WHAT ARE THE STRESSORS – PERSPECTIVES OF COMMUNITY RESIDING

INDIVIDUALS WHO HAVE A SPINAL CORD INJURY

by

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Abstract

The need for research as well as clinical attention focused on the perspectives of individuals with disabilities is being increasingly recognized and supported. Equally recognized among the rehabilitation team and researchers involved in the area of spinal cord injury (SCI) is the highly stressful nature of the return to life in the community from the inpatient rehabilitation centre. Despite this awareness, no research could be found which explored specifically the nature of stressors experienced by individuals who have a SCI and live in the community. The purpose of this study is to address this lack of information by means of an exploratory qualitative study involving a focus group with 5 members. Suggestions from the participants for a better preparation for potential stressors at the rehabilitation centre, as well as for resources and services when living in the community will be described. The findings will contribute to raising general awareness and understanding of the potential stressors experienced by individuals who have a SCI among the research community, individuals who work with persons who have a SCI, including counsellors, society at large, and among individuals with a SCI. As well, the results may guide health professionals in designing ways to better prepare individuals for the return to life in the community and to assist individuals living in the community through effective resources and intervention programs.

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INTRODUCTION

What are the Stressors – Perspectives of Community Residing Individuals

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It is difficult today to open the newspaper, turn on the television or otherwise go about one's day without noticing a reference to the concept of stress. The extent of attention paid to the concept of stress can be seen to relate to the extent of its effects. Stress has been shown to be linked to various physical, mental, and emotional problems and disorders among a variety of populations studied (Dohrenwend & Dohrenwend, 1973; Kessler, Price, & Wortman, 1985; Kiritz & Moos, 1974; Taylor, 1990; Thackwray-Emmerson, 1988; Wortman, 1984). Heightened awareness of the effects of stress in our society has recently resulted in increased attention paid to the maintenance or achievement of good health and thus to the utilization of effective stress reduction or management interventions.

While relevant to the population at large, the maintenance and facilitation of good health is especially important for individuals who have sustained a SCI. Due to the traumatic impact of the injury on body functioning, including physical, mental, and emotional aspects, the detrimental nature of stress can be exacerbated (Bertino, 1989). In the literature on SCI, stress has been linked to an increased incidence of medical complications, an increased frequency of hospitalizations, and detrimental effects with respect to adjustment (Hohmann, 1975; Malec & Neimeyer, 1983; Shadish, Hickman, & Arrick, 1981). Hence, stress reduction or management has important relevance for individuals who have a SCI. Despite its importance, the literature addressing stress and its management

among individuals who have a SCI is very sparse and thus represents a significant gap in need of attention. However, prior to the design of an effective intervention, the nature of stressors which individuals who have a SCI may experience has to be known and its discovery is the goal of the present study.

Another important aspect of this study is the focus on the perspectives of persons who have a SCI, rather than on assumptions made by able-bodied individuals. This aspect thus determined the design of the study to be qualitative. The qualitative design and the focus on the perspectives of each individual lead to the choice of the theoretical framework of stress employed in this study. The model of stress used is one described by Lazarus and Folkman (1984), one of the most comprehensive conceptualizations of stress. This theory regards the individual's context-dependent appraisal of an event as the determining factor of what, and to what extent, an event is considered to be a stressor and thus involves both the environment and the individual's perception.

In reference to the focus on the perspectives of individuals who have a SCI, this attention has long been called for in the literature as well as in practice and is increasingly being supported (Barnes, 1992; Carpenter, 1994; Costigan-Lederman, 1990; Edgerton & Langness, 1974; Gliedman & Roth, 1980). While researchers (Caplan, Gibson, & Weiss, 1984; Hanson, Buckelew, Hewett, & O'Neal, 1993) have commented in general terms both on the stressful nature of the transition from rehabilitation to living in the community as well as on the stressful nature of living in the community with a SCI, no study could be found which delineated the nature of stressors experienced by individuals who have a SCI and live in the community. It is the purpose of the present study to address : a) what individuals who have a SCI and live in the community find stressful, b) what the implications of those stressors are, c) what suggestions the individuals in the

study have for being better prepared for the return to life in the community after inpatient rehabilitation, and d) what suggestions the participants have for effective resources and services for individuals with a SCI living in the community. The purpose of this study is to address these questions by means of a qualitative study involving focus groups. Focus groups are group discussions with approximately 6 to 12 individuals per group who are homogeneous with respect to the issue under discussion. A moderator skilled in group functioning serves as the group leader (Krueger, 1994).

Chapter II

REVIEW OF THE LITERATURE

This chapter will present literature related to each aspect of the present study. First, literature pertaining to stress and its measurement will be discussed. Second, Lazarus' and Folkman's (1984) theory of stress will be described. Third, literature regarding the consequence and effects of a SCI will be presented, followed by a discussion of literature which addresses stress reactions in individuals who have a SCI. Next, the methodology of the present study, the focus group technique, will be described in detail, including its strengths and weaknesses. Finally, the researcher will outline her conceptualization of disability and her biases.

Stress and its Measurement

This section will review definitions of stress, describe how stress has been measured, including inherent methodological problems, and address some of the theories of stress presented by leaders in the field.

The scientific study of stress commenced in the 1930's with the work of Hans Selye (1950) who defined stress as a disturbance in the physiological homeostasis of the individual. A more recent definition has conceptualized stress as a "state of imbalance that results from any demand to adapt or change, a perceived threat, a challenge to one's ability to cope or perform, or unmet needs, or lack of resources " (Sutterly, 1986, p.42).

Although methodological advancements in the assessment of stress have been made, conceptual clarity and measurement of stress remain problematic. The traditional measurement of stress is based on the checklist format pioneered by Holmes and Rahe (1967) where the number of stressful life events and their

inherent stress weightings are summated. Methodological issues in the measurement of stress consequently involve mainly this method of inquiry. Among them are retrospective bias, timing of measurement, and length of sampling interval (Bower, 1981; Monroe, 1982; Tausig, 1986). The susceptibility of self-report life event checklist formats to retrospective bias involves the influence on the number and quality of events recalled. The number of events has been found to diminish over time due to forgetting (Jenkins, Hurst, & Rose, 1979; Monroe, 1982; Uhlenhuth, Haberman, Balter, & Lipman, 1977). The failure of the participants' mood state at the time of the measurement to precipitate the recall of stressful events or situations has also been cited as a problem area (Bower, 1981; Clark & Teasdale, 1982). The length of the sampling interval is another issue under discussion (Tausig, 1986). A long enough interval must be included so that a valid range of life events can be sampled without simultaneously accruing too much retrospective recall error (Tausig, 1986). Retrospective intervals of six to nine months are generally regarded as appropriate (Sheridan & Perkins, 1992).

Empirical attempts to extract contextually meaningful categories of stressors have been hindered by the restricted pool of event checklists where most checklists contain a common set of stressors generalized across population groups (Thoits, 1987). Thoits calls the validity of such a generalization into question and argues that specific experiences define the type of stressors encountered and that studies addressing stress should focus on a 'unique stressor model'. In the case of individuals with disabilities such as a SCI, this would translate into the need to sample stressors experienced by these individuals. A number of studies suggest that different types of disabilities give rise to unique sets of stressors. For example, Caplan, Gibson, and Weiss (1984) have found evidence that SCI and brain injury are each distinguished by their own set of

stressors.

Considerable discussion has also been held regarding the methods of weighting events (Grant, Swetwook, Gerst, & Yager, 1978; Rabking & Struening, 1977). Rabking and Struening report only modest predictive validity ($\underline{r}$=.17 to $\underline{r}$=.34) between the results of event checklists and adjustment outcomes. Efforts to increase predictive validity with different weighting systems have failed (Mueller, Edwards, & Yarvis, 1977; Ross, & Mirowsky, 1979). A number of researchers have explanations for these difficulties which involve the assumption underlying the approach to stress research discussed so far (Arnold, 1960; Brown, 1973; Lazarus, DeLongis, Folkman, & Gruen, 1985; Lazarus & Folkman, 1984; Parkes, 1971). This assumption presupposes that the stressfulness of an event is intrinsic to it and that everyone exposed to a certain stressor will be affected in a similar way (Monat & Lazarus, 1991). Due to the great variability in the response to stressful life events and the resulting research focusing on the moderating factors in the response to stressful life events, this assumption is strongly criticized by the previously mentioned researchers (Arnold, 1960; Brown, 1973; Lazarus, DeLongis, et al., 1985; Lazarus & Folkman, 1984; Parkes, 1971). Alternatively, these authors argue that the stressfulness of an event is mediated by the meaning the individual attributes to the event and that the same event may have very different meanings to different individuals and to the same individual in different situations and at different times (Lazarus, Delongis, et al., 1985; Lazarus & Folkman, 1984).

A final, and crucial, complicating factor in the study of stress expands on the earlier mentioned factor of the mood state of the individual at the time of measurement affecting the recall of stressful events. This factor involves the assumption made by researchers that participants are aware of their stressors (Bargagliotti & Trygstad, 1987). In reality, as Bargagliotti and Trygstad point out,

"some stressors are labeled taboo, recall of others creates discomfort and therefore they are not readily recalled, and/or chronic stressors may not be in the forefront of awareness and therefore go unnoted" (p. 171). In this study, it is hoped, that the qualitative methodology as well as the specific technique, focus groups, will ameliorate some of these limitations. The specific methodological aspects referred to here will be outlined in later sections.

While the bulk of the research investigating stressors is based on quantitative studies, one study employed and compared quantitative and qualitative methodologies in examining work-related stress (Bargagliotti & Trygstad, 1987). The researchers found that the sources of stress detected with the different methodologies differed. While the quantitative study identified discrete events as the sources of stress, the qualitative study described sources of stress related to interactional processes of events occurring over time.

Lazarus' and Folkman's Theory of Stress

The following section outlines the view of stress proposed by Lazarus and Folkman (1984) which will serve as the conceptual basis for this study.

The term stress is used in this study to describe situations, or stressors, which tax or exceed a person's physical and/or psychological resources (Lazarus & Folkman, 1984). Distress, a related concept, is considered to be the emotional response to stressors (Tate, Maynard, & Forchheimer, 1993).

The view that stress is mediated by the meaning the individual attributes to an event, put forth by Lazarus and Folkman (1984), demands that stress is regarded as a function of both the environment and the individual's perception. Hence, what and to what extent an individual considers an event or situation to be a stressor reflects the individual's context-dependent appraisal of it. According to Lazarus and Folkman, there are two major forms of appraisals : primary

appraisals and secondary appraisals. Primary appraisals serve to evaluate the significance of a specific event with respect to well-being and involve judgments of whether an event is irrelevant, benign to positive, or stressful. Secondary appraisals serve to evaluate coping resources and options and address the question 'what action can I take ?' Coping resources including physical, psychological, social, and material aspects are compared to the demands of the situation. The focus in this study will be on primary appraisals as they deal with the stress section of the stress-coping equation. According to Lazarus and Folkman, three stressful appraisals are possible : harm/loss, threat, and challenge. Harm/loss refers to physical or psychological harm already done, whereas threat refers to potential harm or loss. Challenge refers to the opportunity for growth, mastery, or gain.

The process of appraisal is affected by a series of person and situation variables. Among the most important person factors are beliefs and commitments. Beliefs are notions about reality that serve as a perceptual lens. Generalized beliefs about control regarding the extent to which individuals assume they can control outcomes are among the beliefs which influence primary appraisals. A well known conceptualization of control beliefs is Rotter's (1966) internal versus external locus of control. An internal locus of control describes the belief that events are dependent on one's own behaviour, whereas an external locus of control presumes that events are dependent on chance, luck, fate, or powerful others. Rotter (1966, 1975) proposed and subsequent studies confirmed (Archer, 1979) that control expectancies have their greatest influence when situations are ambiguous or novel. Under conditions of ambiguity or lack of clarity in the environment, the person makes inferences based largely on experience and personality dispositions, including beliefs, in order to understand the situation. Conversely, if the situation is not ambiguous, inferences will be

based more on situational characteristics than on personality dispositions.

As mentioned earlier, commitments also have an important influence on primary appraisals as they reveal what is important to the person. Commitments involve values, ideals, and goals. Thus, an event that involves a strongly held commitment will be judged as significant with respect to well-being to the extent that the expected outcome harms or threatens that commitment (Lazarus & Folkman, 1984).

Situational factors such as the nature of the harm or threat, the familiarity or novelty of the event, the likelihood of its occurrence, the timing, and how clear or ambiguous the expected outcome is, can all influence primary appraisals. It is important to note, here, that appraisals of harm/loss, threat, and challenge are not mutually exclusive, but can occur simultaneously. For example, in the case of an individual who has a SCI, the return to the community from the rehabilitation centre may be appraised as both a threat and a challenge. The challenge appraisal may involve the potential for gains in freedom, self-determination, knowledge, and skills, whereas the threat appraisal may involve the risk of facing unexpected obstacles (Lazarus & Folkman, 1984).

Spinal Cord Injury

The following section discusses some of the consequences of a SCI, present the rationales for the present study's focus on individuals with quadriplegic injuries, and cite SCI incidence rates.

SCI can result in quadriplegia and paraplegia. Quadriplegia, depending on the level of injury to the cervical spine in the neck and the completeness of the transection of the spinal cord, generally involves loss of or impairment in motor and sensory functions below the level of the lesion, involving the trunk and all four extremities. Paraplegia results from injury below the cervical level to the

thoracic or lumbar regions and depending on the level and completeness of the injury involves impairment in or loss of sensory and motor function in the lower extremities and usually the trunk (Bromly, 1985). Other physical consequences of SCI may include loss of control of bowel, bladder, and sexual functioning, pain, risk of pressure sores (areas of skin breakdown resulting from unrelieved pressure as a consequence of the lack of sensory stimulation to shift position), and increased risk of respiratory and urinary problems (Lee, Ostrander, Cochran, & Shaw, 1991). Some of the psychosocial consequences that may be experienced following SCI will be discussed in later pages. For additional physical and psychosocial consequences and complications of SCI, the reader is referred to works by Ozer (1988), Trieschmann (1988), and Zejdlik (1992).

