening, and working

on his car. Sybil, who was 68 and had had SCI for 26 years, thought that her habits had changed over the last few years:

You want to sit down more; you want to get really easy [relaxed?].
Sometimes I take it easy, but then I say no, no, no, because when I
take it easy too much, I get lazy and my muscles get weaker.

Though Sybil's increased fatigue in recent years was evident, the fear of losing strength provided motivation for her to continue exercise classes at Lyndhurst. The point to emphasize is that participants with long durations of SCI were experiencing a physiological aging process that they considered different from adverse effects due to overuse of certain parts of their bodies, but related to living several years with impairment nonetheless. These effects were affecting their daily routines in terms of recreational activities and efficiency in completing ADLs and IADLs.

Participants with short durations of injury, on the other hand, communicated few concerns about a gradual weakening of their bodies related to SCI. Instead, such health issues that had originated prior to SCI were discussed. One participant mentioned osteoarthritis. Anthony, in comparison, explained that the health issues that were experienced while aging with SCI were trivial compared to the SCI itself:

When I was 70, I was flying high... I didn't realize how lucky I was.
But when you hit a brick wall, you know, you're gonna have high
blood pressure, or you have to take something for cholesterol, or
something like that... these are all minor things. Anyways, the SCI
really hits you like a brick wall.

Short-duration participants' only health concerns were related to the short-term impacts of SCI. While some of these participants might have 'had SCI while aging', none were deemed to be 'aging with SCI' in the same way as their counterparts with long durations of injury.

Level 1 subcategory (Health): Overuse of the body due to SCI

Participants with short durations of SCI did not refer to any overuse of certain parts of their bodies in order to compensate for a lack of functionality. Two long-duration participants, however, mentioned how overuse of certain limbs had led to a loss of function. Emma, who at 67 years of age had had SCI for 47 years, discussed certain physiological problems and their corresponding impact:

I still live in the same apartment, but things are becoming harder now because my shoulder's so bad. I have rotator cuff problems, and I've been taking cortisone, which really helps but that only lasts for so long. I've been having problems for years; it's just getting worse. I've had to stop exercising. Things at home now are harder to reach. My transfers in and out of my chair are now a bit harder. One of my big bugaboos is washrooms.

Multiple functional issues had resulted from the debilitation of Emma's shoulders, primarily as a result of pushing her manual wheelchair for so long. Besides difficulty with ADLs such as moving her body, Emma's inability to exercise promoted a further loss of strength and an increase in fatigue. In comparison, Michael also experienced deterioration in his shoulders and wrists due to physical stress from his job, that of a recreational counselor. His involvement in wheelchair basketball at the national level for 15 years promoted additional decline. Yet he indicated that certain structural issues had accelerated the weakening of his body: for instance, the need to push 60-lb wheelchairs in previous decades instead of 20-lb chairs as used in 2006. He also observed that many socioeconomic elements such as gas stations and grocery stores had increasingly adopted more 'self-serve' features than before that made adjustment of daily routine difficult for an aging person with SCI:

I don't have the strength to transfer, folding, in and out, in and out; if something goes wrong... in the old days, for

instance, they used to pump gas. You used to get your gas, your oil, your windshield washing—things are not more difficult now than they were in those days. Everything's such a factor. You have to hustle. It's more individualized with the technology—it's hard to believe with the technology that they have now. Little things like that—driving your car, going out and having a good time. I can't do that without it hurting.

Michael was commenting that the transformation of infrastructure such as the reduction of full-serve gas stations had sometimes resulted in a less accessible environment.

Physical aging, he felt, had rendered him less able to respond to these changes. Some participants with long durations of injury had been accustomed to using supports such as manual wheelchairs for decades after injury; these supports were part of their daily routines. Aging in recent years, however, meant that many supports that they had been accomplishing certain tasks with had been found inadequate. This raised the dilemma of having to pay for new supports that would make accomplishment of an activity easier, or risk losing the ability to complete the activity. Finally, even though older supports may be less efficient than newer ones, persons with long durations of disability may refuse to switch to the latter out of habit.

Level 1 subcategory (Health): Strength and confidence

Keeping physically active aided participants in maintaining or building health and strength. In turn, new levels of health and strength instilled the confidence to take on a more socially and physically active lifestyle, thus giving rise to even greater health, strength and confidence. Here, the activities that the person enjoyed participating in before SCI, as well as the resources that the person had to be able to enjoy those activities, had an impact on the physicality of the lifestyle that was undertaken after

injury. For example, Anthony, who had had SCI for 1.25 years prior to being interviewed, enjoyed the habit of long, brisk walks on Saturdays to the St. Lawrence Market in Toronto before sustaining injury. As such, after incurring incomplete quadriplegia, he set a walk to the St. Lawrence Market as a goal. While he had not accomplished this goal at the time of interview, he had confidence that he would and strove to go for walks whenever he could.

Physical rehabilitation was observed to be an important element in maintaining and regaining health and confidence, especially for participants with short durations of injury. These participants connected rehabilitation to regaining some physical aspects of their lives, prior to SCI, that they had lost. This brought on feelings of confidence.

Herman, who had paraplegia, explained:

Physio's been helping me a lot. When I'm lifting weights in the gym, it makes you feel alive. Even your legs; you have to make sure your legs keep pumping, because if they come out with new technology, like that stem-cell stuff, you have to be ready. If you're not active, and they can do something for you, that would be no good. You have to keep that hope going. It's hard to do.

Herman connected his rehabilitation efforts to his sense of 'normality,' or not having a disability. Likewise, Anthony described a reconstruction of himself as only being temporarily impaired by emphasizing the connection between walking and his life prior to SCI.

At the time of the accident, I was like a basketcase. However, in very short order, I lifted out of bed, in an overhead lift and so on. In very short order, I was able to... they got me on my feet, and that was really great. I couldn't walk, but just the fact that I could do that again [stand up]... I focused everything on getting walking ability back. ... January 2005, I kinda graduated out of the wheelchair.

Though Lyndhurst staff told him that he might have set his limits for rehabilitation too high, Anthony desired to regain 'normal' functioning in the hope that he could rise above his perceived status as a person using a wheelchair. While his mobility could indeed be improved by using a wheelchair, Anthony's emphasis on establishing a routine that would portray his impairment as temporary suggested an aversion to being labeled as a person with a disability. Anthony noted that some rehabilitation staff encouraged his regaining of mobility, sometimes to the point where he considered them over-aggressive in their approach. Barnes et al. (1999) explain that rehabilitation personnel often attempt to 'normalize' the disabling consequences of impairment. Impairment, however, does not necessarily preclude the chance of having a meaningful life.

Thus, participants with short durations of injury emphasized two elements within their rehabilitative exercise. The first was that regaining physical function would be invaluable for ADLs and IADLs at present and in the future. Secondly, these participants felt that they would be recovering some sense of 'normality' that was lost with SCI. Furthermore, the presence of Lyndhurst as a rehabilitative unit represented an excellent socioeconomic support for these participants to regain physical function, discuss any negative attitudes toward their disability, and interact with individuals with similar disabilities.

Though they had been physically vigorous in previous years, only 1 of 4 participants with long durations of injury indicated that she had an adequate exercise routine. Sybil observed that exposure to Lyndhurst's exercise programs had resulted in increases in her strength as well as confidence.

Sometimes I have pain, but since I do exercise I feel much better. I told you, mentally, physically, I feel better. Because

some people, sometimes it's more mental. You see, I meet people here who are like 'yeah... yeah...' they don't talk. I ask what's the matter? I say let's go for coffee. They don't want to see nobody. They feel bad because they've had an accident. I meet wives who say, talk to my husband to make him feel better. Now, I make them come to fitness centre!

Sybil's confidence was seen in interactions that she had with other persons with SCI at Lyndhurst who appeared downcast, only to often be convinced into participating in exercise classes with her. Not only did exercise increase her strength; it represented a social activity in which she felt good by being encouraging to other individuals who were downcast. The other three participants with long durations of injury stated, however, that they now had inadequate exercise routines. This was not from any lack of motivation to exercise, but due to physiological processes of aging, overuse of certain parts of the body, and a dearth of recreational programs for older persons with SCI.

For example, Michael felt that his independence had been curtailed by a lack of recreational programs for aging persons with SCI outside of those offered at Lyndhurst. Physical programs that did exist for persons with disabilities who used wheelchairs were primarily for younger people. This was unfortunate, as Michael's passion for basketball had endured to the day of the interview. His drive to teach and motivate others could be seen in his occupation as a recreational counselor. Yet Michael complained that few physical recreational activities existed for older persons with SCI. The problem was not the lack of recreational facilities, with most, if not all, being fully accessible in his locale in the Greater Toronto Area; it was the lack of programs.

There's a basketball program up in Burlington. I'd heard about this program, despite inquiring about it. So I called this coach and asked if there was anyway I could get into a recreational basketball league. He said no, just competitive. I asked, is there anyway I could be of assistance, because that's what I did for a

living, right? He said no. So I asked if there's anyway that I could come up there and play? He said no, he really only takes people 25 years of age or younger.

Michael's frustration was evident: "I was trying to be helpful. I mean, they might learn something from me because I did it for so many years, but they weren't interested."

Unfortunately, lack of programs for aging persons who use wheelchairs may be due to low numbers of potential participants. Or, it may be a result of ageist attitudes that presume the reluctance of older persons to participate in social activities and that they have little to offer younger generations. Lyndhurst identifies the need for such programs for seniors with spinal impairments, but the facilities were far from where Michael resided. Lack of access to social activities, especially in the winter, had brought on a sense of boredom and melancholy in Michael, and he was less motivated than before to go out and search for things to do. At the same time, Michael's health outcomes had been negatively impacted as he considered basketball to be his only form of exercise. Withdrawal from his job due to debilitation of his shoulders had exacerbated his isolation, and though he had a fully accessible apartment, he found the community outside socially inaccessible for lack of activities. Thus, his independence, or the sense that he had control over as many variables of his life as desired, had diminished.

Level 2 subcategory: Perceived disability

Spinal cord injury caused a transformation in participants' daily routines with their ways of life prior to injury having been significantly altered. Those who described their experiences following SCI felt that many capabilities that they previously had were lost. The variety of responses that participants gave in demonstrating how they coped with

having an impairment, or how they had moved on from coping with an impairment, suggests that adjustment to SCI is not a linear process (Trieschmann, 1988).

Responses of participants with short durations of SCI indicated that their injury was still one of the main focal points in their lives. That is, they appeared to still be adjusting to having a disability. William conjectured that his disability might have been linked to fate in that none in his family had experienced disability or illness until they were of advanced age:

... there's people who've had cancer to deal with in their family or serious illness. We had none of that up until this happened to me. Maybe it was just our turn to have something really negative to hit the family. I don't know, that's maybe the only way I can justify what's happened to me, is that maybe it was our turn to have something. Thinking of it that way, I'm so thankful it happened to me and some other member of the family. If my son who's 18 had had a farming accident and it had to put him in this position, I just don't know how I would have dealt with it.

For William, experiencing the impairment was almost unfair; discussing the possibility of fate was needed to help justify his feelings of loss. Furthermore, his premise that it was better that he incurred SCI than his son indicated a belief that impairment did not allow for many positive life experiences. Hence, it was better that he had SCI than his son because he had had 56 years of good memories already. This illustrates the disengagement from social life that persons may experience when incurring a disability in older age. Negative feelings provoked by the impairment may promote the attitude that withdrawal from social activities in one's later years is 'normal.' An economic consideration was evident in William's explanation as well: owning a successful fuel distribution business in a small community, he could afford to disengage from his occupation and be content with what he had accomplished prior to sustaining SCI.

Herman, in contrast, felt that his attitude toward accumulation of material goods put him in good stead for coping with SCI:

We live in a materialistic world. We want, want, want. If you stop and think differently, you'd say, I need this. You'd be content just with what you have. Much better quality of life then. ... It helps my situation to think that... to be content with less.

Having less and, in turn, wanting less, in terms of socioeconomic goods, was similarly equated with having a disability. Persons with recently incurred disabilities would be best off by having few expectations as to the activities that they could accomplish. Thus, they would feel less distressed if they did not gain their desired outcomes. For disability theorists (Oliver, 1990; Corbett, 1997; Barnes et al., 1999), this concept is located within an individual model of disability. Persons with disabilities' apparent failure to adjust to new routines ignores the structural and cultural factors that contribute toward their location as sick, dependent individuals. A decrease in expectations for a good QOL following SCI is not contingent on the impairment itself, but from discrimination and a lack of material resources. Morris (1991), however, argues that the distress of incurring impairment is indeed tragic and 'real' for persons with disabilities; disability is not only propagated by structural and cultural factors. To deny persons with SCI the validity of their emotional and physical pain at their loss, to amount it to social factors, cheapens their experience of impairment. Perceived loss of functionality is as 'real' as socioeconomic factors of disablement. As Sybil noted, "after the accident, everything changed. Life is not there anymore. You lose everything." Capabilities are not the only components of the former life that have been experienced to have diminished: a person with SCI may also experience a loss of able-bodied identity.

Jessica's perceptions of disability were different than those of other participants in her short-duration cohort in that she did not view her SCI as devastating. While she had not accomplished her goal of walking on a regular basis, she had rehabilitated to a certain extent that she felt comfortable with her progress. Moreover, use of her electric wheelchair had convinced her that she could accomplish most of the IADLs that she had undertaken prior to injury. Thus, the sense that she was regaining her physical function to some degree had helped her cope with SCI. In turn, the use of new supports assisted in reducing the impact of disability on her life.

While adjustment of daily routines to accommodate SCI was important for short-duration participants, the lack of centrality of SCI in the daily routines of those with long durations of injury was also reflected. Furthermore, years of living with their disability had made these participants aware of structural inequities and discrimination against persons with disabilities in society. Variations in the ways that they had adapted their daily routines to living with SCI, however, were evident. For example, Emma recollected several instances in which she had applied for jobs to be a medical secretary, only to be turned down at the interview when an employer found out that she had a SCI and would need accommodations above what that office offered. As a result of this discrimination by would-be employers, she was forced her to re-examine her approach to applying for jobs.

... this is something I argue with other people in chairs: we ask whether we should indicate out front in our resumé that we are in chairs, or do we surprise them [employers]. And I usually come out and tell them. The other argument is no. But I say that if you don't come out in the resumé, you'll not get anywhere in the interview because they're stunned.

Emma's tactic gave the employer notification in advance that she would potentially need accommodations above what the workplace currently offered. Nonetheless, indicating her disability status saved her the anguish of knowing whether she did not get a job because she had a disability and the employer was not willing to accommodate; because she was less qualified than another applicant; or because her disability led the employer to believe that she was less qualified than another applicant. Adjustment of her routine in applying for jobs came as a result of negative social stereotypes toward persons with disabilities. She outlined her approach in preparing for outcomes:

... don't build your life around the wheelchair. ... I decide I want to do something, and I just go ahead and I start preparing to do it. And then I factor in the wheelchair. But by that time, all my plans are in place and I say, uh, the wheelchair's gotta be factored into that.

Emma, in this case, was explicating her preparation for a trip to Florida a few years ago. Though her children questioned whether she would be able to support herself, she found the matter of getting on and off a plane and exploring a foreign environment while having SCI trivial. Thus, Emma considered the presence and accommodation of her SCI as second nature in her daily routine. While she certainly acknowledged herself as having SCI, she emphasized that people's negative attitudes toward her impairment were not going to hinder her from doing as she pleased. As a result, activities that some would find unusual for a person with SCI to accomplish became commonplace. Emma also emphasized, however, that her approach of advocating for herself was not without cause. The conditions by which she felt it necessary to advocate for a more equitable environment were borne from raising a family for 20 years after SCI before getting a divorce, and receiving scant financial support in her aim to finish school and enter the workforce.

Persons with disabilities are often regarded as ‘inadequate’ because of the assumption that they cannot take pleasure in available socioeconomic benefits as others do (Hunt, 1966). Thus, when they participate in pursuits that make them happy, they are extolled for their heroism because they do not ‘fit’ into their assumed role as sick and dependent entities. Emma admitted that while participants in her SCI peer support group looked up to her for exciting stories that they felt they lacked in their lives, life had just been “normal” for her: “It’s no different than an able-bodied person, except that I do things a bit differently to get to that spot.” She stressed that her activities were not to be lauded but simply accepted as one person’s interests, regardless of age or disability. Adjustment of her daily routine came by way of accepting the loss of her able-bodied identity and advocating to acquire the supports that she felt necessary for a satisfactory life.

Sybil, in contrast, viewed her disability in a similar way as Herman. That is, she felt that she had lost the ability to participate in various activities such as paid work and certain social outings with her family. Yet she also felt that her disposition toward life assisted her in dealing with the negative affects of her disability.

If I drink coffee, I like milk. If there’s no milk, no big deal. I say, thank God I’m alive. Thank God I have my hands; I can wash my face; dress; a lot of stuff. I cook, knit, bake; I do what I can. ... Other people moan and say, “I can’t do this.” I say, get up! Look at me, I’m cooking! Like, I babysit my grandchildren. My sister asks me, how do you do it? I say, I do it.

Sybil’s sunny disposition may not be the only reason for her attitude toward her disability. Unlike the other participants with long durations of injury who stressed their independence as being of crucial importance for QOL, Sybil emphasized happiness and family as two important indicators. Sybil’s continuing marriage, in comparison to those

of the other three long-duration participants that had ended prior to their interview, may provide an explanation. That is, close proximity to her spouse, children and grandchildren gave her ongoing social and financial support, obviating the need to advocate for herself in such environments as the paid workplace. Furthermore, Sybil, who incurred SCI at the age of 42, had been much older than the other participants with long durations of SCI, who had a mean age at injury of 19.6 years. She had not experienced many of the structural inequities such as inaccessible buildings and transportation that had affected the others as they endeavoured to participate in activities such as finding work or raising a family with SCI. These were contributing factors as to why her perception of disability, of being limited in capability but being happy for what she could do, was closer to the views of the participants with short durations of injury.

While every participant described their experiences of injury as being traumatic, some participants were observed to have adjusted their daily routines with SCI better than others. These participants had managed to incorporate their disability into their lives to the point that their injuries were only seen as one facet of their existences, not the overriding aspect. Though some participants noted that they had a certain disposition that enabled them to cope well with SCI, variables such as income, marital status, age at time of injury and duration of injury were observed to be influential factors in participants' adjustment. Yet as Herman noted of his experiences with other patients at Lyndhurst, "one guy was in denial for 1 year, one for 4 years." Disability is not only composed of environmental antecedents that shape people's views; on a certain level, the physical and emotional pain from sustaining impairment is an individual's experience.

Compared to participants with long durations of injury, participants with short durations of injury were observed to be in the midst of establishing new daily routines. Quality of life for those in this group was based on how well they were adjusting. Unfortunately, negative attitudes toward disability prior to SCI contributed toward some participants' adoption of rehabilitative routines that sought to eradicate their impairment. The realization that impairment was permanent was difficult for some participants to accept. In contrast, participants with long durations of injury showed positive adjustment toward their SCI. Routines had been internalized several years ago, with QOL being emphasized as full participation in society.