The present study will focus only on individuals with quadriplegia. Inclusion of individuals with paraplegia is beyond the scope of the study. As well, the present study will involve only individuals with quadriplegia who live in the community in apartments or houses, not in institutions, extended care facilities, or group homes. The rationale for this focus is the fact that the ultimate goal of rehabilitation is the return to independent living in the community and the fact that the stressful nature of this return has been previously identified (Frieden & Cole, 1985; Pollack, Zuger, & Walsh, 1992; Tate et al., 1993; Versluys, 1984). As well, a better preparation for potential stressors at the rehabilitation centre and effective assistance for individuals who live in the community has been called for (Caplan, et al., 1984; Dew, Lynch, Ernst, & Rosenthal, 1983; Tate et al., 1993) and necessitates the exploration of the nature of stressors experienced by individuals who live in the community.

With respect to incidence rates in Canada, the annual report of the Canadian Paraplegic Association (1993) quoted 583 SCIs for 1992-1993, 303 of which resulted in quadriplegia. The ratio of males to females was 3.5 to 1.

Approximately 62% of SCIs occurred to people between the ages of 15-29. In examining the most prominent causes of SCI, motor vehicle accidents ranked first by accounting for 35 % of all SCIs, falls followed with 16.5%, and criminal and farming injuries ranked third with 14.2%.

Quadriplegia, affecting approximately 0.001% of the population is a low incidence, but high cost, disability which requires tremendous changes in a person's life. One of the salient consequences of quadriplegia is dependence on others (Trieschmann, 1988). Activities of daily living such as bathing, bowel and bladder care, dressing, shopping, preparation of meals, eating, and transfers into and out of bed may require varying degrees of assistance from others. Given the injury's effects on nearly every aspect of a person's life, it is thus hardly surprising that research has identified the stressful nature of a SCI (Caplan, Gibson, & Weiss, 1984; Cruse, Lewis, Bishop, Kliesch, Gaitan, & Britt, 1993).

Spinal Cord Injury and Stress

This section describes some of the research studies which address the topic of stress in individuals who have a SCI. Although no studies could be found which focused on and identified the nature of stressors experienced by individuals with a SCI, several studies have documented the existence of stress reactions. Potential stressors have also been deduced from adjustment studies with individuals with a SCI.

One study which utilized the Recent Life Changes Questionnaire, an inventory of potentially stressful life events, asked 30 individuals with a SCI about events that happened to them six months pre-injury and six months post-rehabilitation discharge. Participants reported more than 3.5 times higher life change units (LCU), indicating the amount of stress induced by an event, post-injury (Caplan, Gibson, & Weiss, 1984). Due to methodological problems such as

the utilization of an inventory not developed or standardized with individuals who have a SCI and the subsequent exclusion of stressful events related specifically to the SCI such as loss of control over bowel and bladder function, these results undoubtedly represent a conservative estimate of stress. The reliability of recall for distant events can also be questioned. Moreover, the earlier mentioned criticism of this method of inquiry with respect to the exclusion of an assessment of the subjective meanings of the events, applies to this study as well and may thus exacerbate or ameliorate the stressfulness associated with the event. To cite an extreme example from the study, one individual with a SCI reported post-discharge events representing 555 LCU, while another person with a similar injury reported 141 LCU.

Another study has found that 29% of 28 participants indicated significant levels of distress (T-score > 70) five to six years after the injury as assessed by the Symptom Checklist-90-Revised (Derogatis, 1977), which measures the degree of psychological distress through 90 symptoms rated on a four point Likert scale (Hanson, Buckelew, Hewett, & O'Neal, 1993). Furthermore, psychological distress has been identified as the single most important indicator of psychological adjustment after SCI (Shadish et al., 1981). Tate et al. (1993) measured levels of psychological distress among 119 individuals with a SCI through the Brief Symptom Inventory (Derogatis & Spencer, 1982), a symptom checklist that provides an overall index of distress. They found that psychological distress was significantly higher one year post-injury when compared to results obtained on admission and at discharge from the inpatient rehabilitation centre. The prevalence rate for the elevated distress was 28%.

Dew et al. (1983) conducted structured interviews with 110 men with a SCI and found that participants felt that a large proportion of rehabilitation was accomplished after discharge from the rehabilitation centre. Specifically, Dew et

al. determined that many difficulties such as emotional, financial, and family problems developed after discharge from the rehabilitation centre. Earlier research in the United States also supports this finding that many rehabilitation programs do not teach the necessary practical skills which could ease adjustment (Felice, Muthard, & Hamilton, 1976; Morgan, Hohmann, & Davis, 1974). These findings are somewhat dated and focus on rehabilitation centres in the United States. A more current and local assessment of the rehabilitation programs from the perspectives of its users would undoubtedly prove useful. Other researchers (Dew et al., 1983; Frank & Elliot, 1987; McHugh Pendleton, 1990; Tate et al., 1993; Vargo, 1982) have called for more research focused on the experiences of individuals after discharge to ascertain how rehabilitation programs could be rendered more effective as well as to identify their limits and to aid in the development of community programs that could ease the transition from institutional to community living. The present study intends to address these issues as well as respond to other researchers (Pelletier, Rogers, & Dellario, 1985; Thurer & Rogers, 1984) who have called on counselling psychologists to develop psychological services which address the needs of individuals with physical disabilities.

While researchers have documented the existence of significant stress reactions among individuals with a SCI, and many have called for more research in this area, only one reported study exists which made reference to a stress management intervention with individuals who have a SCI (Bertino, 1989). This study, however, only examined the change in knowledge with respect to stress from pre- to post-intervention and had only seven participants. This lack of effective interventions which address the psychosocial needs of individuals who have a SCI is especially disconcerting when one considers the increasing numbers of deaths reported following SCI which are attributable to preventable

causes such as self-neglect, alcohol and drug abuse, and suicide (DeVivo, Black, & Stover, 1991; Geisler, Jouse, Wynne-Jones, & Breithaupt, 1983). Estimates of preventable deaths following SCI have ranged from 9% (Charlifue & Gerhart, 1991) to 34% (Trieschmann, 1988). While some of these studies can be critiqued on methodological grounds for their failure to include non-disabled populations matched for age, sex, and socioeconomic status, the stress factors which can tax the coping resources of individuals who have sustained a SCI and can play an important part in preventable deaths, cannot be ignored.

In response to the call for research focused on the perspectives of individuals with a SCI and on the development of effective interventions addressing the psychosocial needs of these individuals, this review will now apply Lazarus' and Folkman's (1984) theory of stress to people who have a SCI. Based on this theory, the individuals' reactions to the realization of what quadriplegia means in terms of daily functions as well as future plans and goals may significantly affect their appraisal of stressors. The evaluation of what is considered stressful is believed to be intricately tied to the hopes, dreams, attitudes, values, beliefs, and understandings of each individual. Similarly, factors including prior life history, concurrent life stressors, sociocultural attitudes, social and financial resources, response of others to the injury, lifestyle adjustments, personality factors, and personal issues are likely to influence the experience and appraisal of stressors (Caplan et al., 1984; Dew et al., 1983; Drayton-Hargrove & Reddy, 1986; Frank & Elliot, 1987; Tate et al., 1993).

While no published studies could be found which specifically investigated the nature of stressors experienced by individuals who have a SCI in a qualitative manner, several researchers have drawn conclusions pertaining to stressors based on both qualitative and quantitative adjustment studies. For example, the literature on the psychological aspects of disability provides a

multitude of examples that demonstrate the potent source of stress which negative attitudes by non-disabled individuals represent for individuals who have a SCI (Curcoll, 1992; English, 1971; Rothschild, 1970; Wright, 1983). Curcoll describes attitudes of rejection and coldness as stressful situations for which appropriate coping strategies must be learned. Further, Ray and West (1983) conducted in-depth interviews with 22 people with paraplegia and found that sexual difficulties, changed body image, as well as the pity and patronizing attitudes of others were potent sources of stress for these individuals. Other researchers conducted 110 structured interviews with men who have a SCI and found that many of them experienced recurrent physical problems, pain, social isolation, unemployment, and a fixed standard of living which likely represent stressors (Dew et al., 1983). The high unemployment rate of 51.3% reported in a study of 154 individuals with a SCI lends support to the findings of the previous study (DeVivo, Rutt, Stover, & Fine, 1987). If dissatisfaction is equated with stress, then the findings of researchers assessing the life satisfaction of men with a SCI indicate that the participants' dissatisfaction, or stress, was greatest in the area of intimate relationships (Carlson, 1979; White, Rintala, Hart, Young, & Fuhrer, 1992). Researchers investigating the impact of SCI on marital status have also found fewer marriages and more divorces compared to the general population (DeVivo & Fine, 1985; DeVivo & Richards, 1992; Dew et al., 1983).

Furthermore, since adjustment to SCI is viewed by many researchers (Trieschmann, 1988) as a life long process, and since it has been found that the passage of time since injury did not allay the distress experienced by 53 individuals with a SCI (Frank & Elliott, 1987), the concept of chronic stress warrants consideration. Chronic stress has been conceptualized as a situation in which individuals are affected by continuous and multiple changes, demands, threats, and deprivations (Fried, 1982). Chronic stressors are stressors

comparatively broader in nature and longer in duration than transient, short-term stressors. Collectively, chronic stressors may summate over months or years to produce measurable increases in what is commonly referred to as psychosocial strain (Cohen, 1986). Researchers such as Cohen have indicated that there is a substantial cost to dealing with chronic stressors, resulting in a drain of effective coping efforts, thus lending support to the importance of effectively addressing chronic stressors.

The Focus Group Technique

This section will address the background and details of the focus group technique, including its strengths and weaknesses.

The use of focus groups dates back to the 1930's when social scientists used this technique as an alternative to individual interviews (Krueger, 1994). A more refined development of the technique began in the 1940's with Merton and his colleagues (Merton, Fiske, & Kendall, 1956). Despite their origins in social science, focus groups have been used predominantly in marketing research to determine customer attitudes about products and services (Krueger, 1994). Recently, focus groups have been increasingly incorporated into health research (Cook Merrill, 1985; Emery, Ritter-Randolph, Strozier, & McDermott, 1993; O'Brien, 1993; Richter, Bottenberg, & Roberto, 1991; Saint-Germain, Bassford, & Montano, 1993).

Focus groups provide a multitude of uses. They can be utilized to generate constructs, models, and data for instrument development, to learn more about a specific topic, to identify issues, experiences and perspectives, as well as to assist in the evaluation of programs and products (Kingry, Tiedfe, & Friedman, 1990; Stewart & Shamdasani, 1990). The main premise of focus groups is that the use of the group interaction is believed to produce data and insights that would be

less accessible without the interaction found in a group. The disclosure of rich information is believed to be facilitated by the homogeneous nature of the group and the support received from other members and the moderator (Costigan-Lederman, 1990; O'Brien, 1993). Due to the importance of the homogeneity factor, purposeful sampling, rather than random selection, is the method for participant recruitment (Krueger, 1994).

Merton et al. (1956) cite four criteria for effective focus groups : a) covering a maximum range of relevant topics; b) providing data regarding the participants' experiences, bases for attitudes, and opinions that are as specific and detailed as possible; c) fostering interaction that explores the participants' feelings in some depth; and d) taking into account the personal context that participants use in generating their responses to the topic.

The size of the focus group ranges from 6 to 12, although this is flexible and productive groups can be conducted with fewer or more participants (Morgan, 1988). Discussions take place in a comfortable, informal, non-threatening setting, last from one to three hours, and are based on questions posed by the moderator. The group leader or moderator requires skills in facilitating effective group functioning and is of key importance in the successful outcome (Stewart & Shamdasani, 1990). The following are some of the responsibilities and requirements of a moderator : to (a) create a non-threatening, supportive atmosphere that encourages all participants to share their views; (b) facilitate interaction among group members and moderate equal input from participants which may require appropriate attention to both shy and dominating group members; (c) effectively use probing comments, transitional questions and summaries; (d) express oneself clearly; (e) be a good listener who quickly comprehends the essence of what participants are communicating via verbal and non-verbal means and is empathic regarding the way participants feel about the

issue being discussed; (f) understand the issue being discussed, but remain unbiased and non-judgmental with respect to participants' responses; (g) keep the group on task, but be flexible in terms of unanticipated events; and (h) be spontaneous and lively (Fern, 1982; Krueger, 1994; Morgan, 1988; Stewart & Shamdasani, 1990). Researchers trained in counselling who possess a sound knowledge of and experience with these criteria are ideally suited for this moderator role.

Focus groups have many advantages over other data collection techniques. Among them are the benefits of group synergy and spontaneity which are similar to brainstorming and yield rich, in-depth information (Krueger, 1994). The group's combined insights will often exceed by far the total of the individual members' insights, because a comment by one participant may trigger a new insight for another participant whose comments may, in turn, stimulate another member (Kingry et al., 1990; Popham, 1993; Stewart & Shamdasani, 1990). The collaborative social nature of the data gathering procedure capitalizes on people's social, interactive nature and potentially yields a rich array of insights and information (O'Brien, 1993). Data collected in this manner in a group setting are also considered to be more ecologically valid than data collected without group interaction (Albrecht, Johnson, & Walther, 1993). The latter two aspects address a fundamental assumption underlying focus groups – that "the world constitutes not one experiential or material reality, but multiple realities that interact with and play off one another " (Brotherson & Goldstein, 1992, p. 335). Brotherson and Goldstein urge that research addressing potential intervention programs must address these multiple realities. Focus groups are specifically designed to elicit multiple perspectives.