Level 3 subcategory: Societal supports

Adequate societal supports were essential in effecting participants' sense of independence. Societal supports were items that improved participation in socioeconomic activities and were available on a needs basis. That is, income from work was not considered a societal support, as it was based on merit.² Societal supports that participants discussed were accessible housing, paid personal support for ADLs and IADLs, and government income programs.

Level 2 subcategory: Housing

The lack of accessible housing in Metro Toronto for persons who use wheelchairs sometimes forces them to live in nursing homes that, while accessible, have been built with persons of advanced age in mind. Herman, who was only 53 years old and sustained

² WSIB benefits were considered needs based as they were provided on the premise of applicants' inability to generate income due injury in the workplace.

SCI four months before interview, had to live in a nursing home until accessible accommodations could be found.

Across the street, there's a building that is built by the government. These apartments are all wheelchair-accessible. There's four people in the whole building that have wheelchairs. The rest are all able-bodied. That's a big injustice. How can they rent those apartments to able-bodied people, when there are so many people with wheelchairs looking for apartments? ... You're hitting walls everywhere when you're in a wheelchair.

Herman's plight has been a concern for persons with disabilities living in Ontario for several years. With devolution of social housing to municipal governments by the province in 1997 (Dunn: 2003) and the weakening of legislation protecting low-income tenants, persons with disabilities often encounter difficulties finding affordable, accessible housing. Granted, with Herman's injury occurring in the workplace, his work benefits allowed him to find housing at market value and alter it to his specifications free of charge.

While the occurrence of SCI was traumatic for him, Herman said that he did not feel especially depressed until he was relocated to the nursing home with people of advanced age. Though he had little in common with them, he felt as if he had been wrongly placed with people who he perceived to be near the end of their days.

I'm not out of shape. And I'm young; I'm not 92 years old. ... I look at these people who are here: 80; 85; 90. I look at them and they may be 85 years old, but at least they're walking. They can do something that I cannot do. Whereas I was so active before, I was doing things that people my age couldn't do. Like wild dancing; dance all night. All of a sudden, boom! Everything stopped.

Herman felt doubly indisposed toward his placement in the nursing home. Not only did he not identify with most of his co-residents because he did not view himself as being old; he was also depressed at being placed with older people who supposedly lacked the

capacity to accomplish many pursuits that he did before his SCI, yet could walk. With paraplegia, Herman had been bereft of walking, a mundane experience for most people. While it may have been inaccurate to locate those at the nursing home as aging ‘unsuccessfully,’ it was unfortunate that Herman was placed with people who were perceived to have so much ability when he appeared to not have fully adjusted to his life with SCI yet.

Level 2 subcategory: Paid support for ADLs and IADLs

Paid help for ADLs and IADLs was a topic mentioned by most participants. Participants were either pleased with the paid care that they received at home, or did not comment on its efficacy.

Two of four participants with short durations of injury had paid assistance with their IADLs and ADLs. Of this group, Herman asserted that poor work by personal support workers (PSWs) had negatively affected his care. Whether because of lower incomes than nurses or because of lack of prestige, the PSWs were not dedicated to their work. These disrespectful attitudes among staff had reinforced the feeling that he was not in control of his care.

[What would make my life better?] To be able to afford to be more independent. If I had a million dollars, of course, I could have a real nice place and a nurse 24 hours a day. It would make my life way easier. ... Here, there’s not too many nurses. There’s a couple, but the rest are all PSWs. So they come here to do their job, but you can tell that they’re not really enjoying the job that they’re doing. So that makes you feel even worse about this condition that you’re in.

In contrast to being able to physically perform one’s ADLs and IADLs, Herman’s definition of independence consisted of having control over the manner in which those

activities were to be performed. Physical completion free of help from others was not a prerequisite for independence.

Two of the four participants with long durations of injury had paid support for their ADLs. Here, age and disability were observed to intersect when participants with long durations of injury discussed independence in the context of prospects for long-term care. In these cases, participants understood that they would have to rely more on others for assistance with ADLs as they grew older and their bodies lost functionality. Michael, who lived in housing for designated for persons with disabilities, saw many aging persons around him and clearly had concerns about the future as he aged:

I just hope that my mind and brain can stay competitive, so I don't have to have someone tell me that life is gone and I can't look after myself, and someone has to feed me; that kind of stuff. ... And I can see that around me. Yeah, I don't want anyone to take care of me; I want to be independent and look after myself.

Michael assumed that life would be over when he aged to the point that his independence in maintaining his daily routines free of others was compromised. His lack of identifying with many other persons with disabilities, particularly those with cognitive impairments, had influenced his notion of independence in that he did not welcome an increasing use of supports to accomplish activities as he got older.

In contrast, Emma, in her definition of QOL, observed discriminatory attitudes that pervade the care in nursing homes and other facilities for aged persons. She concluded that if that is the quality of care that she could expect, she did not want it:

QOL is as much of your independence as you can keep. I know I'm going to lose some of it. I really really want good care, but I also want people to respect me for who I am, not a person in a wheelchair but a human being. And I see seniors right now, how they're treated, so I can imagine, already in a wheelchair, how some are going to be treated. And I'm not happy about it. ... They don't get the best of care; they don't get their hair combed;

might miss baths; might not get meals on time. Sometimes the aid helps herself to the chocolates! I don't want that. I want some dignity and respect in a place that I go. My life isn't going to be as good as it has been, but there's no reason for it to go downhill just because I'm a senior.

In this context, Emma used both definitions of independence in order to describe her QOL concerns. She believed that her ability to accomplish ADLs and IADLs without relying on others would diminish, primarily due to physiological weakening of her body. On the other hand, she realized that the second given definition of independence, having as much control over one's activities as possible, would be achievable if she had proper care supports in place. Proper care, however, did not simply mean having support staff to deliver services in residences for older individuals; it encompassed an attitude of respect for a person as support for ADLs and IADLs was given. This was found lacking in many nursing homes. Emma deplored the image of seniors as sick and dependent; as such, she felt that the derogation of seniors with previous disabilities would be doubly negative.

Level 3 subcategory: Work

Some participants reported enjoyment gained or lost from involvement/cessation of paid work and volunteer activities. Involvement in paid work and volunteering was not a significant priority for most participants with short durations of injury. All were observed to be putting their energies toward adjusting their daily routines to live with a disability. One participant shifted his priorities to retire as a result of his SCI while another was receiving Workplace Safety and Insurance Bureau (WSIB) benefits. Paid work was not a priority for participants with long durations of injury either, but extracurricular participation was a greater priority for some of them, with two engaged in volunteer activities. One long-duration participant was receiving long-term disability

benefits at the time of interview and was on track to continue collecting them until retirement.

Spinal cord injury was attributed to shifting the priorities of one of the short-duration participants into retirement. Anthony had enjoyed his job as a mechanical engineer and had worked past the age of 65, only stopping when he was injured at the age of 70. With his family being financially comfortable, Anthony was not concerned with the loss of income incurred from retirement. Also, Herman, who was receiving WSIB benefits after sustaining SCI in a construction accident four months before the time of interview, was not concerned about paid work so much as feeling that he had lost several functional capabilities.

William was the only participant in the study who was currently employed. Operating a family-owned fuel distribution business in a small rural community, William's SCI was difficult not only because he felt that he had lost his independence, but because he felt separated from his work, which had been his passion. In order to stay involved with his business, he made necessary accommodations and shifted his role from physical distribution of the fuel to an administrative capacity:

It's [the work's] certainly impacted by the injury because I don't put in nearly as many hours as I did before in my daily routine. ... The work I do now is more or less managing, looking after the financial end of things. ... I look forward to continuing doing that, and I know I won't be spending of course as many hours [working] as I did before.

Age, centrality of work and adjustment to SCI in one's life appeared to be important factors in assessing the impact of SCI on work in the daily routines of persons with short durations of injury. The age factor suggests that a participant such as Anthony who was past the age of 65 when incurring SCI was preparing to leave the workforce. Work had

been the central component within William's life prior to SCI, and his commitment in ensuring that his business continued to thrive was a factor in his involvement following injury. Also, as owner of the company, William had the ability to tailor his tasks and supports to fit his needs. Others in dissimilar positions of power, however, might have quit, having anticipated employers' reluctance to accommodate their needs. Finally, adjustment to disability affected Anthony and Herman's motivation to work, as organization of their supports and getting accustomed to new daily routines had occupied much of their time.

Of the four participants with long durations of injury, only Sybil had ceased paid labour permanently following SCI. This might be attributed to her age at injury, as she had been over 20 years older than the other three participants when they had incurred injury. As she had previously worked in custodial services, she might have found it difficult to consider changing careers in her 40s. Yet she continued to cook, knit and bake at home for her family. Emma, who had been enrolled to start nursing education at the time of injury, gave up these aspirations and worked domestically, bringing up two children.

When I had my accident, we were on the way to Toronto. He [her ex-husband] was looking for a place to live, I was on the way to see if I could finish my nursing. That ended that. That ended my career. So I put Emma up on the shelf and became a wife and mother for 20 years.

After her divorce, she became a secretary for over 20 years. Recently retired, she helped facilitate a peer support group for persons who had recently incurred SCI. Sybil and Emma's experiences suggest that the presence of family at home, combined with

attitudes toward gendered division of labour, might have encouraged them to take a domestic role following SCI.

Norman transferred his knowledge and connections with various sports organizations for persons with disabilities into executive positions with nonprofit associations, but retired in 1993 because he wanted to free his labour from being tied to income generation. As such, he relied on personal investments as his source of income and volunteered at the Metro Toronto Zoo on a seasonal basis. Michael, a recreation counselor for 23 years before ceasing employment because of debilitation in his shoulders and wrists, had enjoyed his work and was upset at having to collect disability benefits until retirement.

Category: Social support and social relationships

Adequate social support was observed to be important for people in the years directly following SCI. People with short durations of injury were more apt to refer to their families and friends as ‘supportive’ of their adjustment to SCI than those with long durations of injury. Friends were described as being supportive in a temporary capacity, when individuals had just recently started rehabilitation and were still perceived to be absorbing the shock of sustaining SCI.

Level 3 subcategory: Non-familial social support and social relationships

Non-familial support among participants was divided into two smaller subcategories: support from neighbours and the outlying community, and support from friends.

Participants indicated that previous social support from their community in the fashion that it had been given had not been known.

Level 2 subcategory: Community social support

William, who had SCI for 10 months, operated a business in a small community and recounted the support from acquaintances, being those with whom he usually had only sporadic contact in his life:

I've had an awful lot of friends that have come by to see me, and wish me well and that's a very positive experience, to know that I had that many people that care as much as what they've shown over the last ten months, just the general neighbourhood and how they've responded to help us out.

William implied that while its inhabitants are generally tight-knit, the visiting of so many neighbours following his SCI was certainly an unexpected, yet positive, experience. Indeed, the occurrence of an event that is considered traumatic and tragic may result in an inflow of emotional support from acquaintances who would otherwise not be present in an individual's life. In comparison, Jessica, who had SCI for 3.5 years, met several neighbours who she had not known prior to injury, and even received support for her ADLs from a neighbour at home.

We've been here 15 years. Except for our neighbours on both sides, we knew nobody. And I know everybody now. Bob [Jessica's husband] took a year off work to be with me. And the lady across the street, who I'd never met before, but she saw the ambulance take me away. And she came over to find out what happened, when I was out of the hospital. And she said to Bob, "We'll look after her." And she did. She came over a lot. A complete stranger.

Thus, acquaintances that had heretofore not been present in a person's life may, following traumatic SCI, give emotional support or assistance with ADLs if close in proximity to where the individual resides. This may be based on each person's identity

as a mutual neighbour, with support for others who are physically near being the ‘neighbourly’ thing to do when one has such a traumatizing experience, regardless of how well they knew each other before. Jessica indicated that while some neighbours had assisted her with support for ADLs and IADLs, most had given emotional support by being present at important times in her rehabilitation. For example, her whole neighbourhood had assembled to watch her walk without the assistance of a wheelchair.

Level 2 subcategory: Social support and social relationships with friends

Besides support from acquaintances, participants with recent SCI remarked on the emotional support that they had gotten from long-time friends and family following their injury. Herman, who had incurred SCI 4 months ago, recounted how he had 17 people visit him on one particular day while rehabilitating as an inpatient at Lyndhurst, with people also visiting him while at a hospital outing at Parry sound, 2.5 hours’ drive away [3: 1-5]. William, in comparison, had several friends who had driven him over an hour away to Toronto for physiotherapy three times a week for three months prior to the time of interview.

Participants with long durations of SCI, on the other hand, counted their friends as both sources of support for coping with their SCI as well as other facets of life besides their disability. Michael, who had SCI for 42 years, iterated that one of the constants in his life was the presence of friends:

I have friends that I’ve had for a long time. And I feel very proud of that. I have friends that know me, we talk together, that I’ve known for 25-30 years. I like that. I can call quite a few people that know me, if I have any trouble, any problems, they help me. I think that’s key.

In addition to having friends on whom he could rely if he needed emotional support for coping with his SCI, Michael, from his time on the Canadian men's wheelchair basketball team and as a member of a classic automobile group, had several friends who had gotten to know him because of personal interests as well as his identity as a person with SCI. His experience suggests that friendships made after sustaining SCI may or may not be related to the injury itself. In any event, their locus does not necessarily consist of emotional support for coping with SCI.

Loss of friends that one had prior to SCI was also reported among participants with short and long durations of injury. Herman intimated that a person whose life had undergone such a sweeping change as his has, would have discovered who his 'true' friends were.

The good ones support you; the other ones, they say call me; and then you call them; excuses. At the same time, you realize that people have their own lives to live. They cannot be there for you all the time.

Herman's distinction between friends who are present and those who do not give support when called upon while a person is adjusting to SCI was premised on two possibilities. The first was that the friends who did not appear were not particularly involved in his life prior to SCI. As such, they do not feel particularly responsible to him. Or, it is possible that they did not wish to be around him because they perceived that his impairment would make the proceedings awkward. Herman rationalized their responses by stating that one should not feel entitled to friendships; friends are always changing, and an individual should feel privileged to have good ones. Yet it appeared that he felt that his impairment had created a wall between he and some of his friends.

In comparison, Sybil, who had SCI for 26 years, gave more insight as to the reasons for some friends' disengagement:

You know, they call, "How are you," you know, but... you know... they seem afraid... I don't understand why people are not going to see people wheelchairs. Seems like they stay away. ... The friends I had before, I didn't see a lot of friends because they stayed a little bit far away from me. But, thank God that you meet more people, and more people that are more understanding.

Sybil observed that she had indeed lost close friends because of their derogation of her disability. Her remark that they may have been afraid of socializing with her begs question of what they were afraid of—whether it was because she was perceived to be less 'human' than them; whether she was observed to be too 'different' than the Sybil they had known before, thus diminishing their desire to want to reacquaint themselves with her; or whether they could only identify her as a person with an insurmountable problem and could not see her character past that. This was what she had been implying. Importantly, Sybil met many new friends in the years after SCI, especially at Lyndhurst. Lyndhurst provided an environment in which persons with spinal impairments could identify with others who may have been experiencing similar adversity. Or, they could meet people who shared the identity of having a spinal impairment and make friendships based on common interests.

Emma had a similar experience with some of her friends following her returning home from rehabilitation at Lyndhurst. The friends who remained constant for her from before injury, however, were not deterred by her disability. "The chair doesn't bother them; you know, they're like, "Oh, you need a hand with the washroom? I'll take you." Those who had been most helpful to Emma were able to separate the trepidation of

encountering a new event from the reality that their friend could have benefited from assistance in accomplishing an ADL.

These examples suggest that social support for persons with SCI is often of the double-edged variety. Participants were grateful for the encouragement that friends and acquaintances gave. Much of this support, however, emphasized the tragedy of impairment instead of the full life that could be ahead. Thus, the QOL of persons with short durations of injury was impacted by negative attitudes toward disability. In contrast, family members were more encouraging toward short-duration participants' experiences of disability and supported them in accomplishing activities that they found meaningful. Participants with long durations of injury, however, were less inclined to discuss how family and friends were present in a 'supporting' role. Friends and family members who had treated participants as pitiable beings had been disparate from their lives for several years, and relationships with family and new friends had less of a tragic note.

Level 3 subcategory: Familial social support and social relationships

Not surprisingly, family members played an important role in supporting participants with short durations of injury. Of the 3 short-duration participants who had spouses, each spouse was observed as crucial in providing emotional aid as well as support for activities of daily living (ADLs). Children were also observed to be helpful in a number of capacities: William's son seemed interested in taking over the family business, and William would have liked to work with him. He felt that this was not possible after his SCI, but related, "I can still be here and advise him and pass the knowledge that I've

gained over the years on to him, and try to help him out as he continues on...” The fiduciary relationship that is created between parent and child; i.e. the parent taking care of the child until the child becomes old enough to take care of the parent as (s)he ages, may be an important factor for older persons coping with SCI. Not only do children provide emotional support for a person’s coping with SCI; the presence of a child may alleviate fears that one’s family will not be properly taken care of in the future. As such, duration of injury may not be as influential a factor in this particular phenomenon as age at injury. That is, William’s age, the age of his son and the perception that the former would have been passing the business on shortly, was more significant than the SCI. William felt that the business was running well and would continue to do so, as his workers’ responsibilities had changed in order to accommodate the loss of his physical presence at the job site.

In turn, some persons with SCI felt that their families and friends provided the best emotional support by treating him/her as they did before SCI. Thus, persons who had recently sustained SCI felt well when interaction with family was ‘positive,’ or not always dwelling on one’s SCI. Herman, who had fallen in a construction accident several years before his recently sustained SCI in a similar accident, recounted

Even before, during my first accident, people would come to the hospital and I was the one cheering them up. They would come there, they would be sad for my case; and I would be cheering them up! But now, it’s hard to keep cheering up people; I realize that I need some cheering up. And people are sad about your situation. One guy in Ottawa called me up; he’s crying. I said, “Please don’t call me when you’re crying. I’m not depressed; you’re going to depress me.” That’s the worst thing you can do to someone like this. It wasn’t helping.

Herman maintained that his upbeat personality was partly responsible for his commencement of successfully coping with SCI. He had begun looking to the future, noting that he had started to accept the permanence of his injury and would be looking for supports such as housing and paid private care shortly. As memories of the SCI continued to trouble him day and night, he felt that the best thing friends could do was not to bring up what he, and they, considered to be a tragic ordeal. Anthony, who had SCI for 1.25 years, remembered similar concerns:

Friends have been really good; family's been great. I could just sit there, and I don't even think I've got a spinal cord injury. People don't really bring it up... and I'm really glad when people don't bring it up. They have a sign on the door [at Lyndhurst], "Please wash your hands before you enter." They should have a sign saying, "Please don't talk to the patients about your injury; about your operation." There are visitors like that in there, and every once in a while you have a friend like that, who spends all the time talking about it.