Another advantage of focus groups is that a high degree of interaction can be observed on a topic in a limited period of time. Researchers can efficiently

orient themselves to a new or relatively uninvestigated field, because the group interview can provide useful data with little direct input from the researcher. This method of inquiry thus provides for the involvement of members of the target population in determining which and how issues raised should be addressed. This involvement with respect to individuals with disabilities has, as mentioned, long been called for and is increasingly being supported both in clinical practice and in the research literature (Barnes, 1992; Carpenter, 1994; Cook Merrill, 1985; Costigan-Lederman, 1990; Edgerton & Langness, 1974; Gliedman & Roth, 1980). In line with the latter, Carey and Smith (1992) have found that the inclusion of individuals who have AIDS in the process of program evaluation has led to a noticeable improvement in client participation. They further stress that incorporating the perspectives of patients in a medical environment through qualitative research enhances the validity of research results.

With respect to the proposed study with individuals who have a SCI, another advantage of the focus group technique is the oral nature of data collection. This method is ideally suited to individuals who may not be able to write or who have difficulty writing. The use of focus groups also allows the researcher to have direct contact with the participants and permits the clarification of interview questions as well as responses (Krueger, 1994). Finally, the results of focus groups do not require statistical knowledge for interpretation, and can be readily understood without mathematical or research training (Caplan, 1990).

Despite these numerous advantages, there are also some drawbacks of focus groups to be considered. First, the researcher needs to be skilled in group process and qualitative inquiry (Kingry et al., 1990). Researcher bias, as with other methods of study, can also be a problem if researchers are unaware of their biases or predetermined ideas regarding the findings and do not act to minimize their

influences. Hence, the validity of the findings is directly related to the insight and objectivity of the researcher (Krueger, 1994). Next, the number of questions that can be answered in a group setting is limited. Merton et al. (1990) estimate that no more than 10 questions can be answered during a focus group session. However, if the topic has a high emotional content, there may be time for only two or three broad, open-ended questions because the participants may have many experiences and opinions to share (Merton et al., 1990). Furthermore, Janis (1972) cites the potential influence of dominant members on other participants, or of the subtle group pressure to agree with the majority, as a disadvantage of focus groups. A skilled moderator creating a safe, cohesive atmosphere where different perceptions and experiences are invited and normalized should, however, reduce the latter two potentially detrimental effects.

Researcher's Conceptualization of Disability and Biases

As rigorous qualitative inquiry demands, it is important to note the conceptual framework from which the researcher is operating. Furthermore, the need to be aware of the influence of researcher bias on data gathering, analysis, and interpretation in qualitative research, including focus group research, has been emphasized (Krueger, 1994; Morgan, 1988). This section will thus delineate first the researcher's conceptualization of disability and second her biases.

Examination of the western society in which we live shows that the focus is predominantly on the individual rather than on the connectedness with the family, society, or even nature. However, the role of society in shaping the individual cannot be ignored. Numerous researchers (e.g. Marinelli & Dell Orto, 1991; Nagler, 1993; Oliver, 1993) have documented the influence of society on the individual's personality, 'mode of operating in the world', career orientation, leisure activities, and goals. Hence, it has been established that society can have a

powerful influence on the individual. This concept of social influence will be applied specifically to individuals who have a SCI and taken one step further to agree with researchers who attribute the creation of the concept of disability to a large degree to society (Mackelprang & Hepworth, 1987; Phillips, 1990). It is our society and the associated environment inflexibly calling itself 'normal', 'right', and 'desirable' which, in the opinion of the researcher, fosters the establishment of the concept of disability. Alternatively, a society not passing these judgments, holding open and accepting attitudes to differences on any levels of being, and an accessible environment would, in my opinion, significantly reduce the concept of disability. In line with this view, Wolfensberger (1980) suggests that "deviancy is not within the person; it is within the imposed social roles, the values, and the perceiver's interpretation" (p. 13). Thomas (cited in Carpenter, 1991) suggests :

> I am persuaded that one of the failures of our society is not its treatment of the disabled person (though there are wide gaps and inequalities here) nor its lack of sensitivity to needs... but its failure to comprehend the normality of [disability]. It is the overwhelming insistence that we perceive and encourage 'the disabled' to perceive themselves as deviant that is the root of the problem. (p. 175)

Another important aspect of disability is the language used when referring to a person with a disability. The implication in our words is that the 'dysfunction' lies within the individual and that the onus for change and adaptation thus rests with the individual. That deduction, in my view, is flawed. I believe that the responsibility for change and adaptation should rest equally on both the individual and society. In support of this view of physical disability, several researchers have questioned why the environment, including physical, social, attitudinal, and financial aspects is so often neglected as a source of enduring stress for individuals with a physical disability (Santana Carlos, 1977;

Turner & McLean, 1989; Wright, 1980). A story entitled 'The adventures of the disabled village' by Vic Finkelstein (date unknown) effectively relays some of the aforementioned concepts with British humour (see Appendix H).

Addressed next is an identification of some of the researcher's biases and her experiential background which contributed to the formation of some of these biases. In terms of experience, I have worked with individuals with physical disabilities as a personal care attendant for the last four years. I have also completed a three-month social work/counselling psychology practicum at the local rehabilitation centre, the British Columbia Rehabilitation Society (BCRS), GF Strong site. In working with individuals with physical disabilities, I see myself as an advocate, supporting the client's rights for self-determination and independent living. I also succor the pursuit of equaling the opportunities available to individuals with disabilities to those available to able-bodied individuals. With respect to rehabilitation, I regard a client-centered, comprehensive approach, including physical, mental, emotional, and spiritual dimensions, tailored to the needs of each individual, as crucial. I further advocate an approach which fosters and respects client self-determination and is as 'real-life' and applicable to the community life and discharge living environment of each client as possible. In terms of the strategies used to reduce the influence of researcher bias on data gathering, analysis, and interpretation, they will be discussed in the next chapter entitled 'Methodology'.

In conclusion, this chapter gave an overview of stress and its measurement and outlined the theory of stress utilized in the study. It described SCI and its implications and included stress research performed with individuals who have a SCI. The chapter delineated the details of the focus group methodology employed in this study and ended with a discussion on the researcher's conceptualization of disability and her biases.

Chapter III

METHODOLOGY

Research Questions

The questions addressed in this study include : What did you find stressful when you made the transition from the rehabilitation centre to returning to living in the community (major question) ? What were the implications of those stressors (major question) ? What suggestions do you have for a better preparation for potential stressors prior to discharge from the rehabilitation centre (minor question) ? What do you find stressful in your lives right now (major question) ? What implications do those stressors have (major question) ? What are your suggestions for effective resources and interventions for people who have a SCI and live in the community (minor question) ?

Participants and Procedure

Ten individuals (to allow for a 50% attrition margin) were recruited from the BCRS and the British Columbia Paraplegic Association (BCPA) (see Appendix A for Recruitment Notice). Criteria for participation included : a) being diagnosed with quadriplegia, but not high lesion (injuries at C4 and above); b) having lived in the community for a minimum of 1 year; c) being between 2 and 8 years post-injury; d) being between 19-45 years old; and e) having undergone rehabilitation at the BCRS, GF Strong site. The rationale underlying the 1-year criterion is that in addition to being able to comment on the stressors during the transition period after discharge from the rehabilitation centre, enough time would have passed so that participants would be able to comment on stressors they experience now or have experienced while living in the community. The 2-year post-injury criterion is based on the fact that the time in the acute care, the

rehabilitation centre, and the 1-year community living criterion add up to approximately 2 years.

The participants included 5 individuals with quadriplegia, 3 men and 2 women with ages ranging from 22 to 28, post-injury time intervals ranging from 4.5 to 10 years, and injury levels ranging from C 2 to C 6. One woman did not meet the pre-determined injury criteria as she sustained a high lesion injury at C 2, was injured 10, instead of the maximum 8 years ago, and did not undergo rehabilitation at the BCRS. The established research criteria were waived for this individual in the face of other considerations. No other woman who met the research criteria could be found and the researcher judged it, based on the screening interviews, as important for the process of the focus group to have at least two women. All participants except for the woman with the high lesion injury used manual wheel-chairs for mobility.

Social workers at the BCRS and rehabilitation counsellors at BCPA explained the study to their clients who met the criteria for participation. Any interested participants' names and phone numbers were recorded with permission for the researcher to contact them. The researcher contacted each interested participant by phone 2 weeks prior to the beginning of the focus group (see Appendix B for Initial Telephone Interview Protocol). At this time, participants were asked for a preferred day of the week and time for the group meeting and an in-person individual interview was set up with each participant 1 week prior to the beginning of the group sessions. Participants were also told that they would receive a $20 restaurant gift certificate as part of the study.

During the in-person, individual meeting (see Appendix C for In-person Interview Protocol), the study was explained in detail, and informed consent (see Appendix E) as well as demographic data (see Appendix F) were obtained. At the same time, the participants were also asked to think about and write down or

make mental notes of what they find stressful, including implications, in their lives right now, as well as when they were first discharged from the rehabilitation centre. The location, dates and times of the focus group sessions were confirmed and participants were contacted again on the day before the start of the sessions to remind them.

The focus group met in a conference room at the BCPA once a week for a total of three times. This site was chosen for the following reasons : a) it was considered a neutral site (the rehabilitation centre, for example, seeemed to hold a lot of memories and history, and was not a place some wanted to go back to); b) it was centrally located and accessible; c) it fit the budget of the research project in that its use was free of charge. Each focus group meeting lasted 2 hours. The group sessions were audiotaped and moderated by the researcher. Participants sat around an oval table where light refreshments were made available to create a comfortable, social atmosphere (Krueger, 1994). The tape recorder was placed in the centre of the table and was active throughout the sessions.

In order to be able to make detailed process observations, the researcher kept a research diary documenting happenings, perceptions, and reactions each week. To maximize participants' responses to each others' contributions, to encourage diversity, as well as to reduce the potentially biasing effects of group pressure or 'groupthink', the researcher emphasized and supported the importance of each person's experience and normalized differences in experiences. Participants were told that there were no right or wrong answers to the questions they were being asked and that the focus was only on their own experiences and perspectives. They were also told that they may find that if someone talks about having a certain kind of experience, others might say that their experiences are different. The researcher indicated that this dynamic is quite normal as we are all individuals and different in some way and asked

participants to identify their differences in experiences or perceptions.

The first focus group session started with an introductory autobiographical activity, a summary of the purpose of the focus group, an explanation of the role of the moderator, and the setting of group norms (see Appendix D for the Focus Group Protocol). A broad definition of what the researcher meant by stressors was also given. The researcher then asked the participants to discuss what some of the stressors were which they encountered when they were discharged from the rehabilitation centre and returned to living in the community. Thirty minutes prior to the end of the first session, the researcher asked participants to address what some of their suggestions were as to how they could have been better prepared for some of the stressors prior to discharge. The researcher then summarized the main stressors, implications, and suggestions which the participants discussed and verified correct understanding, accuracy, and completeness. Next followed the termination 'Round Robin' during which participants were asked to comment on how they found the meeting, anything that they wished to add to what was said, anything they liked, disliked, or wished to change about the format of the group meeting.

The second focus group meeting followed the same format as the first meeting with the exception that the discussion revolved around what some of the stressors and their implications were that participants experienced right now or have experienced while living in the community. The process of the focus group was changed slightly so that a more detailed description of the data was possible. Once an issue was raised, participants were each asked to address whether they considered the issue raised a stressor for them or not, and if so, to identify an experience they had relevant to this issue. Thirty minutes before the end of the session, participants were asked to discuss their suggestions with respect to how some of the stressors could be alleviated.

The third meeting followed the same format as the second meeting. At the end, the researcher confirmed that following transcription and identification of categories of stressors, she would phone the participants for one more group meeting to validate the categories and to confirm that the written information represents what the participants intended to relay. The moderator then thanked everyone for participating and distributed the gift certificates.

Data Analysis

The analysis process was performed with the guideline in mind that it must be verifiable and allow another researcher to arrive at similar conclusions given the same raw data (Krueger, 1994). The researcher was thus keenly aware of the fact that she, as any individual, is vulnerable to selectively hear or focus on comments that support her biases. The background, training, and experiences of the researcher are all bases for the formation of biases. While it is not possible to become a tabla rasa, researchers performing rigorous analysis are challenged to strive to become more aware of their biases and identify them as such.

The analysis of the present study attempted to raise the level of understanding to a new plateau. According to Krueger (1994) the best analysis occurs in environments where there is free exchange of ideas, insights, and perspectives, and alternative views are sought and examined. In the present study, this process took place by clarifying and checking for understanding and meaning with the participants, as well as by exploring ideas and perspectives with colleagues and the research committee. According to Krueger much of the analysis is influenced by the mental makeup of the analyst. Whether analysts are open to new ideas, able to step outside of their personal experiences and perceptions and express ideas from the perspectives of others affect the quality of the analysis. Students in counselling psychology who have special training and

experience with these challenges would seem to fit the analyst described by Krueger.

The audiotapes made of the sessions represented the main data of the study. They were transcribed verbatim and analyzed using methods described by Morgan (1988) and Krueger (1994). After several thorough readings of the transcript to get a sense of the data as a whole, the researcher identified and coded categories of stressors. Each instance of a stressor was marked and coded according to possibly multiple attributes. All occurrences of dialogues containing the same codes were then grouped together. Some categories were evident during the focus group discussion while others emerged during data analysis. Once a new category was selected, the researcher went back to the transcripts to confirm its importance and to select quotations which illustrated this category. There was thus a cycling back and forth between the raw material in the transcript and the more abstract determination of which topics were going to be included in the final report. The material in the transcript served as a source for potential quotes for confirmed code categories and as a source for new code categories. The order of the topics raised by the participants served as the main structure for organizing the topic by topic analysis of the discussion. However, not all discussion of a certain category occurred at only one point in the discussion and hence the entire transcript was searched for more information on the selected topic.