Clearly, time should be set aside to reminisce about an incident of SCI. It is certainly traumatic and tragic in the sense that many aspects of life for that individual will not be the same. Moreover, a sense of loss may be felt in that the new life following SCI is perceived to be inferior to the one before. The event of SCI may also be traumatic for friends and family of the individual, as life for *them* with him/her has changed as well.

Yet Herman and Anthony iterated two responses: (a) life is indeed not over after SCI, though family and friends' continued emphasis on the tragedy of the incident makes them feel as if it is; and (b) while the SCI is an intensely negative experience for all who know the individual well, it is still that individual who must solely adapt to living with previously unknown physical limitations, new supports to achieve outcomes, and the derogation of persons with disabilities in society. Herman and Anthony felt that the onus of talking about the SCI should have been on themselves and not their families and

friends. Barnes et al. (1999) indicate that discrimination against persons with disabilities occurs by depicting their lives as tragedies with no chance of a positive outcome. This may be the case especially when a person acquires impairment after having developed relationships as a person without disability over several years; i.e., (s)he had been known as a person without impairment, with others having certain hopes and expectations of him/her. Relationships, then, are adversely affected when family and friends emphasize not only the tragedy of the impairing incident, but also the perceived tragedy of the person's life after.

It is this positing of disability as unending personal tragedy by friends and family that causes some persons with SCI to emphasize acceptance of a disability as soon as possible. Emma, who had her SCI for 47 years, stated

...you also learn that you have to take care of people around you emotionally. Because they don't know what to do with you. They always want to rush and help you. I tell these people that it's nice to have help, but you have to do things for yourself. You don't want to hurt their feelings, but you have to say no; I'll do it. If you can't do it, at least try, then ask if they can please help you. But if you're going to let these people take care of you as if you're sick—and you're not sick; you have a spinal cord injury and you have rehab and you're well, and you're not sick. ... You have to accept it. If you can't accept it, you're going to sit in your room and watch TV all day.

Emma had excellent relationships with her family and friends, but the price was that she had to remind others for many years to be respectful of what she could accomplish, and not to assume that she was incapable of achieving her desired outcomes. Also of note was Emma's comment that persons with SCI are not necessarily sick—sick implying incapacity to take care of oneself and depending on others. Neither are persons with SCI to be looked upon as 'brave' when tasks that able-bodied persons carry out are accomplished (Oliver, 1990). Though she was the one who experienced the accident,

Emma thought it odd that others only perceived her as an object of pity, lacking the resources to assist others' coping. She iterated that comforting others does not solely lie in the realm of able-bodied persons; persons with disabilities must fight against the notion that they cannot contribute positively to relationships.

Participants with short and long durations of injury who did not have family members present in their daily lives tended to emphasize the need to regain or maintain independence in ADLs and IADLs more than those who were living with family. It is possible that the presence of a partner diminishes the perception that the onus for negotiating challenges in the life of the individual with SCI is solely on his/her shoulders. Norman, who was 62, single and had had SCI for 42 years, articulated the impact of a partner on independence:

I've found that when I live with other people, I tend to get lazy. They do things for you; natural thing. They help you unzip your coat; they help you get dressed; help you do this, do that. Natural response. Glad for their help. But then, it starts to eat away at your independence. Now I often think, Jesus, if I was in a long-term relationship, I could become a potato in no time.

Norman claimed that the many years of living single had forged a strict regimen by which he maintained his independence. This regimen, however, would have been in danger of collapsing if he lived with a partner. Not only would he have lost his current routine; the two would have had to create a new routine for living together, something that he was not prepared to do at that point in his life. Norman later moderated his stance made in the previous statement:

Now the other thing is—the complications due to aging; hemorrhoids, all that crap—that would really be unpleasant for a partner. Which also mitigates toward getting into any kind of relationship. So, that's the things you deal with. Like, I've got people who could be partners in life. Do I want to adjust my schedule to theirs? That's just part of getting along. Maybe not. But that's got nothing to do with disability.

Norman also felt that the change in daily living routine brought on by physiological changes from aging would have put strain on a relationship. He also mentioned that at this age, he was not prepared to adjust his routine to coincide with that of another person. As such, Norman's mitigation of his reason for not wanting to live with a partner appeared to be an aid in helping him cope with having a disability and being alone.

In contrast, participants living with family members reported that their daily routines blended in with those of their partners'. Support from their partners aided their independence in the broader definition of the term: having greater control in accomplishing ADLs and IADLs. Jessica's husband took a year off of work in order to assist her as she rehabilitated and grew accustomed to a new daily routine. Also, Anthony's wife reduced her volunteer time at a hospital in order to give him the best support possible. Though he felt as if he was a burden on his wife at times, she continued to be encouraging and did not allow him to be down on himself for having a disability for long.

Perceptions of QOL

Definitions of QOL

When asked for their definition of QOL, participants generally described indicators of QOL as opposed to giving a definition that considered what one has versus what one does not have, and evaluating the worth of that difference. An exception was found in two participants. Herman, who had had SCI for 4 months, stated

QOL is to be able to, first of all, come to a certain degree of acceptance of your situation. That is very important. You have to accept what happens to you; if you don't, your QOL

will be down, Everybody's got their own QOL; for me, it would be able to be active in every aspect of my life; ... QOL means understanding what you can do with what you have.

For Herman, QOL first meant accepting the limitations that would come with SCI. Not only had the processes by which he accomplishes ADLs and IADLs changed, but his identity had also been transformed into one in which he felt severely limited. From that, Herman pointed out that he had to look ahead and understand what he was capable of. Quality of life, Herman continued, differed for everyone, but an individual would have a better chance of having a good QOL if (s)he did not have an excessively materialistic lifestyle. In this way, he felt that his disregard for material luxuries prepared him well for living with SCI; ergo, his low material expectations steered him for a life in which low functionality was to be assumed.

A major difference in defining QOL was found in Norman's response. Norman, who had SCI for 44 years, formed a taxonomy for QOL, suggesting that it first meant having good relationships and meeting basic necessities such as food and shelter. After a minimum of these variables has been obtained, comfort level was to be estimated: "how comfortable are you? Could you be more comfortable?" Thirdly, he iterated the importance of having passion in one's life, or something that drives him/her to excel. Norman affirmed that the thought of SCI did not figure greatly into his daily routine; that is, he had internalized the phenomenon of SCI with the result that it had lost much centrality in his existence. Thus, his definition of QOL encompassed all individuals, not just those with SCI.

Of the remaining three participants with short durations of SCI, Anthony combined acceptance of SCI with having an enjoyable life filled with challenges. For him, coping with SCI was a challenge that made life worth living. Jessica located QOL

as independence, defining it as being able to accomplish activities similar to those that she was completing prior to SCI. When queried further, she stated that successful completion of activities did not have the requisite that she would have to be able to walk for long periods.³ In other words, Jessica attributed her definition of QOL to the second given definition of independence, being able to have control over one's activities. Accomplishing her outcomes was of prime importance; the manner in which they were accomplished, including the supports that were used, was secondary. William intimated that his interpretation of QOL had shifted after SCI, with less emphasis on work and more emphasis on a balance between work and leisure time with family. This, he had yet to achieve.

Quality of life to me means you need a balance in life, to be able to enjoy it fully. You need to have a certain amount of work and a certain amount of play and recreation. That's the part of it I missed out on, was the recreation, the free time, I burdened my life down by working too many hours...

An age aspect was seen as well,, as he had been considering reducing his work schedule in order to enjoy a less rigorous lifestyle. This decision had been based on the success of his business over 30 years and the diminishment of his role as a parent with his children leaving the house. Thus, as per activity theory (McPherson, 2004), William and his wife were looking forward to engagement in new pursuits prior to SCI. He believed that his reduced functionality from SCI had made this opportunity less feasible.

Two of four participants with long durations of injury described QOL as being related to independence. The first, Emma, considered QOL to be control over all of her

³ Jessica had actually walked a few steps over a year before the interview.

activities, with an emphasis on receiving respectful care when needed in the future. In contrast, Michael considered QOL to be the independence gained from having accessible housing and amenities:

As far as a wheelchair person is concerned, there's a lot of things you can do right now if you're in the right spot; if you live in the right spot. Depends where you're at. It's not like in the old days, when you couldn't get into places. Movies, grocery stores—a lot more open now. You couldn't go to certain places. Cause you were asking people to lift you here, lift you there. I hated that. They teach you to become so independent.

Sybil, another participant with a long duration of SCI, described QOL as being determined by happiness, with a key to happiness being support from family. From these answers, participants with long durations of injury were interpreted to have substantially 'disengaged' their definitions of QOL from their lives prior to SCI. That is, the difference between life before injury and life after no longer required accepting. For 3 of the 4 long-duration respondents, accepting had happened many years ago. For Norman, disability had not affected his desire or ability to live life to the fullest, as he considered his life just as rewarding as it had been prior to injury.

Rating QOL

This category, based on question 9, received far more than a simple rating from participants. Rationales for their answers were given, with answers from questions 5 (How would you describe your life? What is going well? What isn't going so well?) and 10 (What would improve the quality of your life?) providing additional information. Participants with short durations of injury generally rated themselves to have lower QOL

than participants with long durations of SCI; one participant with long duration of injury did not give an evaluation, as the question was not understood. Furthermore, the presence of spouses for participants in both groups resulted in emphasis on the importance of family support and maintaining good relationships with family. Those who were not married emphasized the importance of their regaining or maintaining independence.