The categories of stressors represented comments made by a minimum of two individuals and, for most of the categories, by four to five participants. Under each category of stressor, the number of people who identified a particular topic as stressful is indicated. While most attention was placed on identifying evidence that repeated and was common to several participants, some attention was also placed on determining the range and diversity of experiences and

perceptions. Comments containing enthusiasm and high emotion were identified. Once the categories of stressors were determined, overarching themes were outlined. These themes were delineated by the participants' comments that were repeated in a minimum of five of the categories of stressors.

In the 'Results' section, each category of stressors and overarching theme are identified and supporting statements as well as verbatim examples taken from the discussions are included with pseudonyms used in place of the real names of the participants. The analysis reflects both an ethnographic and qualitative summary, relying mainly on direct quotations of the group discussions as well as a numerical description of the data, identifying the number of individuals who considered the issues raised a stressor.

Two Master's students familiar with qualitative research and disability issues, verified the categories of stressors and overarching themes identified by the researcher. This entailed reading through the uncoded transcripts and verifying, adding, or deleting any of the categories, overarching themes, and their descriptions which the researcher gave the two students on sheets separate from the transcripts. Any changes they suggested were then discussed with the researcher's supervisor as well as with the participants and included on the participants' authority. During the final group meeting, three months after the last focus group meeting, all of the categories of stressors and overarching themes were verified by the participants. Their disagreements or comments regarding additions or deletions were recorded. As part of the accuracy check on the categories, participants were asked whether, in review of the stressors, there were any additional stressors that they did not discuss and if so, what some of the barriers to disclosing them were and how this could be changed. Throughout the development of the final thesis copy, meetings were held with the members of the supervisory committee to discuss the findings. Drafts of the 'Results' and

'Discussion and Implications' sections of the thesis were given to committee members for review and comment.

Strategies Used to Reduce Researcher Bias

The strategies used to reduce the influence of the researcher's biases on data gathering, analysis, and interpretation include the following. First, I tried to make myself as aware as possible of my biases through reading appropriate literature, self-exploration, and asking for evaluations from some of my long-time, trusted clients and friends. Second, with respect to data gathering, analysis, and interpretation, I collaborated on several occasions with the members of my supervising committee, all experienced in my field of study. Third, during data gathering I frequently checked with the participants for correct understanding of their comments. Forth, following the identification of the categories of stressors and overarching themes, these were verified by two colleagues familiar with disability related issues and qualitative research. Finally, the categories of stressors and overarching themes were also verified through a final group meeting with the participants.

Limitations of the Study

One of the limitations of the present study is the fact that the findings cannot be generalized to the population of interest due to small sample sizes and purposeful sampling (Stewart & Shamdasani, 1990). However, the depth of obtained information can be used to guide quantitative studies that allow generalization as well as be utilized to guide other qualitative studies. The assumption that participants are aware of their stressors which may, in fact, be erroneous, may also be a limitation to this study (Bargagliotti & Trygstad, 1987). It is hoped, though, that the group setting which fosters the triggering of experiences and perceptions among the participants will aid in ameliorating this

limitation. As well, the fact that participants were given two weeks to reflect on the stressors in their life and were asked to make written or mental notes of them prior to the group session is expected to further reduce this limitation.

Another complication of stress research is that by its very nature, reflecting on and sharing stressors may be unsettling for the participants and thus may not be readily engaged in. Two aspects of the methodology employed are believed to attenuate this factor : (a) the establishment of a supportive, non-judgmental atmosphere where participants share common characteristics; and (b) the identification with others and the inherent normalization in listening to others who are dealing with similar circumstances.

A further limitation of any method which relies solely on verbal expression is that it may provide only a partial view and lacks the dimension of action (Margaret McCuaig, personal communication, November 20, 1995). Although techniques such as participant observation and interviewing significant others in the participants' lives may aid in reducing this limitation, they are beyond the scope of the study.

In review, this chapter presented the research questions addressed in this study, the methodology followed, and the data analysis utilized. It also identified the stategies used to reduce research bias and described the limitations of the study.

Chapter IV

RESULTS

In this section the main categories of stressors obtained from the data collected through focus group sessions will be outlined (see Appendix G for Categories and Definitions of Stressors and Themes) and described with information from the participants, including direct quotes. The participants' suggestions, if any, of how the stressor could be alleviated will be presented at the end of each category of stressors. Under each category of stressors it will be indicated whether the identified issue was a stressor only in the transition period after discharge from the hospital or whether it represented an ongoing stressor. It will also be indicated how many people found a particular topic stressful. In order to accurately represent each category of stressors, it was necessary to utilize some quotes more than once, if none of similar content were available. The order of presentation of the categories of stressors follows the sequence in which they were discussed by the participants. The reporting of the results is according to the narrative focus group style (Krueger, 1994).

The researcher wishes to note at the outset that the participants were at the rehabilitation centre from four to eight years ago and thus some of the issues addressed may be different now. Also, some of the issues brought up will be specific to injury levels. That is, some of the issues brought up by some people were not an issue for others because they have different physical abilities. In addition, certain issues were of concern at one time, but not at another.

1) Attendant care

One of the stressors which all participants who used these services agreed on was attendant care. Attendant care refers to the individuals who provide paid

assistance to people with disabilities in areas of personal care such as getting up, helping with bowel routines, having a shower, getting dressed, meal preparation, cleaning, and shopping. Most of the comments in this category refer to the care received from individuals who are hired through attendant care companies and then sent out to the client, as opposed to clients hiring attendants on their own. This category was stressful for the participants after discharge as well as currently, but the aspects that were stressful changed, as will be described in this section.

The aspects of attendant care which were described as stressful were : a) the high turnover of attendants, b) the frequent training of new attendants, c) the quality of the care, d) the lack of preparation for this experience when the participants left the rehabilitation centre, e) thinking about the 'right' attendant leaving, f) being dependent on someone else's schedule and the inherent lack of spontaneity, g) safety issues (experiencing the consequences of the attendant's oversight), h) the perceived reluctance on the attendant's part to change a certain routine, and i) the lack of resources to hire on their own.

Rocky comments on one of the aspects : "the high turnover – twelve people in a year." "Six people in four months", Chuck adds. "Even for housecleaning service I went through three companies because the work wasn't done properly, until I hired on my own", Rachel explains. Rocky continues : "you're always training someone new, just when you get to the point that you don't have to tell them everything, there is someone new – plus the quality of the people and the care, and the fact that you're not prepared for this experience when you get out of rehab", "and, you're not in charge of the employee, they answer to you but also to the company and that's awful." Rocky remarks : "now that I am hiring on my own, the stressful part is when I want to change a routine, the attendants have a little trouble with that, because you get into a routine, and people love routines and I like to break it and change it once in a

while so I don't get bored and sometimes it's hard for people to keep up with me, and stick with me on that."

Maria shares her feelings : "for me it's just the anxiety, hassle, and pain in the butt of training someone new – I want to get up and do what I've planned to do that day, I don't want to have to talk someone through it – just more steps in the extra things you have to do." Rocky knows from experience : "and it might be two weeks until you're back up to snuff where you can be up when you want to be up." Maria responds : "ya, you have to plan to leave the house an hour before, instead of half an hour and all the planning and thinking ahead of all the steps that you take for granted with someone that really knows you well." Chuck shares similar experiences : "same with me, when I first moved into my new place and they were sending me a different person every day, and you have to tell the same thing over and over, but now it's alright, now I've found the right one, but I guess I'll have to go through it sooner or later if she leaves." Maria admits : "and that's a bit of a stressor, too, just thinking that this person is going to leave when you find someone good", others agree.

Furthermore, the participants agree with Rocky : "your life entirely depends on someone else's schedule, there are set times every day that the attendant comes in, so there is no chance for spontaneity either." "You can't have structure to your own life, because you're relying on someone else who may be unreliable", Rocky explains. "When people don't show up, I can't get out of bed", he continues. "Also", Rocky adds "when I started to hire attendants on my own, there were no resources – that was very frustrating, so I got my own business going, connecting people who want to work with people who need good workers." Rocky still has the floor : "safety is another issue – my attendant didn't put my chair together properly after she took it out of the car, didn't make sure the wheel-locks were in – I just about lost a wheel and that means my head

hitting the ground." "Another time another attendant put a really sharp knife in the drawer, instead of the holder, well, I cut myself good and deep – this issue is major especially when you got different people coming through all the time and also, the more dependent you are the bigger an issue it becomes."

Suggestions : The participants' first suggestion regarding attendant care was to be better prepared prior to discharge from the rehabilitation centre. "Opportunities to interact with speakers with a SCI who live in the community and have personal experience in this area" were considered to be crucial elements of such a preparation by all participants. Also supporting such training at the rehabilitation centre was Rocky's comment that "our limited physical abilities to demonstrate to new attendants what we need them to do is a stress factor". As teaching by example may no longer be a viable option with some aspects of their care, competence with different teaching skills may be required. With regard to Rocky's comment on the lack of resources available when he started to hire on his own, Rocky and Brody indicated that both the BCPA and Rocky now have lists of 'good' attendants available for work. All participants advocated the practice of hiring on their own and identified that attendant care has become less stressful since they hired on their own.

2) People's looks, comments, and behaviours

People's looks, comments, and behaviours refer to the daily reactions the participants encountered mainly from able-bodied individuals. Some of the aspects which were frustrating included people not listening and not respecting the participants' 'no, thank-you' response to their offer for help, making assumptions without asking or listening to the answer, and treating them differently. Another stressor involved the participants' feeling that not only were their efforts for independence not respected, but they often felt engaged in

the fight for independence. A further aspect addressed the participants' perception that they were regarded as having low IQ and a mental problem by virtue of their physical limitations. It was also stressful to receive ignorant comments such as 'you'll get better', or 'you're too pretty to be in a wheel-chair'. Having to answer questions from friends or dates and explaining the particular ways the participants performed activities of daily living over and over again was another stressful and frustrating aspect. As in the previous category, feeling unprepared for these experiences contributed to their stress factor. This category was stressful for everybody, but less so for Maria who is ventilator dependent and did not get as many reactions as the others because she is always with someone. This category was also more stressful for the participants when they were first discharged from the rehabilitation centre and then less so when they developed skills of dealing with the reactions from other people.

Rachel emphasizes that what made those experiences with other people especially stressful was their frequency : "when you leave the rehabilitation centre I don't think you're prepared for the attitudes that you are going to run into on a daily basis, it's not every once in a while that you run into this – you meet ignorant people everyday, everywhere you go and everyday it's like, although you're fine and having a good time, you've managed to forget about being different and then someone comes along and throws it right back in your face that you have a different way of doing things." "You got to explain it all every time you meet someone new, like friends or dates – the same thing over and over again", Chuck continues. Brody remarks : "people want to be helpful, but they don't know how, they make assumptions without asking and listening to the answer." With regard to respecting the person's independence, Rocky relays : "even though I look like I am having a hard time when I am wheeling along, that's my exercise, then someone comes along and starts wheeling my

chair, my reaction – 'hey man, when you're in the gym, no one comes along and helps you pump weights'." Brody mentions the classic : "you're going out with a friend and the bartender asks your friend what the person in the chair wants." Rocky reinforces : "wheel-chair equals low IQ, braindamage."

On being treated differently, Brody reports : "when I bump into someone, they'll apologize – 'hey, it was my fault', if I was walking the guy may have punched me out or sworn at me, now they are treating you totally different because of being in a chair", others agree. Brody adds : "they assume automatically that it's their fault, because we are disabled and we couldn't do that." Rocky reinforces : "they turn and see you and the assumption is that they were wrong because you are in a chair – I think that is more stressful than the actual incident itself, is their assumption of what they see in you, they see you outside of the group, outside of normal people, so you can roll over someone's foot and you get away with it because you're in a wheelchair, anybody else they would just grill." Maria adds : "they'll treat you like you're deaf, they speak really loudly, almost scream because they think you can't hear." Everyone also agrees with Chuck's comment : "they meet the chair first and some people don't get beyond it, they see the chair and not the person in the chair." He continues : "people come up to you and they don't even say 'hi', they say 'what happened to you', they don't really want to meet you, they just want to know what's wrong with you – just because you're in a wheel-chair doesn't mean there is something wrong with you, you don't change, well you do change, but not", Brody interrupts : "my friends say that I am the same person, same prick, just smaller, shorter, and more demanding."

Rachel refers to some of the comments she gets : "what I find most frustrating is that people always want to tell me that I will get better, 'you're going to get better, you just have to work at it' ", others agree. Brody remarks :

"even family does that too." Rachel continues : "do I look sick, I don't think so." Maria notes a difference in her experiences : "I don't find that I get approached that much, not nearly as much as it sounds like you guys do, may be because I always have someone with me." Rachel responds : "I get approached daily by at least two people." Chuck adds : "I find that people are even scared of me."

Attitudes or behaviours of family members can also be stressful – "they want to help too much and don't seem to understand the meaning of the word 'no' ", Brody reports. Rocky explains : "you're going from being really independent, at least for me, having moved out early and so on, to wham, you're right back there with mom and dousing those maternal instincts is a lot harder the second time around." Brody agrees : "the family still helps me too much, you waste so much time saying 'no, no, I can do it, don't'." Rocky continues : "even if you lay down the simplest of rules 'if I want help I'll ask' ", "they go 'let me do this for you' ", Brody adds. Rachel empathizes : "it's just because they love ya, they want to make it easy for you, but the independence thing clashes with that really well", everyone agrees. Rocky comments : "the more I can do for myself, the better I feel", again everyone agrees.

Brody shares his unique approach with his family : "I'll do examples for them instead, because otherwise they won't listen to you, you feel frustrated and helpless when they don't listen to you and do what you ask, that is, not help, leave you alone, so one example is : I was struggling a little bit with doing the vacuuming and my sister walks through the door and sees me vacuuming and says 'Brody, don't do that, I can do it quicker' and grabbed the vacuum and in a whisk she's got it done and I'm like, 'great', so I purposefully got a plant and dumped some dirt out, looked at it and my sister went 'well, aren't you going to clean that up', I said 'you did a good job the first time, what's the matter with you this time and then she goes 'I get it, you want to do it by yourself, fine' – so I use

little tricks like that to send the message because I'm sick of letting the hot air go and them not listening." "Other times", he continues "I'll be cooking something in the kitchen and my mom will hear a noise in the kitchen and next thing I know, she'll be standing right behind me and I'll go 'remember the barrier, if I drop something or make a mess I'll clean it up, if I need help I'll ask and that's my region right now'." Rachel adds : "ya, what part of 'get out' don't you understand ?"