Participants' responses in rating their QOL suggest that the persons with short durations of SCI had adjusted less to the individual aspect of their impairment as well as structural and cultural barriers toward disability. 'Acceptance' may be considered a key word. In contrast, not only had a sense of 'moving on' been adopted by the participants with long durations of injury, there was an emphasis on accomplishing those activities that one found worthwhile; i.e. becoming more independent in the second given definition of the word. The centrality of SCI in the immediacy of their lives had diminished. Within this sample, however, there was variation as to the effect that SCI had on their daily existence. One participant furnished a response similar to Herman's definition of QOL, saying that her cheerful countenance and need for nothing but the bare socioeconomic necessities allowed her to take her SCI in stride. On the other hand, another participant had fully absorbed the experience of SCI into his daily routine so that he did not think himself as 'living with SCI.' The two other participants with long durations of injury emphasized their independence as being indicative of their QOL; this independence was gained, or was being lost, due to the availability of suitable supports.

Of the participants with short durations of injury, Anthony reported that he felt good about coming back to Lyndhurst for physiotherapy, as the sight of recently injured

patients gave him a positive feeling of how far he had progressed since incurring SCI. He gave his QOL a rating of 9 out of 10, partly based on the positive support from his family. Furthermore, this rating was given with a retrospective outlook, with Anthony stating "I've had a life that's been ok; everything else has been pretty good, so, what the heck! It would have been 10 before my accident!" While life certainly was not over after SCI, Anthony had counted himself lucky that he had only incurred injury at the age of 72:

We had one chap [in his peer support group]; he was 18 years old and he was going to go to [the University of] Waterloo to be an engineer. He was on his way in, and I was on my out [of the working world], and we had some pretty interesting conversations. He could hardly talk, let alone move himself. And, when you see something like that, you think, God, I'm the luckiest guy in the world. I've had over 50 years on him, and life's been wonderful.

The implication was that sustaining SCI was tragic at any age, more so when one is younger because of all the experiences lost through disability. The referent point in this case was the impairment, with little regard as to the lack of supports that could facilitate good communication, the ability to accomplish more by moving less, or discriminatory attitudes that might get in a young person's way. Furthermore, a disengagement approach suggests that SCI incurred at an older age is more acceptable than a young age because of the individual's gradual withdrawal from productive activities and relationships (Morgan & Kunkel, 1998). As a result, the value of older people's socioeconomic contributions came into doubt.

William felt that his QOL based on adjustment to SCI was 6 out of 10 because he could not accomplish the physical tasks that he could prior to injury. On the other hand, the event of the SCI had brought his family closer together in the attempt to give him the best support possible. As a result, William judged the quality of his family life to have increased since SCI to 7 out of 10, with the only limitation on greater participation in

family activities being his impairment. At the same time, the altering and accommodation of his new work role gave him the satisfaction of still being involved in the operation of his business. William indicated that his life would be better if he could regain the full use of his right hand, which had been injured in his accident. An interesting aspect of this response was William's separation of QOL into two spheres, that of adjustment to living with SCI and that of family. This indicated William's belief that proper familial support and adequate economic resources could compensate for loss of functionality.

Herman judged his QOL to be 4 out of 10 because of his having to adjust to a "new life" with SCI. He cited structural issues such as the lack of space at the nursing home he resided in, even compared to Lyndhurst, and the target population of the home being seniors of advanced age, not younger persons with disabilities. Herman's most pressing issue, however, was that he did not yet know his limits in trying to establish daily living routines:

I don't know what my limits are yet. Because of my wrist... that's a big limitation. It's a brand new life. I'll find out a lot when I'm by myself. Right now, even though I have a lot of people helping me, I'll know better when by myself.

At the time of interview, Herman observed that his lack of adjustment to living with SCI had been a result of having little control over his care. Not only was he living in an environment in which he felt that he did not belong; he also emphasized that living by himself would encourage him to accomplish more activities independent of help from others. Fortunately, Herman's injury at the workplace made him eligible for workers' benefits that gave him sufficient income to be financially independent. These benefits

were crucial in that he could then afford to buy property at market value and have the costs of retrofitting it to his needs subsidized. Herman could not think of any particularly positive aspects in his life save for the strong relationship that he had with his daughter.

Jessica rated her QOL to be 7 out of 10. Though she did not give a rationale for her evaluation, she did indicate that better finances would improve her QOL:

I can manage to get around and not worry about the walking.
What would improve my life? Money. I mean, I know money
is not the most important thing in the world, but it does help.

As Boschen et al. (2001) suggest, the costs of supporting a SCI can be substantial, especially for persons who do not receive insurance settlements as a result. Jessica was injured at her home; hence she was ineligible for workers' compensation benefits. In addition, her husband took a year off of work to help support her. This left the family in need of extra income in order to supplement costs for various accommodations.

The rationales that participants with long durations of injury used in rating their QOL were observed to be similar to the indicators that they had given for judging a person's QOL. Sybil, who had said that happiness gained through interaction with family was important for QOL, rated the quality of her life as being 8 out of 10. Though family was part of the reason for that rating, she also explained

... I am the type of person who is content with smaller stuff;
maybe I can say 8. Because I am not the type of person who
says, I don't want to talk to you because you did that; you
made a mistake. Sometimes you never know the person.
... But we have to be flexible.

Sybil believed that she lost opportunities to participate in certain activities with family members, such as walking her children down the aisle at their weddings, or dancing with her husband at parties. Yet she felt that she was well equipped to deal with these setbacks, as she had a buoyant disposition. As a result, this 'flexibility' in not placing too

many expectations on herself or on others had been useful in helping her cope when faced with derogatory attitudes or lack of supports. At the time of interview, Sybil had concerns about the health of her kidneys and the pain that she was experiencing from sitting in one position for too long.

Michael reported that he felt “pretty good” about his QOL. This evaluation came from having a job that gave him a good salary and benefits. Furthermore, he had a fully accessible apartment and few expenses because of his long-term disability insurance coverage. On the other hand, his estrangement from work, his house and his garage for auto work, had deprived him of many activities that he had gained immense pleasure from in the past. He felt that the loss of strength, mobility and flexibility in his body, as well as overuse of his shoulders and wrists from sports and his work as a recreation counselor, were the main reasons for his moving to an accessible apartment. Yet the unavailability of recreation services dedicated toward persons of age using wheelchairs has caused feelings of boredom and isolation.

In turn, Emma rated her QOL as being “very good,” or 9 out of 10. Her independence, or perceived control over the most important aspects of her life, was the most satisfying aspect of her life. Also, Emma mentioned helping others in roles such as leader in a peer support group for newly injured persons as a rewarding element in her life. Her shoulders had debilitated to the point that she needed a more accessible apartment, and had been put on a waiting list for one.

Conclusion

While the small sample precluded generalization of observations, a number of inferences from analyses of participants' transcriptions were made. Spinal cord injury was less central in the daily routines of participants with long durations of injury than those of participants with short durations of injury. Also, QOL held different meanings for all participants in the study. Yet, in discussion of QOL, most participants with short durations of injury discussed the need to adjust to the social and functional ramifications of SCI, while most participants with long durations of injury emphasized their independence, representing positive adjustment. Participants with short durations of injury rated their QOL lower than their long-duration counterparts. Furthermore, most participants who were living with spouses emphasized positive relationships with family as the main determinant in establishing QOL.

Age at injury, duration of injury, work status and type of work were significant factors in some short-duration participants' evaluations of their QOL. Two of the participants with short durations of injury considered that they had been near the threshold of retirement/semi-retirement when they had incurred SCI. This cushioned the impact that SCI had on their QOL, as they claimed that their productivity would have been diminishing in the next few years regardless of their injuries. Importantly, one participant's continued employment was based on ownership of his business and the ability to tailor supports and tasks to his needs and desires. Above all, variation in QOL among participants was represented by the difference between the socioeconomic circumstances in which they lived and their expectations for what they were supposed to have.

Comparisons of this study's results to those of other qualitative inquiries indicate several parallels. Duggan and Dijkers (2001) reported that only one participant defined QOL along their lines, being the evaluation of the difference between socioeconomic and personal achievements and corresponding expectations. Likewise, only one individual in this study gave a similar definition, with one other participant attaching an evaluative aspect to QOL. Another notable comparison is that participants in Duggan and Dijkers' (2001) study who cited personality factors, attitude or inner strength as an important aspect of QOL were most likely to be older or living alone. In turn, most of the participants with long durations of SCI in this study cited an attitude of keeping as much independence as possible as important in maintaining their QOL. Those who mentioned independence as a crucial factor were living alone.

Maintaining independence was also crucial among participants with progressive neurological disorders in a 1995 study by Engstrom and Nordeson, with living on one's own terms, living in a sense of affinity, and feeling that life is meaningful being important indicators as well. To contrast, varying definitions of independence were used in the present study, with 'living on one's own terms' being included as but one definition. Finally, excluding one participant, all who rated their QOL in this study gave a rating of at least 6 out of 10. That is, QOL figures were positively skewed despite the observation that many felt constrained by socioeconomic barriers or lack of functionality. This is consistent with Crewe (1996) and Duggan and Dijkers (2001) who observed most participants to state that they had good or excellent QOL despite their iterated concerns.

In contrast to this study's results, Boswell et al. (1998), investigating focus groups of adults with SCI of various ages, identified level of resources, opportunities to

work and attitude toward life as crucial life domains in determining QOL. Resources included food and shelter, transportation, and financial income. Most participants in this study, however, did not identify level of resources as instrumental domains of life, with three short-duration participants emphasizing acceptance of SCI and long-duration participants emphasizing independence. The opportunity to work was not a priority for any participants in this study, given that most of them were near retirement age.

Limitations

This study did possess some significant limitations that diminished the value of the findings. The small sample size was the first limitation, in that the findings from interviews with eight participants could not aid in generalization of theory for persons with SCI. Given the small number of participants, it might have been more useful to exclusively conduct interviews with participants from one duration cohort.