Brody remembers another example : "I wheeled over something the wrong way and fell out of my chair and my mom was looking at me from the living room and goes 'hhhh' and then the look on her face, but she just turned around and watched TV – she knows what the consequence is if she would have said something or would have run up to help me, no, it's like 'you sit there and if I need help I'll ask' – they do catch on once in a while." Rocky shares his approach : "I resort to stronger language and that does help, so now my family and friends know that if they ask me and I say 'no', if they don't comply, I'll make life hell for them because I want to do it, I want my struggle, that's mine." All participants do agree, though, "it's just human nature, wanting to help when you see someone struggling."

Rachel brings up something that was very frustrating for her, although perhaps not necessarily an experience unique to people who use wheel-chairs : "I moved out a week ago and originally I was going to be on my own, but as it turned out a friend of mine needed a place and ... so she's moving in, and then we went to my family's place for dinner ... and six out of twelve people came up to her out of my earshot to say 'we are so happy you are going to be there, it's so nice to know', oh, and she told me because she knows I am perfectly capable of doing things for myself ... and we're like 'ahhh for crying out loud', even this included my sister and my dad – I got this terribly accessible building with this

24-hour guy there to help me if I need help and you're worried about me – hello." "Also", she adds "anytime I go near my dad, I cannot go two feet before he's got both hands on my wheelchair and I'm like 'mmmm, let go, let go (screaming), I can do it' and I know, they're just trying to make it easier." Along similar lines, but with respect to his attendant, Rocky mentions : "one of the girls that works for me has been with me for three years and she still doesn't know what the hell I can do and what I can't do, so that was a good lesson for me – it doesn't matter how long someone spends with me, the human interest to help is a lot stronger than the ability to learn." He continues : "I really struggle with that a lot, that was a big thing for me before the accident so when it happened it was like, if I can pick up this cherry I am going to damn it and stay out of my face." "With the people who don't know me, I kind of just let it go by, the people who are close to me, they know my boundaries and that's really what it is, is learning what those boundaries are and learning to respect them and ya, it might take me five minutes to struggle and it's painful as hell for them to watch, but they know that that's what it is, it's mine and it's a standard rule, if I need help I'll ask and it's amazing how quickly people forget that", he explains, others agree.

Rachel thinks back to some of the attitudes that she encountered at the first place she worked after her accident, a resource and support organization for people with physical disabilities : "I felt a lot of hostility from the people that worked there (who also used wheel-chairs) because I could stand up, and they would say things like 'if I could walk, I would walk all the time', and I am thinking – I can't believe that you of all people are saying that, and they'd ask, 'well, how long ago did you get injured' and I'm like 'last summer', they go 'and you're here', I'm like, 'ya, isn't that what the idea is, go back and work', and it was like 'you should have stayed home longer', and it wasn't from everybody ... and it wasn't in public, it was very hush, hush, and I was like totally shocked ... and

cut myself off from people in chairs ..., I didn't seek out wheel-chair sports, I didn't seek out anything (related to people with disabilities)."

Suggestions : Being prepared for the reactions from the general public was one of the participants' suggestions to reducing their stressfulness. "Expect the reactions to always be different – everyone has different attitudes", Chuck explains. "Bring speakers in from the community who have a SCI and develop skills of dealing with attitudes, comments, or behaviours", suggests Rocky. "I think trying to educate people about what it's like for us is the main thing", adds Chuck. With respect to family, "get them to respect 'if I want help, I'll ask' and accept and act in accordance with 'the more I can do for myself, the better I feel' ", continues Brody. "Use humour", Brody advocates. He gives an example : "my sister and I will go to the mall and sit there and I go 'how many people are going to come up to me and say 'I have a brother who is in a chair, etc.' ' and my sister will go, 'oh it's not that busy, may be one' and sure enough someone will come up to me and go 'oh, I got a cousin who is in a chair'." Brody explains : "you make it so that you don't get stressed out, but make it into a thing where you can enjoy yourself at it, laugh at people's ignorance, but not laugh at them, laugh with them, so you're part of it, too."

3) Accessibility

Accessibility in reference to people who use wheel-chairs refers to the architectural modifications made to buildings, side walks and other parts of the environments in order that people who use wheel-chairs can travel in the environment without restriction. Inaccessibility was stressful for everyone, but less so for Maria who always has someone with her to help. It also was more frustrating for the participants when they were first discharged from the rehabilitation centre. Two aspects of accessibility addressed by the participants

were the lack of accessibility of the environment and the definition of accessibility which is not uniformly applicable to everyone with a disability.

Rocky explains : "it's the definition of accessibility that's the problem – you phone a restaurant, they say they're accessible, but they aren't, even though they're up to regulations, the bathroom door swings the wrong way, it's too heavy, etc." Brody remarks : "side walks not being cut-out at one end, doors with slopes to the door where you have to open the door at the same time as push your wheel-chair uphill and, to top it off, the door opening out." Rachel adds : "ramps that are too steep", "door knobs", Chuck continues. "Just because a door is wide enough doesn't mean it's accessible, just because you can get into the front door of the restaurant doesn't mean it's accessible, because the bathroom may not be", Brody reports. Rocky comments : "when places aren't accessible, your plans need to change – I find that pretty stressful and your independence goes, too." He continues : "if you're meeting some friends and they have to pack you up stairs to get in there, you can't drink because you can't go to the john and you can't move or wheel around, or you go to some places and they say that their bathrooms are accessible and they are not, so you're bugging someone for an old pop bottle or something and then again your independence goes, I find that is pretty stressful." Rocky remembers a recent example : "I took a course in January and where I went they had to pack me up and down stairs and I couldn't get into the john, I couldn't get any privacy to do it myself, that was not fun at all."

Suggestions : When asked for suggestions regarding the lack of accessibility, Chuck remarks with some humour : "automatic doors everywhere would be nice." On a more serious note Rocky adds : "have people in wheel-chairs try out the accessibility of new buildings before they are approved by the building code."

<u>4) Transportation</u>

Transportation refers to wheel-chair accessible methods of commuting, including : cars and vans that are specially equipped so that individuals who have a SCI can drive them; the handyDART buses with lifts driven by B.C. Transit employees for which a ride can be booked three days prior to the desired trip date; transit buses that are wheel-chair accessible; the Skytrain; and wheel-chair accessible taxis. Transportation was stressful for everyone before they got their own transportation and continues to be stressful for the person who does not have his own transportation. Some aspects which made it stressful were : traveling via handyDART which can take all day for one trip, the lack of spontaneity, the attitudes of drivers, as well as the lack of accommodation for possible medical complications while on the bus or while out and needing an earlier return ride home. Another stressor was feeling like a burden on family and friends. Also, vans with the necessary modifications are very expensive both to buy and to maintain.

Rocky explains : "transportation, getting around, is very stressful – handyDART is a nightmare, taxis are expensive, if you want your own vehicle it's going to cost a lot and not only buying the vehicle, but maintaining it too." "HandyDART", Rocky continues "if you have an appointment at 1:00, your whole day might be shot waiting for the ride and waiting to get back – they may pick you up at 11:00 or 12:00, then you have your appointment from 1:00 to 2:00 and they may pick you up at 3:30, so your whole day is gone." "Especially when it's only a fifteen minute distance", Rachel adds. "Plus", Brody elaborates "they may pick you up at 3:30 but not get you home until 5:00, because they pick other people up and drive you around – the cheapest scenic tour around, $1.35." Chuck comments : "I experienced handyDART when my van was in the shop and I needed to be at a place 20 minutes away at 10:00 – they told me they would be

there at 7:00 to pick me up." "HandyDART is good for people who have a lot of time on their hands, who don't have a life", Rocky concludes. "It's good as a transition until you have a vehicle", Brody adds.

"You're a big burden on your family, you got to ask them for rides, you got to work around their schedule, you're a burden on your friends, you don't even want to phone up your friends", Brody explains. Rocky jumps in : "you don't want to go out because you don't want to put these people out and you know it only takes so long before you burn them out." Brody responds : "your good friends don't mind, they don't care if you're in a wheel-chair or whatever, but you feel yourself that you are a burden on them because they got to hall you into the car, hall you out, put your chair together, take it apart, so you don't experience the world out there because you don't want to be a burden on the world or your friends." Brody continues : "if you have your own transportation you can do what you want when you want and do whatever stops in between – there is a lot out there that you can experience, but until you have your own transportation, it's hell out there." Rachel relates : "it's just to be half normal – your life isn't normal when you have a fifteen minute appointment that's going to take you an entire day, that means that you can't do anything else, you can't have a job, you can't go to school, because you can't get more than one thing done in a day."

"Also", Rachel continues "when I was using handyDART, it was like they are doing you this huge favor and they expect to be treated as if they were doing you this huge favor and I didn't like that, I didn't like the attitudes." "Plus, it's so frustrating, I couldn't handle it, having to wait three hours and then they drive you around – what if you need a bathroom in all that time that they drive you around or what if you get really dizzy and you need to lie down, you don't have that option when you're stuck in the bus – it's a good service, it's great that they

have it, I mean it's better than nothing, but it needs improvement", she adds and others agree vehemently. Rocky remarks : "with handyDART, too, you can't just say 'I'll meet you there tomorrow, you got to phone three days ahead." Yet another aspect involves "finding a job which is really hard if you just have the handyDART to work with, because each day it would take you forever just to go for interviews, but then once you got the job, how do you get to the job on time, efficiently – you don't have a life, your life or your schedule is entirely dependent on everyone else's schedule", Rocky indicates with frustration.

Brody thinks of another important point : "you could have complications at the place where you are at, say a job, and what are you supposed to do – wait for six hours for the handyDART return ride ?" He explains : "you never know what's going to happen to you where and when, and you want to be prepared or leave at the appropriate time, not wait three or four hours – you could have unexpected bowel movements, dysreflexia (a life-threatening medical emergency which can lead to high blood pressure and stroke), and so on, or the company you are with, you might have gotten into a disagreement and you don't want to be there any more."

Suggestions : One of the main methods of commuting addressed by the participants in this study was the handyDART bus which could be greatly improved by accommodating the booking of trips without prior notice, the participants suggest. "I know they have more vans than drivers right now and it's a shame to see all those vans just sitting there, just poor planning, really", remarks Rocky. With respect to taxis, Brody emphasizes : "there needs to be a good system for screening the drivers of handicapped cabs – some drivers slam you right ahead, don't care about your feet, strap you down with just one strap on the front and one on the back – I have fallen over sideways, forwards, and backwards just because the guy hasn't bothered to lock me in right, so, training of

drivers, [is very important]." "Awareness of the different needs for different chairs – electric and manual is also very important", adds Brody. With respect to public transportation, Brody states : "continue the modifications to buses to make them accessible." With respect to the extraordinary costs of buying one's own wheel-chair accessible van, those costs, the participants suggest, need to be decreased.

5) Finances

Finances refer to the participants' financial matters including dealings with insurance companies or the Ministry of Social Services for medical supplies, equipment needs, and disability pensions. This issue proved stressful for everyone on an ongoing basis. The aspects which were stressful included having to fight for necessities, receiving no assistance until the person has no money left, the lack of an individual approach from government and insurance services, having lots of extra expenses, and being overcharged for products and services.

Brody begins : "the fact that you have to fight for everything, get doctor's notes – so much paperwork that sometimes if you have the money, it's less hassle to just pay for it yourself than to go through all the procedures." "And the government (Ministry of Social Services) doesn't do anything until all your insurance money or your own money is gone, so although I need to buy a machine so I can breathe, the government won't pay for that, I have to buy that myself because I still have some settlement money – and they are $15,000 a piece, the chair I'm in is $30,000, so I have got to think, I need this much money for attendant care, I need this much money for this, okay, I guess it's been about eight years since my injury, I can probably invest in an electric chair now, up until that time I was in a manual chair that was a real piece of", Maria asserts.

Rocky jumps in : "and there goes your independence out the window", Maria agrees.

Brody shares his opinion : "the Ministry and ICBC (Insurance Company of British Columbia), they'll put a barrier between you and your independence." Maria responds : "they make it black or white and everyone is so different that there are a lot of gray areas", everyone nods in agreement. Rachel gives an example : "I found that because I wanted to buy a car – well, ICBC under Part 7 (No Fault Accident Benefits) will give you $15,000 to buy a car, but it has to be new, has to be two door, has to be this, has to be that, well for someone who has a lot of upper biceps strength, throwing your wheelchair behind the seat and getting it out may be fine, but for me, I can't do that now, never mind five years ago when I needed to buy a car – a four door would have been ideal for me but I couldn't get a four door – they didn't look at the individual case."

Rocky brings up another issue : "there is no encouragement for people on Ministry (Ministy of Social Services) funding to get a job, because the Ministry chops your money in half right away – where is the transition ?" Brody concludes : "being disabled is not fun financially", "we've got all these other expenses", Rocky adds. "Maintenance on the wheelchair – it cost me $246 to do maintenance on my wheelchair and I could have spent another $150", Brody recounts. Rocky continues : "wheelchairs are basically bicycle technology, but you are paying a medical price for an off the rack item." Brody's turn : "I bet you a manual chair costs at the most $1000 to build", others agree, "yet these people are dinging us for $3,500 or more." Maria takes it up even higher : "my electric chair is $30,000", Brody asks "how much work is actually on this chair, probably $10,000 at the most and that's parts, labor, shipping, and handling included, but I think I want to have $18,000 extra in my pocket and this person will need it, she will buy it." Maria continues : "that's the same with the ventilators, they are about $20,000

a piece and if you can buy your own, the government is not going to buy you one, plus you got to have two if you are going to have one, mine are both in for repairs right now and one will cost $2,000 for what I had done to it, and they stopped making it so it's obsolete now, and for a visit by these people who insist that they visit you, it's like $100 a visit, and they'll come over, see that you're breathing, go 'okay, she's alive, okay, bye' – I am not paying you $100 for that."

<u>Suggestions</u> : While all participants agreed that there needed to be a solution with respect to the extraordinary expenses encountered following a SCI, everyone also agreed that it was a complicated matter and no one had a solution to offer. Brody wonders : "I don't know whether before our time people weren't vocal enough, because now even if we do say something about the overcharging, it's not going to be heard." Rachel considers : "that's the problem, though, with this sort of thing, because it is specialized equipment and it's built by companies that only build specialized equipment so they aren't making $18,000 profit, because they are only making five or six chairs – what the government needs to do is to incorporate them into a business that's profitable all the time or they have to give them a tax break."

6) Insufficient focus on the mental and emotional aspects during rehabilitation

This section addresses the participants' comment that after sustaining a SCI, during rehabilitation, there was not enough attention paid to the mental and emotional aspects of their lives. Although this heading focuses on the time in the rehabilitation centre, rather than on living in the community, it is included here as its effects were felt by all participants when they were discharged and lived in the community. Its effects lessened as time after discharge increased.

"The focus during rehab was definitely on the physical things and a lot of the mental and emotional aspects fell by the wayside", Rocky states with

everyone's agreement. He continues : "also, there is a lot of pressure [on] goals, goals, goals, goals, the word comes up like a hundred thousand times and I think that they are not very sensitive to process and they're more goals, get this, get that, get this, get that, instead of the process and what you are going through emotionally or spiritually or whatever, there is not really a heck of a lot available for the headspace, there is a psychologist and a psychiatrist, and that resource has not been very well exploited, so there are resources there, they are just not very well organized" and "somebody could say hey, I really want to talk to someone, but I don't want a Ph.D. behind his name, I just want somebody to talk to and there is not that much of that there."

Rocky indicates, though, that while he and another participant were at the rehabilitation centre, there was one person who did address mental and emotional aspects – a social worker with quadriplegia. "We were lucky, we had this person and every Wednesday night he would have people come in who were in chairs and lived in the community, but when he left that resource was gone, and I keep thinking and thanking my lucky stars that there was someone there like that for that – I can't imagine life without it, I try to imagine sometimes where I would be and what my attitude would be like without having had [him] there and him bringing people from the community for discussions and I can't even imagine what it would be like, the impact is incredible", everyone shows their agreement. Brody remembers : "the person used to bring in different guest speakers with different disabilities, ventilator dependent, quads, paras, people who are ambulatory and we used to sit there and shoot questions at this person and that helped us out tremendously, but at the time we didn't think it was that beneficial to us as it is now – he gave us insight on what to expect so we were way better informed than the people that left the centre later." Rocky concludes : "that's probably the most valuable resource I

found there."

Suggestions : With respect to the insufficient focus on mental and emotional aspects, the participants emphasized that guest speakers with a SCI who have lived in the community for some time were extremely beneficial for obtaining knowledge, understanding, and a feeling of support. They also strongly agreed that the presence of and connection to a staff member during rehabilitation and after discharge, a buddy in the community who has a SCI, is invaluable : "have a mentor there [whom] you can ask questions, that's very, very important, that's essential." Rachel commented on the benefit of a meeting like the one organized for this study : "it's really neat to talk to people and go 'oh God, I'm not the only person that has the same frustrations', because I didn't have anybody to talk to about them, it was really good, I'm really glad that you guys were really, really open and it was really nice." "A buddy system would be really important", Rachel confirms. "Longer-injured individuals should go to the hospital and rehab centre to talk to newly- injured clients to show them that you can make a life for yourself", adds Chuck. Rocky continues : "they (health professionals) need to be more sensitive to the process, what you are going through emotionally or spiritually, and have more organized resources for that."

7) Lack of individual approach during rehabilitation

This heading refers to the participants' unanimous feeling that they were not treated as individuals during rehabilitation – unique and different from others on many levels. This included not being treated as an individual with respect to their injury and the fact that even though it was common knowledge that everyone differs in their physical abilities, even with the 'same' injury, this awareness was not put into practice. The participants also felt that they were not being treated as individuals on mental and emotional levels, including what was

important to them and what their wishes, needs, and goals were. As a result of this approach, being told 'you can't', and having many limits set on them, they felt that their abilities were restricted and a lack of belief in their own abilities was the outcome. The participants also felt that the lack of an individual approach during rehabilitation resulted in a lack of preparation for some of the challenges they faced after discharge. In addition, they felt that someone else was making their decisions. Inherent in this category is also the aspect of being expected to fit into a predetermined system.

As in the last section, the stressors addressed in this section focus on the time in the rehabilitation centre, rather than on living in the community, but again, the effects were felt by the participants when they were discharged and lived in the community. As mentioned earlier, this lack of an individual approach also applied to government services and insurance companies which the participants were dealing with while living in the community.

Rachel begins : "the thing that made things even worse and could have been improved upon for me was that they were using the textbook", everyone agrees. "You're a 5-6 quad and you can do this, you can't do that, well that wasn't right for me," she explains. Rocky cuts in : "I don't think that's right for anybody." Rachel continues : "and then wheel-chair class, well, I don't want to go to wheel-chair class, what I want to do is to be able to do this for myself and what I ended up doing is checking myself out long before a reasonable discharge date, and I probably could have benefited from wheel-chair class, but by checking myself out, at home I could figure out ways for me to do the things that I wanted to do for myself and the wheel-chair thing came on its own, but the way other people were doing stuff, that didn't work for me and they weren't willing to see that – some of my individual therapists might have been, but overall they weren't, ... so I think it should be a lot more individual."

"Well, it's really quite simple", Rocky concludes "each person has different needs." He adds : "when I was there I wanted to work on bed mobility, but the beds they've got are not very wide, so how do you work on bed mobility, then I saw one of the guys brought in a double bed, so I put in a request to work on it, but you couldn't raise it up so the nurses would have had to bend over too much to do my care, so again I had to put my rehabilitation process on hold for their convenience and when I left they said transferring is unreasonable, well, I have no problem transferring and the thing is I would have had that skill a lot longer if a nurse had said, 'well, I don't really want to bend over and strain my back, so give it your best shot' and to see how much I could do – that aspect of my rehab was totally confounded for six to eight months, and even when I got out, the support and encouragement to try things outside of the physio department are just not there."

With respect to the preparation for some of the aspects that were unique to each person's life after discharge, Rachel remarks : "I don't think you can really prepare anyone for everything other than tell them that you are going to hit up against things that are going to frustrate you, prepare to be frustrated, prepare for things to piss you off on a daily basis, and to have ways to deal with that", strong agreement from everyone is heard. She emphasizes : "I really would like to have been told 'be prepared for things to piss you off on a daily basis' – many things are frustrating, but you got to know that that's something that's just going to happen, but you don't know, when you first get out, you think that you go home and everything is just going to be great."

Brody comments on the lack of opportunities for self-determination during rehabilitation : "there is someone else making your decisions, you're told what and how your programs run and why, you're being treated like a textbook case, they're treating you like a C5 quad, but even different people with the same

injury are different in what they can do and what they have done, I guess, is taken an average of 10 people and said, well with that injury you can do this, this and this, meanwhile a lot of C5s can't do that and a lot of C5s can do more than that." Rocky agrees : "I can't even think about the things that I never bothered to try until I was at home and had no help there, and it's been a long process of opening up to what I can and can't do and what I couldn't do last week I can probably do this week, and that's ongoing." Brody adds : "the physios, they find out you can't do it one week and don't try whether you can do it the next week – people change and I have and this is what I am doing now", others agree. Brody stresses : "they (the physios) tell you what you can't do and you never try it, when all it may be is weak muscles." Rocky agrees : "they go 'these are the muscles you have, this is what you can do' and it's not like that at all, we're not machines, but they evaluate you as a machine." Rocky hypothesizes : "I guess it's a starting point with the physios, but I don't think it's emphasized that it's just a starting point."

Rocky continues : "I just feel really strongly that if they had taken more of an individual approach, I would have been much further ahead – I mean they are trying to focus on getting me up in the morning, well shit, for me it's much more logical and intelligent to work on trying to get into the sack, because I need help doing bowels and changing domes and everything else in the morning, it's going to take me years before I get anywhere with that, but getting in the sack at night, that's major, and if we would have started to work on that first, but that was deemed unrealistic, transfers were deemed unrealistic, 'transfers unlikely' was the actual wording and how many guys out there get put in that box – when you're a square peg trying to be fit into a round hole."

Rocky analyses : "you're a quad, you are no longer a person, you're a quad." Brody throws in some humor : "paras, quads, apes that's about how you

are treated." Brody adds on a more serious note : "they don't listen to the client's needs and what the client is trying to tell them", everyone agrees. Maria comments : "to have the input from people with the injury was a big push during the development of the high lesion program, but now at meetings the only people who will be talking are the doctors and like Rocky said, they know dick." Rocky concludes : "the amount of recovery that you want, get, have is directly related to the environment that you're in as soon as it happens and the possibilities are endless if you're allowed to decide what you want and have someone there who is further along to show you that."

Rachel brings up a point which pertains to the lack of an individual approach with respect to having been the only girl when she went through rehabilitation : "I didn't have a very good experience in the hospital at all or the rehab – I didn't find it easy to fit in with people while I was there, part of that was ..., that I was going home, that I was getting return, and the fact that I was the only girl there that was awkward, I felt kind of left out, I didn't feel part of the group, I felt on my own, nobody to talk to that knew what I was feeling."

Suggestions : The participants had numerous ideas regarding the lack of an individual approach during rehabilitation. Maria starts : "get people who have been through it involved in educating, support, and decision making." "Because we have access to direct knowledge", Rocky adds. "Meetings that involve topics that concern patients should involve patients, very much so, both new patients and people like ourselves who [have lived with the injury for a while] and can come back and contribute", Maria continues. Rocky advises : "be aware that the facility's interpretation of what your injury is may be really quite different from what you might be capable of five, ten years down the road, and a textbook is only one view of what your injury is, but people aren't textbooks." Brody emphasizes : " they got to look at the individual and assess his [/her] needs

and what he [/she] is capable of."

When asked what the approach to rehabilitation would look like if they were going to design it, responses were as follows : "a lot more personal"; "not static in its attitude and in its design"; "individualistic and there is no such thing as a norm or a textbook case"; "eliminate the word 'can't' and focus realistically on pushing the barriers"; and "not only should the people in wheel-chairs who live in the community come in and talk to the clients, but also come and talk to the staff, so you can see, oh, my God this person is totally different from what you would expect from their level of injury – it could help everyone." With respect to the minority of women with a SCI at the rehabilitation centre the participants suggested that the person be connected with another woman who has a SCI and lives in the community with whom she can consult and discuss concerns with.

8) Change from a schedule to no schedule

This section refers to the transition from a very scheduled day during rehabilitation with doctors', physiotherapy, occupational therapy, social work appointments, and the like, to having the whole day to themselves when they went home, unless they had planned to go to school or work right away. Boredom was one of the inherent results of this stressor and excessive alcohol consumption was one of the potential consequences. The lack of preparation for this situation during rehabilitation contributed to its stressfulness. Two of the participants who did not go to school or work right after they were discharged found the lack of a schedule stressful. The others did not as they went to school or work following discharge. For the two participants who did find this to be an issue, its stressfulness dissipated with an increase in the length of time post-discharge.

Rocky remarks : "another thing that the facility does not prepare you for is that the facility is on a schedule and you get out and your whole day is yours and that can be a difficult transition, because you eat at certain times you have physio at certain times, you get into a routine and then you leave and you get the carpet pulled out from under you." Brody admits : "well, I resorted to alcohol and drugs, wake up at 4:00 in the afternoon, have a big Mac, go to the bar, get drunk, do whatever, go to bed at 6:00 in the morning, wake up at 4:00." Rocky jumps in : "turn around and do it all over again." Brody continues : "I probably did that for a year and one day I woke up and said 'I'm broke, what the hell am I doing' and then the lights opened up and I realized that there is a lot more out there, but you got to know what's out there for you, you are so ill informed when you get out." "So", Brody concludes "at first, my way of dealing with boredom was drinking myself into oblivia and then going to bed – that took care of time." Rocky supposes : "I think the first year boredom applies probably to everybody, depending on your situation – you go through this life changing thing, you're in an institution where your whole day is scheduled and then you get out, and what do you do ? – that's where drugs and alcohol come into play a lot, people are bored, it's at least something to do."

Suggestions : With respect to being better prepared for the change from a rigid schedule during rehabilitation to unscheduled time at home the participants recommend : "the week or month before discharge, do extraordinary things, like get out of the norm, get out of the routine and do things you haven't tried before." Rocky shares : "what I did the last month was that I didn't go to any classes, I did nothing and I got a lot of flack from that, but it was because I was concerned about how it would be when I got home and what I am going to do with my time there, I wanted to do that before I left and have a chance to think about it, go outside of the norm, go out of that routine, because you loose your IQ

points (during rehabilitation), you go to sleep because you don't get a chance to think, because everybody is thinking for you in some capacity."

9) Insufficient information on community resources when leaving rehabilitation

The following paragraph describes the participants' comments that they had insufficient information about topics like financial help, transportation, recreation activities, and other resources for people with a SCI when they left the rehabilitation centre.

According to Chuck : "that's the biggest thing, the lack of information about what's available when you get outside the rehab centre, they don't really go over that when you are in there, not at all." Brody continues : "we would have needed information about recreation activities, financial help, transportation, and other resources for us – hooking you up with another person that's been in the community for a while who can help out, show you things", others agree. Rachel remarks : "ya, because when I was in the hospital I was the only girl and there are some differences between guys and girls and related to injuries that it would have been nice to have had someone to talk to, or if there was a woman living in the community that had been through it that would have really been good to talk to."