One significant limitation in the current study was its cross-sectional nature: it only investigated persons with SCI at one particular time in their lives. This was in contrast to a longitudinal study that can examine participants over a long span of time. The drawback to the cross-sectional approach was that it could not establish whether age or duration of injury was the crucial indicator of QOL. If age had been positively correlated with QOL, the implication would have been that life experience was especially important (Kemp & Ettelson, 2001). If duration of SCI, on the other hand, was positively correlated with QOL, then specific experience with a disability would have become the overriding factor (Kemp & Ettelson, 2001). Researchers (e.g., see Krause, 1998) are still undecided as to the extent of the impact that both age and duration have on the aging

process for persons with SCI. For example, Krause's (1997) study found that, independent of age, participants with a longer duration of SCI were more adjusted and more likely to be both employed and married than others. In contrast, only one long-duration participant in this study was married, compared to three of the four short-duration participants.

A further problem in researching aging with SCI was that survival effects might have influenced results (Adkins, 2001; Kemp & Ettelson, 2001). For example, the rudimentary care and technology available to SCI survivors in the 1950s suggests that persons who sustained injury in that decade yet live today are somewhat the 'exception' to the 'rule' of life expectancy in those years. Increased adjustment among persons who had had SCI for a long duration may have been a result of a "selective process" whereby people who did not adjust to SCI would have died earlier than those who did successfully adjust (Krause, 1998). Thus, were a long-term survivor to be compared to a younger individual with a shorter duration of SCI, the positive outcome of the long-term survivor may have led to the conclusion that people's health improved as they aged with SCI. Survival effects, however, suggest that the younger individuals with shorter durations of injury might not have survived had they sustained injury in the same decade as the older survivor (Adkins, 2001). This study may have been affected by such a phenomenon. Three of the four participants with long durations of injury spoke about their resiliency, although it is difficult to ascertain whether or not they were imbued with some sort of survivor effect.

Another limitation inherent in this study is that it cannot be claimed that the participants represented the views of a complete spectrum of persons with SCI, for it is

assumed that persons who had not adjusted to life with SCI would have been more reluctant to discuss their experiences. In contrast to those persons, participants must have felt comfortable enough with their disabilities in order to have in-depth conversations with a researcher. That is, their adjustment was to the extent that they felt that they could be asked questions about potentially troubling aspects of their lives. Finally, some concerns exist that research on a single domain of adjustment to SCI such as QOL does not adequately represent the various impacts on reintegration. Instead, a more extensive investigation that examines impairment, activities, social participation and QOL is recommended (Boschen et al, 2003). As such, the results of this QOL study could not be extrapolated to account for the total experience of adjustment to SCI.

Implications for further research

This study may be best considered as an exploratory investigation into the field of subjective QOL of aging persons with SCI. While none of the results can be generalized to the population as a whole, this study did raise interesting questions for further research. For example, while the role that income level had on participants' abilities to readily purchase supports and cushion their withdrawal from paid work was not explicitly investigated, several participants, explicitly or tacitly, indicated their financial status. Measuring income levels can help researchers understand what types of supports aging persons with SCI pursue, given particular incomes. Also, gender and cultural influences on SCI were not taken into account in this study. Incorporation of these dimensions of analysis in future investigations could assist in providing a richer description of structural issues persons with SCI face. Finally, as iterated in the previous section, participants

with long durations of injury might have possessed a survivor effect that enabled them to survive with injury for 25 years or more. In addition, all respondents must have felt good enough about their situations that they would volunteer to participate in the study. Future qualitative investigators in this field would do well to develop methods by which they could interview people with diverse QOL, not only the ones who had adjusted best to SCI.

Implications for social work: walking a fine line between coping and unmasking structures

The experiences of SCI that many participants discussed in this study have raised a salient issue for social work practice: the dilemma of adjusting to a perceived 'new life' with obstacles that had heretofore not been contemplated. These obstacles include adjustment to lack of function, adjustment to attitudes toward disability, and structural barriers that hinder fuller inclusion to pursue desired outcomes. The point to emphasize is that, whether brought on by structural inequities or 'disabling' attitudes imparted by others or themselves, several participants from both groups felt distress at their circumstances revolving around SCI.

This line of thought should be qualified, for many disability theorists (Oliver, 1990; 1996; Shakespeare, 1994; Barnes et al., 1999) assert that disability is a social construction, with the actual impairment being inseparable from a 'disabling' environment of structures and attitudes. While this may be the case, persons with SCI have an important point of reference in their conception of disability that those persons with disabilities from birth lack, being the memories of life before SCI. Dismay at incurring disability was iterated in several interviews, expressed in such ways as relief

that it had only been acquired later in life; a lack of association with most persons with disabilities, as they were seen to be so 'different' from a participant; and the oft occurring exclamation that life would never be the same after SCI, probably taking a turn for the worse due to lack of functionality. More than participants with long durations of SCI, short-duration participants demonstrated that some of the most 'disabling' views did not necessarily come from others without disabilities, but from their own attitudes toward disability.

As previously discussed, the paramount concern for persons with short durations of injury did not appear to be the possession of sufficient resources for independence but rather adjustment to a new disability. Most of these participants had already acquired, or were in the process of acquiring, adequate supports. Furthermore, permanent disengagement from the workforce cushioned these participants from many disabling attitudes that they might have encountered if involved in a productive capacity. Granted, disengagement from work might have been itself influenced by an ageist perspective that older people have little to offer. Nonetheless, many short-duration participants saw themselves as 'normal' people who had been permanently flawed.

For social workers, the question then becomes how to assist persons in attaining the proper resources to achieve their desired outcomes. The suggestion is that workers must be careful to not trivialize individuals' sense of loss by indicating that perception of that loss arises from cultural derogation of persons with disabilities and an unjust lack of socioeconomic supports for persons with disabilities. In other words, social workers' first responsibilities, apart from facilitation of available material resources for clients with

SCI, is to help them cope with their ‘personal troubles,’ even if the worker discerns the problem to be more akin to a ‘societal issue.’

Unfortunately, coping, or the psychological efforts that people employ to master, tolerate, reduce, or minimize stressful events (MacArthur & MacArthur, 1999), has been denigrated in much structural social work literature as representative of an ecological approach to social work. That is, helping another cope implies trying to optimize the adjustment of an individual to his/her environmental conditions (Coates, 1992) instead of challenging the “liberal/capitalist/patriarchal social order” that pervades relationships and reinforces inequality (Coates, 1992: 127). For example, Carniol indicates that many “conventional” social work writers do little to unearth the structural causes of inequality:

... from their perspective, they fail to see the system as oppressive. Instead, most of the social work practice literature actually perpetrates the masking process, making this literature and the practice it recommends part of the problem rather than part of the solution. By obscuring the sources of oppression, this literature and its related practices, effectively psychologize problems which are essentially political in nature. This in turn fosters client adaptation to oppressive structures (1992: 10).

It is agreed that structural social work practitioners should involve clients as much as possible to mutually uncover the reasons for material inadequacy, and one of the worker’s first priorities is to assist the client in gaining resources such as money, food, shelter, clothing, and other services (Carniol, 1992). Yet persons who have recently incurred SCI may be grieving at the loss of their assumed ‘normalcy;’ the worker’s first task, then, is to listen, clarify and validate the individual’s feelings. Also, the client may not be properly equipped to change his/her socioeconomic circumstances after first meeting with the worker. As such, the worker’s task is to help the client cope with his/her current material shortcomings. Indeed, clients may prioritize their material

conditions as secondary to adjustment issues that they have and must be respected for those priorities. For example, 2 of 4 short-duration participants indicated that they were not for want of income or other resources; their problems were solely in learning to 'accept' their disabilities. This is a difficult issue for a worker versed in the social model of disability, as the urge may be to present the client with an alternative interpretation to the individual/medical model that has been the hegemonic societal outlook. Yet the temptation must be stymied at that moment, substituted by validation that the client's feelings of inadequacy are understandable and perhaps even warranted, given his/her attitude toward disability before injury.

To contrast against this argument, Moreau et al. (1993) suggest that the first objective in the client-worker relationship is defense of the client against a certain structure, followed by collectivization, or helping the client proceed past individualistic interpretations of his/her situation. Collectivization is begun by pointing out that a client's "physical condition or thoughts or feelings or behaviour or their situation is similar to that of others" (Moreau et al., 1993: 141). Defense may be warranted if the client enunciates a particular structure, person or organization that is causing them stress. In the case of a client with a short duration of SCI, however, it is possibly more difficult to suggest that disability is caused by negative societal attitudes toward persons with impairment because his/her stance toward disability may be firmly entrenched in an individual mindset. To suggest otherwise may harm the client-worker relationship, as the client may feel that the worker is not properly attuned to his/her immediate needs: listening to, and validation of, concerns that are raised. Furthermore, to point out that others may be in situations similar to what the client is currently facing trivializes the

client's position as an individual with valid problems. Granted, Moreau et al. (1993) imply that collectivization occurs some time after commencement of the client-worker relationship, but the means by which each objective progresses to the next are all too facile. Such tactics may be easier to accomplish if the client first iterates that social structures, apart from what is individually experienced, are responsible for inequality. Insisting that larger societal structures exist when a client only senses individual loss, however, suggests that the worker is trying to force an agenda rather than ameliorating the client's immediate needs.