Rocky remarks : "the [rehabilitation] centre is isolated from the community", yet, "community is a huge aspect of [rehabilitation], that's where you are going to spend the rest of your life so you got to get ready for it", emphasizes Maria. Rachel comments : "I mean you're going to run into problems anyway, but there are some things that you could have tried out at the centre and troubleshot while someone is there, especially because you weren't connected or knew of information regarding resources after discharge, otherwise that's going to slow down the transition."

Suggestions : The need for the rehabilitation centre to be more connected with community resources was emphasized by all participants. Rocky suggests : "there are resources that don't cost a thing such as bringing people in to speak, and a buddy system – someone who lives in the community and can give helpful hints." "The community is a huge aspect of it – that's where you're going to spend the rest of your life, it needs to be addressed thoroughly", stresses Maria.

10) Approach to alcohol and drugs during rehabilitation

The participants commented that there was no resource for people who wanted help with alcohol and drug problems during rehabilitation and identified this as stressful. This issue was of importance to everyone who wanted help. The participants also objected to the rehabilitation centre's current zero tolerance policy on alcohol and drugs and found the policy stressful because it implied the lack of a normal life during rehabilitation, not being treated as an adult, the lack of experience and knowledge of how to deal with the reactions to alcohol and drugs after a SCI, and someone else making their decisions. The zero tolerance policy, as the participants explained, implies that if individuals with a SCI come to the rehabilitation centre with alcohol on their breath, this may be recorded and after three warnings, the individual can be discontinued from the inpatient rehabilitation program.

Rocky explains : "I just find it interesting, they call it rehab, but somehow they seem to exclude someone's substance problem from that, like what's the difference between rehab of the physical body and rehab for substance abuse, they are more than likely related and it probably put the person in the chair, statistically speaking, in the first place."

Brody describes the current policy of the rehabilitation centre : "what the centre has right now is called zero tolerance, which is good for the centre, I guess,

that's all it's good for, not good for the patient, because if a guy goes out and has a couple of beers and they get a whiff of it and it's written up and this guy is 19 or 24 or whatever years old ... and is given a warning and then the second or third time he's out." He continues : "when I was there I got drunk a lot and I learned about taking in water to prevent a bladder infection and not being able to void, about dysreflexia and so on, and the client now has no knowledge when he leaves the centre about being dysreflexic with alcohol because he has never experienced it, so what does the person know to do, either you got to be really good in reading up on it or phone 911", others agree. Brody concludes : "so the person gets shitfaced at home, passes out", Rocky interrupts : "not aware of any of the complications", "and in the morning when he wakes up, finds out that he has a bladder infection from hell, not aware of how he got it, what to do, so the centre is saving their butts with looking good in the media, I think."

Rachel gives her opinion : "the way I look at it – these people they get injured, they are 19, 34 years old, why shouldn't they be able to do what they would do otherwise, what would they be doing on a Friday night – going to the bar with their buddies, why shouldn't they be able to do that now and be able to learn how it's going to work with them, learn from their mistakes, instead what they are saying is 'no you can't do it', so not only have you changed your life with the injury, but now you have to change and you can't do any normal things, that's not right." Rocky continues : "and who are they to make the moral judgment, that's not their affair at all, if I am an alcoholic, there is no way that a zero tolerance policy is going to do me any good at all, so one of two things are going to happen – either I get kicked out or I find another way to drink and my problem continues and that's why I think AA or NA or any of the 12 step programs are really important for that because there is no judgment there."

Rachel emphasizes : "it doesn't help the client to be kicked out of the

hospital – 'you're drunk, you're out of here', thanks, I am 28 or 30 or whatever years old and you're telling me I can't have a couple of beers with my friend." She admits : "when we were at the centre we weren't the sweetest people but we learnt a lot from the extra activities we did, we knew what our limitations were while we were at the centre, you know, like 'I can't have that beer, I got to wait a little while', find out what you are capable of, it's no good for the person to run into problems, I mean you're going to anyway, but there are some things that you could have tried out at the centre and trouble shoot while someone is there, because otherwise that's going to slow down the transition." Chuck asserts : "it'd be better for him to transfer drunk in the hospital when there is someone there, experience it", Rocky agrees : "that's what it should be there for." Brody concludes : "so I guess once you break your neck you're a", Rachel interrupts : "kid again", "there is someone else making your decisions, you're told what and how your programs run and why", Brody continues.

Suggestions : With respect to the lack of resources for alcohol and drug problems during rehabilitation, Brody urges : "they got to address that", "it's very, very important, one of the most important things", Rocky adds. He continues : "most injuries are drug and alcohol related and they don't seem to understand that it's not people whose job it is to do alcohol and drug counselling, those people don't really work, they've never been through it, you need NA (Narcotics Anonymous) and AA (Alcoholics Anonymous) in there in some capacity at least as a funnel to get a good group, because I don't want my doctor to know what my drug problem was, I want a pure group that I can go to and be completely anonymous, and open up, and not have any sense that there will be a repercussion or someone shaking their finger or anything like that", others agree.

<u>11) Weather</u>

The remaining sections describe stressors that are ongoing, rather than most of those addressed earlier which dealt with issues the participants found stressful mainly after discharge from the rehabilitation centre. This section refers to the atmospheric conditions such as rain and snow, as well as hot and cold weather, and includes the restrictions on activities each implied for the participants. Weather conditions were stressful for everyone with the exception of Maria who always has someone with her and uses an electric chair.

"Fighting the weather can be a big stressor, and you have no control over it", Brody remarks with everyone's agreement. "Snow, you can't wheel in", he continues. Chuck remembers : "I got stuck in the snow for two hours once, before someone found me." "Rain – you're sitting, so your whole lap and legs get wet", Rocky adds. "I find that I can't wear a jacket at all unless someone else is pushing me, because unless you are wearing a short-sleeved coat, and I have never seen a short-sleeved winter coat, it gets caught in your wrists, in your hands, and you can't push because you can't get a grip, water on water slides, and then the sleeves get dragged into your wheels and you get all dirty and wet, it's better to just not wear one and freeze", Rachel relays. Chuck agrees : "it's pretty treacherous the weather, you do think twice before you do something – even the heat gets to me too", everyone agrees. "I don't sweat so I usually have to drink tons of water, but I get overheated," others nod in agreement. "In about half an hour", Rachel adds. Brody remarks : "especially driving, if I am stuck in rush hour traffic, it's like 'oh no', I usually find a cool shaded spot, park the car and just sit there and wait for some of the traffic to go by because me sitting in rush hour traffic, I either pass out or get confused." "Wind's good", Rachel throws in, Brody elaborates : "an overcast day is perfect for us."

<u>Suggestions</u> : The participants discussed some creative solutions

pertaining to weather issues. With respect to rain, Rocky shares : "I put an inner tube across my lab, the water just goes straight down between your legs and it doesn't go anywhere because it's heavy, it stays in the same spot, that works." Brody suggests : "work around it, change your schedule, get people to come to you." Rachel mentions : "you can make it so that at least at home, depending on finances, you can get in and out of your home into your car or van without being in the weather, because hopefully if you are going to a store they are going to have covered parking." With respect to the complications the sun can bring on, Rocky suggests : "aloe gel on your forehead, hands or feet helps, that cools you down so that I can stay in the sun as long as I want now."

12) Clothes

The following paragraphs address the stressor which items of dress presented for all participants. Included are : a) the frequent replacement of clothes that get dirty from wheeling or dropping food, or that rip during transfers; b) financial aspects; the lack of a good fit; c) the inability to try clothes on in the store; d) the danger of pressure sores; and e) dressing itself, including buttons, belt, and zippers which can all be obstacles and restrict the choice of clothes.

"Sleeves get dragged into your wheels and you get all dirty", comments Rachel. Rocky remarks : "the clothing thing can be really stressful, because you can't wear too many nice things, it might be nice now, but you go out and it starts to rain and you got nice clothes on and then they're ruined." Rachel shares : "for work I got to wear skirts and suits and you buy them and they are nice for a week and then there are permanent dirt stains or a little rip in the cuff and my clothes are at the drycleaning after one wearing and it's really expensive and nylons – a pair a day, $5 out the window just to go to work, because, for example, the velcro

on the edges of the chair when I transfer." Brody adds : "sometimes it costs more to go to that job than what you get paid." Rachel responds : "ya exactly, between that (the nylons) and $10 to $15 dollars worth of drycleaning." Brody's turn : "I usually on an average have to buy between one and two white shirts a month, summertime is not so bad because I am wearing short sleeves, but wintertime at least every paycheck I buy a shirt just to look respectable." Rachel continues : "and it's hard to buy clothes, I can get stuff that's really great when I am standing up, then when I am sitting down, it doesn't fit so great, so I have to buy stuff that fits in between, so I never get a really good fit – I find it really expensive and really frustrating, getting really good at knowing where to shop, though." Chuck agrees : "same problem, everything is made for people who are walking so as soon as you sit down it fits different, the seams pull in, they are not long enough or not tapered right." Rachel concludes : "if money was no object it wouldn't be that big a deal, you'd buy a new white shirt every week or you get someone to fix things the way you want them, but getting a seamstress to fix a skirt adds another $50 onto the $50 skirt – it's really frustrating."

Brody adds : "just getting dressed sometimes is a pain in the butt – it's so much easier to put velcro straps on all your clothes so you can pull them off real fast and put them on real fast. He continues : "also, a new pair of dresspants take me a good four to five times before I get the button loosened enough so it fits into the hole pretty good – usually when I buy a pair of pants, I sit in front of the TV and do and undo the button so it gets loosened up so I can wear them." Rachel comments : "for me it's the socks, and buttons, and zippers, and belts, if no one is around to help, I don't do it unless I have the time, because it does take tons of time.

Rocky continues : "you go to buy a pair of pants – it's not like you can go and try them on, so you buy the pants, they don't fit, you go back, you try again

and just buy jeans because you know how they're going to fit." Brody agrees : "exactly, Levis jeans, you know exactly the numbers you need, stock up." Rachel remarks : "I do that with everything, if I find something that I like and it fits, I buy it then and I buy more than one, because it doesn't happen that often." Maria adds : "I am kind of lucky in that I always have someone with me, I know how pants are going to fit me [by] how they fit my mom or my sister – I find shoes a big problem to buy", others agree. Brody gives an example : "I bought a pair of shoes that gave me a good pressure sore so that I couldn't wear shoes for two months." "Not just shoes", Brody adds, "seams on pants and back pockets are other troublemakers", others agree, "so you do a weight shift here, a weight shift there."

Suggestions : In response to the problems clothes can pose, the participants had the following ideas. To prevent sleeves from getting caught in the wheels or getting dirty, Rocky shares : "the first thing I do when I buy a sweatshirt is cut the sleeves off." Rachel mentions : "I roll them and get mom to sow them at elbow height." She continues : "shawls work really well, I don't know if guys wear them but for women they work really well." Brody cautions : "be careful of buttons on your jeans jacket down by your sleeves, you should do them up or cut them off because you can get them caught and I have eaten ground – it really hurts." Maria adds : "I have seen jackets that are made especially for people in chairs and they are the ugliest things you've ever seen, sure they can make something but if I don't like the way it looks, I am not going to wear it, and chances are that it'll be more expensive than your average clothes because it's sort of a specialized item", others agree. "What I do basically is to find clothes that are warm but thin, like things made out of Gortex that keep you warm, but aren't really in your way and I'll leave it on all day", Maria continues. Brody suggests : "go to the states and shop – better selection", others agree.

With respect to clothes causing pressure sores, Rocky shares : "I found a good solution for pressure sores – you take golden seal, mix it with Aloe Vera gel and Vitamin A, E, and Zinc, and the fluid will be reabsorbed back in your body and it goes hard." On the topic of foot wear, Rachel suggests : "really flexible fabric shoes are the best thing, they are soft." Rocky has another piece of advice : "don't wear anything new unless you've worn it before if you're going out, because it's like a recipe, if you have people come over, try it before, don't just try it when they are coming over", others agree. Brody remembers : "and if you're going out for dinner find out where you're going and then dress accordingly because I have gone out in a white shirt and white pants and then gone to eat Lasagna – spaghetti sauce does not come out easily." Rachel elaborates : "and it might seem like common sense but especially for us because we make more of a mess usually." Brody throws in some humour : "you can tell what a quad had for dinner by looking at their laps." Rocky concludes : "stay as creative with clothes as you can."

13) Grocery shopping

This section describes primarily shopping for food and its inherent stressors which include : a) items being too high up; b) having to ask for help; c) someone always knowing what you buy; d) having to make many trips to the car when you get home; and e) missing out on new items and cooking ideas if you don't shop yourself. Everyone agreed grocery shopping was stressful.

Rachel begins : "I looked for something in the store and never found it because it was way up there." She continues : "at first you're like 'I don't want to ask, I'll look like a cripple so I won't get that macaroni and cheese on the top shelf', but then you get home and you go, 'I really wish I had that macaroni and cheese, it's done in five minutes'." Brody remembers : "I used to get one of the

clerks to come around shopping with me, but I found it a bit of a hassle just to find someone and I felt really dependent to do my grocery shopping with them and therefore I started grocery shopping by myself and if there are some items that are up higher, at the end of my shopping I ask them to get those, it's faster, and doesn't waste their time as much." He continues : "the only other time I ask for help is lifting the groceries into the car – I just got tired of breaking eggs and milk bottles, it's just so frustrating, picking up a bag and dropping things and that's $7.50 down the drain." Rachel adds : "what I find so bad is : it's tough enough to get them to go around and get your groceries and get them to put them in your car, but then once you get home, you can't carry four bags, you carry one may be, if you are lucky, sometimes you take things out because you can't carry them in the bag so it takes you twelve trips to the car for four bags, because you got to take the eggs out and then you got to take the milk out, and so on."