To be sure, persons with SCI often do face conditions of material inequality (Boschen et al., 2001) and stigmatization on many fronts, as several of the conversations with participants in this study indicated. Yet one notion made explicit by many was that they would need to 'accept' the ramifications of their disabilities in order to proceed toward a satisfying life again. While most persons with long durations of injury iterated that the thought of SCI had become so firmly ingrained into their daily routines that they were often unconscious of it, SCI was still very much a central element in short-duration participants' lives. One short-duration respondent, Anthony, mentioned the need for more services for persons with SCI, but of the coping kind:

They had these focus groups here [at Lyndhurst] and... I was an outpatient at the time. And there were only 6 or 7 people who came to this thing. And that's all they could get, which really bothered me... If they only got more of these things going... maybe I'm out of the loop; maybe they have tons of these things going on... but I gather that they have trouble getting people, and boy, is that ever one way to see yourself, and how to see you, and how to talk to other people. ... [as to why he thinks these groups are poorly attended] I think it's more out of frustration; I think people are shy about talking about it. I once put myself in that category, but once you get there, and some youngster of 25 back in highschool again, breaks the ice... it's really great. People really open up. I really recommend those. I think...

maybe they should hold those as inpatients rather than as outpatients.

These services represented a chance for Anthony to identify with other individuals his age who had SCI as well as to compare his rehabilitation progress with that of others. While his concerns were not materially based, Anthony's association with others with SCI assisted in positive adjustment of his daily routine. Carniol's (1992) motivation for involving clients in groups stems from the hope that these groups will flourish into social movements that will promote equality. In contrast, Anthony's primary aim for joining a group was to meet people with similar experiences who could help him cope with his SCI.

From the array of experiences that participants described in this study, it becomes clear that social workers adhering to the structural approach must be prepared to 'wear different hats' with different clients. Insofar as maximum individual autonomy is preferred, social workers must not force their vision of a client's circumstances onto the relationship. Such tactics only serve to propagate socioeconomic differences between the professional and the client. It is one matter for a worker to be aware of resources that the client did not know; it is another to claim that that client's experience is not special but grounded in broader societal structures. That being said, exposure to systemic lack of resources and discriminatory attitudes over time may indeed inform clients that many of their problems are not individually-based but societal in their context; it is here that a worker adhering to a structural approach may have freer rein to extrapolate on ideas that (s)he feels are closer to 'the nature of things.'

To conclude, this study has shown that a multitude of environmental conditions influence the definitions and indicators of QOL for persons with SCI ages 50 and over.

Some react to these conditions as activists, promoting structural change, while others downplay their disabilities and lead lives that try to ignore the hurt that SCI has 'caused.' For some, time and adequate access to resources may have eroded the centrality of SCI to the extent that they often forget that they have SCI. Still, others, particularly those with short durations of injury, indicate that adjustment of their daily routines is influenced to a large degree by their attitudes toward disability prior to incurring injury. While a worker might feel that an individual's agency is constrained and perhaps determined by his/her material conditions, the worker's understanding that (s)he must fulfill different roles in consideration of clients' desired outcomes is indeed the best way to approach social work practice.

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Appendix A: Research instrument

1. Hi! I've just got to ask you two background questions first, if you don't mind.
These questions are being asked in order to establish whether you've had a spinal cord injury for a short or long time. How old are you?

2. How long ago did you have your injury?

3. Thank you. Please feel free to take as much time as you need to answer every question. Imagine that your life was a story, with each part of your life making up a chapter in that story. What would be the first chapter? [pause for response]
The second one?

4. I would like you to focus on a few memorable incidents or significant episodes that stand out when looking across your life as a whole.
 - 4a. Recall a certain time when you felt great happiness, peace, excitement or some other highly positive emotional experience. Can you describe what happened?

 - 4b. Now, try to remember a particular experience in life in which you felt an extremely unpleasant emotion. Can you describe what happened?

 - 4c. In looking back on one's life, one can often mark a turning point somewhere—a point that marked a change in how you understood who you were. What happened?

- 5a. How would you describe your life, right now?

- 5b. What would you consider to be really good about your life right now?

- 5c. What isn't going so well, and may be even bad about your life right now?
6. You've had your spinal cord injury for a (short/long) time. Has it has changed your outlook toward life?
- 6a. (If so) How would you characterize yourself to have been before the injury and then afterward?
- 6b. (If not) What, about you, has stayed constant throughout your life?
- 7a. How would you define "quality of life"?
- 7b. What do you think of when you hear the words "quality of life" or a "life worth living?"
8. What are the necessary ingredients for quality of life, for anyone?
9. How would you rate the overall quality of your life? (if participant asks:)
You can give me a number or a description, whatever you'd like
10. What would improve the quality of your life?
11. I'm going to return to one of the first questions that I asked you. Go back to looking over your entire life story as if it were a book with chapters. Can you see a central theme that runs through the book? What might that theme (message) be?
12. Is there anything else that you would like to add?

Thank you! Your participation in this study is much appreciated!

Appendix B: Informed Consent

“Subjective quality of life of persons with spinal cord injury, ages fifty and over: views of persons with short and long durations of injury”

Informed consent

Research Team

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Introduction

You are being asked to participate in a Masters thesis project that will investigate perceptions of quality of life among aging persons with spinal cord injuries. Before agreeing to participate in this project, it is important that you read and understand the following explanation of the proposed project procedures. The following information describes the purpose, procedures, benefits, discomforts, risks, and precautions associated

with this project. It also describes your right to refuse to participate or withdraw from the project at any time. In order to decide whether you wish to participate in this project, you should understand enough about its risks and benefits to be able to make an informed decision. This is known as the informed consent process. You should be comfortable that all your questions have been answered to your satisfaction before signing this document.

Purpose

The purpose of this thesis project is to investigate interpretations of the term 'quality-of-life' among aging persons with spinal cord injuries, and how their interpretations have been influenced by their lives' experiences. For the purpose of this study, people with spinal cord injuries are considered to be 'aging' if they are fifty years or over. Two groups of people with spinal cord injuries will be interviewed: those who have had injuries for twenty-five years or more, and those who have had injuries for five years or less. This project will allow researchers to see how people's perspectives of 'quality of life' differ if they have sustained injury recently, as opposed to many years ago. In turn, this study may be used by such organizations as the Toronto Rehabilitation Institute in creating new services, or altering existing ones, to better reflect the needs of aging persons with spinal cord injury.

Procedures

If you agree to participate in this study, you will participate in a semi-structured interview of approximately one to one and a half hours in length. Your interview will be recorded using a digital audio device and will be transcribed for analysis. This interview will be conducted at a place and time of your choosing.

Risks and Discomforts

To the best of our knowledge, there are no risks or discomforts involved in participating in this project. However, it is possible that you may experience emotional distress when reflecting on some questions. If you do feel troubled at any time during the research process, you can contact André Chor, the project's investigator, at (905) 571-0338.

Expected Benefits

In the short term, you may feel empowered by the opportunity to express your own notions of QOL, as opposed to reflecting on QOL criteria that others may have given you in other studies. Long-term benefit is indirect; the information that is provided may be of use to people who have recently sustained spinal cord injury and are interested in understanding the perspectives of those who have likewise experienced it. This research may also be used as a pilot for larger, more comprehensive studies in the future.

Participation

Your participation in this project is completely voluntary. You may withdraw from the project at any time without any impact on the services you are currently receiving or will receive in the future from the Toronto Rehabilitation Institute.

Confidentiality

Your name will not appear anywhere in the summary of findings and thesis report, and all data will be reported as various segments from the interview. Your recorded interview will be kept anonymous in a database, and all hard copies of transcripts will be kept in a locked filing cabinet. Only the principal investigator will have access to the database and hard copies of transcripts. All audio files and transcriptions will be destroyed twenty-four months after thesis approval.

Questions

We encourage you to ask questions and give feedback at any point in the project. Should you wish to do so, please contact any of the individuals listed on the front page of this form. If you have any questions about your rights as a participant in this project, please call **Dr. Gaetan Tardif, Chair of the Toronto Rehabilitation Institute Research Ethics Board at (416) 597-3422 ext. 3730.**

Consent Section

I have been invited to participate in a research study that is investigate perceptions of quality of life among aging persons with spinal cord injury. My participation will only involve my permission to be interviewed by the principal investigator for one session at a place and time of my choosing. This session will be approximately one to one and a half hours long. I understand that the data from my interview will be analyzed for the purpose of comparing them to other participants' responses. I also understand that the project involves publication of a Masters thesis that will report all data as segments from the interview. I recognize that the data from the interview will be destroyed twenty-four months after the thesis has been completed. The project has been explained to me and my questions have been answered to my satisfaction, as indicated by my signature below and that of a witness. I understand that I will receive a copy of this consent form.

I voluntarily consent to participate in this project. I understand that the data collected will be kept in a safe and locked place at the Lyndhurst Spinal Cord Centre.

Your name

Your signature

Witness

Researcher's name

Researcher's signature

Date

Appendix C: Strauss and Corbin's coding paradigm

Element	Description
Phenomenon	The concept that holds coding together. In grounded theory it is sometimes the outcome of interest, or it can be the subject.
Causal conditions	Events or variables that lead to the occurrence or development of the phenomenon. A set of causes and their properties.
Context	Specific locations (values) of background variables. A set of conditions influencing the action/strategy. Researchers often make a quaint distinction between active variables (causes) and background variables (context). It has more to do with what the researcher finds interesting (causes) and less interesting (context) than with distinctions out in nature. Context can be identified with moderating variables.
Intervening conditions	Intervening conditions can be identified with mediating variables.
Action strategies	Purposeful, goal-oriented activities that agents perform in response to the phenomenon and intervening conditions.
Consequences	Consequences of the action strategies, intended and unintended.

Source: Borgatti, S. (accessed January 20, 2005)