Brody remarks : "I used to have a shopping list which I gave to my sister or whomever, but when I found out that I was missing a lot of items that were newer on the market, or sometimes you look at some things and you go, 'hey, lets try this' – you don't get that if you just give your sister a list." Maria adds : "sometimes I find it hard too, because I'll get sick of what I am eating and I just need some new ideas by going around the store." Chuck brings up another point : "I just find I can't get enough into that one little basket, and it's impossible to push the cart around." Rachel takes her turn : "I have accepted the fact that it's easier to take someone with me when I go shopping, but I don't want to, there is always someone there to watch, because they have to be there to help, so you can't say, 'can you hang on a minute and carry the milk, but turn your back for a second, because I don't want you to see me buy this', I mean you have no privacy in what you buy or where you go or how long you're there, there's always someone there."

Suggestions : Some short, to the point, suggestions from the participants regarding grocery shopping : "don't be afraid to ask for help", remarks Chuck, others agree. "They (store clerks) are there to help", others nod "they are really willing, take advantage of it", she continues.

14) Lack of privacy

A stressor for all participants was the deficiency in opportunities to be apart from the company or observation of others. Government or insurance bodies pry into all parts of their lives, other people perform very personal care tasks, family tell them what to do, and they have no privacy with respect to what they buy.

Brody states : "the Ministry or different agency can be a big stressor, too, they want the reason for what you need, your date and time of birth, how many kids you got, you name it, just to get a simple little item – sometimes I'd rather do without, if you want to poke and pry into all aspects of my life – is it really worth it, and how much of that thing am I going to use, so you just say, 'no, I am not up to a big battle today', so I just cozy up to my quilt, my puppy, and the remote control – those days you just don't want to get out of bed", everyone agrees. Rachel adds : "everyone knows everything about your life", Brody interrupts : "what you do, when you do it, how you do it, why you do it."

Maria brings up privacy in the sense of personal care : "the privacy issue with me is that the higher your injury, the more you give up on privacy, it's not 'someone outside of the bathroom' as someone said, it's someone in there with me, so you get to 'oh, well who hasn't seen me', but the people who I have the most trouble with in the sense of privacy is my family, [they say :] 'Maria, you are not getting enough protein in your diet, why aren't you buying this' – 'because I don't want it, let me eat what I want to eat'." Rocky's thoughts on the privacy

aspect with respect to personal care are : "it all depends on what kind of a value you put it on", Brody adds : "and yourself", others agree. Rocky continues : "if your sense of self is really weak it will bother you all to hell, but if your sense of self is strong or you know who you are and in knowing who you are, know that personal care is part of you now, that you are not in denial of it, it's not a big thing." Brody cautions : "but that usually takes some time before you accept it, it takes weeks, months, and possibly a year before you go 'alright this is the way it's going to be'." Rachel remarks : "you get used to it and you accept it and you don't even think about it, it just becomes part of the way you do things, but if you sit back and look at it and say, 'I hate it when someone does that for me', because you really do want to do it for yourself, but there is no possible way, you've tried everything you can think of, but you're just not going to get that finger to do that." She continues : "you still have to deal with it daily, you don't consciously deal with it, but you do deal with it daily and you just get to the point where you are really good at dealing with it."

Suggestions : Rachel has a comment which pertains not only to the lack of privacy, but also to the lack of spontaneity, and related issues which require adaptation. "There is not a lot you can do about it, I think most of these issues there is not a lot that you can do about it, it's just getting used to it and I think it was a big shock leaving the hospital and finding out that all these things had changed, you knew that when you were in the hospital they would be like that but you thought once you went home it would be different and it's not, you just have to learn to do it differently and learn how to adapt to it, accept it or learn not to think about it, I think you just need to be forewarned that things have changed, but warn you in a way, not the way they usually warn you in the hospital, like 'you can't do this', but like 'things are going to be different and you are going to get pissed off, but you are going to get used to it, or you'll find a new

way, you'll find what's right for you, do what's right for you, don't let someone tell you how to do it' and help you with things like that", others verbalize their agreement.

15) Lack of spontaneity

This section describes the participants' frustration with the lack of opportunities to act impulsively, out of their free will. The lack of spontaneity was a stressor for everyone and involved attendant care, their body's mind of its own, transportation, the lack of accessibility of the environment, and doing things with friends, or dates.

Rocky remarks with respect to attendant care : "that can be frustrating, because you want to be spontaneous and there is that schedule, that routine, and may be you want to change that once in a while." Rachel adds : "maybe I don't want to put the left sock on first, I want to put the right one on first", Rocky interrupts : "or may be I don't want to wear socks today." He continues : "when I was with the attendant care companies and training someone different every month, as soon as they were trained and I wanted to do something different or evolve, the person left and I had to train someone new."

With regard to the lack of control over their bodies' functioning restricting their spontaneity, Chuck comments : "sometimes you just don't want to go out when you don't feel right because you don't want to have that problem (bowel accident)." Rachel verbalizes everyone's agreement : "it's not worth the risk." Rachel continues : "in the morning I get up, go to the bathroom and then I can't go anywhere for one hour, even if I haven't had anything to eat or drink."

On the topic of transportation Rocky states : "with handyDART you can't just say to your friends, 'I'll meet you there tomorrow, you got to phone three days ahead – there goes your spontaneity." With respect to the lack of accessibility

of the environment, Rocky comments : "when places aren't accessible, your plans need to change – I find that pretty stressful and your independence goes, too." Regarding dating, Rachel remarks : "they don't see necessarily that there is no spontaneity in my life, I plan everything, it takes time."

16) Dating

The following paragraphs address the stressful aspects involved in initiating and sustaining intimate relationships. This category was stressful for everyone and included : a) having to explain everything to each new person; b) "second guessing" regarding the person's motives; c) the difficulty in communicating the details of the disability with respect to an intimate relationship to someone with no prior knowledge of the disability; d) the fear of the person's reactions to the details of what the disability involves in an intimate relationship; and e) not being approached due to a perceived lack of an independent appearance.

Brody begins : "going out on a date is a big hassle, that's the easiest way of putting it, right ?" "Well, that's the first step", Rachel responds. "It's a hassle", stresses Brody. "Because every time you got to train someone new and every time you got to wonder did they see me first or the chair, you figure that you're a pretty good judge of character, but there is still always a nagging little doubt for the first few times you go out with someone new", Rachel adds. Brody continues : "when I first got injured I was really scared, said things like 'I don't think I like you enough, I don't think I am ready for a commitment', it wasn't that I wasn't ready, I was scared of what would happen after the second or third date and how I am going to present myself or what to do, you get a little bit of input at the centre." "Not much", Rachel disagrees. "So", Brody continues "I took it on my own to find out what I am capable of doing, how I am capable of

maneuvering myself into different positions, to make me and my partner feel special, shall we say." When asked what the scariest part was Brody responded : "I didn't know how she would react to the plumbing system, because you got an extra adapter, you're longer – what we have to do to even make love, different tools that you need, I could go on", "please do", others ask.

Rachel remarks : "I had a date last night and it was a new guy, I had met with him twice and we were very comfortable and I am almost uncomfortable that he is so comfortable so fast, because it's almost like", Rocky interrupts : "what's he hiding", Brody adds : "this is too good to be true." Rachel continues : "and it makes me nervous because I date a lot and actually I haven't had any bad experiences, but I am still always ready for one and it puts me on guard and I don't know whether that's good or bad, because it's not fair to them, they could be in this genuinely and you're always second guessing them at least for the first little while and you wonder how are they going to react to this and that, and it's scary." Rocky empathizes : "it's tough enough without putting a set of wheels into it." Rachel concludes : "I find that the most stressful thing in my life at the moment because I was in a long term relationship when my accident happened and I was in that 'til last August and there was never any second guessing, any questions, he was just wonderful it was like nothing was different, so for me until last August I didn't have to deal with it and last August it was like 'oh, boy, I have to do this' and I knew I had to do it, I knew it was time, but I was like 'do I really want to do this' ?"

Brody shares his approach : "you got to screen them", Rachel agrees : "you got to screen them, ask a lot of questions – you got to be really open right out front." Brody continues : "there is a whole list of questions that you have in your mind", Rocky interrupts : "bleeding hearts need not apply and all that." Rocky admits : "this is something that I have been putting off a lot, very few

relationships since the accident, and part of it was that I was not with anybody before the accident and one brief encounter after the accident and it's something that I stress out about all the time, something I would rather not deal with sometimes, the hardest part comes back to independence – is this person a bleeding heart, are they doing charity, or are they really genuinely interested in me, and is that going to be able to go beyond meeting the chair, meeting me and then meeting the disability itself ?"

Rachel continues : "all those hidden things that you hide so well for the first month, and then sometimes you forget 'oh yes, I forgot I was supposed to hide that, not supposed to, but I forgot that that is something that isn't normal', you know, like the five hours in the morning thing, you don't tell someone that right off the bat that 'gee, it takes me about eight hours to get up in the morning, so don't be in a rush to rush me out for breakfast tomorrow morning, don't think you can just pop in here'." Rocky takes it a step further : "or if someone does spend the night, that someone is coming in at seven in the morning to give me a hand and stick their finger up my butt – I mean, how do you explain that to somebody, or just the fact that if you are having intercourse that there is a chance that you might have a bowel movement or blow a dome (refers to a condom which attaches to tubing and a bag and is the method of urine drainage in men; 'blowing domes' refers to the condom coming off or leaking) or something, these things happen and are they prepared in that relationship to accept that and not only accept that, but are they prepared to help you through it and help you get cleaned up or whatever – how do you approach someone with that ?" Rocky continues : "that's certainly not something that you bring up on the first date – hey baby, how are you with a wad of toilet paper ?"

Rachel concludes : "the bladder and bowel thing is one of those issues you go 'please don't let it happen before we talked about it' – undoubtedly it's going to

happen at some point." Brody remembers : "actually it happened to me once on a first date – I had a dome blow, so I sat there and I had to explain myself to her and she was understanding enough that she realized, going out with this guy in a wheelchair, there is a lot more to it than you see – it's the tip of the iceberg that you see and then there is the big bottom of the iceberg", others agree, "and I was really lucky that she was understanding, but it made me think, what if she wasn't understanding, that would have been really uncomfortable, especially when you went over there and you got to drive her back, so you got to go somewhere first to get changed, then may be, hopefully, come back and pick her up, but by the time you get home you go 'do I really want to come back and face this person, I don't think so'." "First impressions especially", Rocky empathizes. He continues : "and some people like myself need help changing so it's like, 'hey buddy, I just met you, can you put me to bed and change my pants' – certainly not the idea of a first date, definitely no call back on that one", Rocky assures. Chuck adds : "or, everything is going so good and you're cutting it short and they don't know why."

Rachel sees another side : "but in this day and age you don't want to be jumping into bed with just anybody, so may be we're just lucky because we don't even have that option." Rachel continues : "you do want to make sure that this person is pretty selfassured, comfortable, strong, and know who they are", "confident in themselves", Brody adds, "because man they are going to have to deal with some stuff they didn't expect, because they see you and they see me like this, they see me doing things for myself, they see me going to the washroom, they see me going out for dinner, they see me doing whatever, they don't see necessarily that there is no spontaneity in my life, none, zero, zilch, what is that, we plan everything, it takes time." Rocky remarks : "the kitchen table is not an option anymore", Rachel responds : "that takes 10 minutes to get to – it sounds

silly in a way and we can laugh about it, but it's not, it's a major thing, you think about all the time especially when you're starting up with someone new and it's easy when it's just a great guy or a great girl and when you think that I hope that does continue and goes somewhere then it's like 'oh God, can I do this, can I deal with this, can he deal with this' ?"

Brody cautions : "you can easily trust someone and then get really hurt, because you're letting them in there and you trust them enough to poke and pry into your personal life and then they don't feel comfortable and put up this wall and move away, that hurts, it's like 'why did you waste my time' ?" Chuck shares his approach : "I look for straight honesty right away", others agree. Rachel elaborates : "it's like the first telephone conversation or the first time you meet them, lay it all out there, you got to get some interesting topics going right off the bat so that you know – is this person a talker or not, because if they are not going to talk there is no way that you can discuss anything openly if they can't communicate." Chuck agrees : "you got to get them to try and open up right away about themselves." Brody remarks : "I trust the person that comes out with questions rather than me go 'hey, so ...', there are little tests and questions I have for my dates that I kind of present – screening process." Chuck remarks : "just trying to find the right person is the most frustrating or stressful part for me."

When asked about her feelings about and experiences with dating, Maria responds : "I don't mean for this to sound like a sob story or break out the violins, but people are pretty scared of me, guys don't really approach me, I'll do the odd approaching, but usually we end up just being friends – I have really only ever had one boyfriend and he was a real case, but otherwise it just hasn't been, that's the problem, not even getting to those questions, just someone even willing to speak to you in a sense – I'm too needy, I'm too big of a burden, I'm too not independent that they can't see that I am independent, but it's just not as

physically noticeable as it is with a paraplegic, it's very different."

Rocky responds to Maria's comments : "my experience [is], the more dependent you are, the less attractive you seem to be – people approach me more now than three years ago and I am more independent than I was three years ago and that's tough, that's a really tough situation, you work on it as much as you can, I just keep working and doing new things all the time, but man it's tough and they see that and the wall is right there, ... the more dependent you are the less attractive you are." Maria continues : "I can't really go out on a date, it's a threesome no matter what, unless the person by chance is a nurse so what I do is I find someone I like and I hang out where they hang out, but it never really works out, we become good friends, but that's it – it's been 10 years for me, it's gotten (physically) as good as it's going to get."

Suggestions : With respect to dating, Rachel cautions : "prepare to get hurt." Rocky advises : "don't be afraid of it, don't avoid it, but it might take a little getting used to, there are a few more things to think about and if there was an insurance claim, there are a few more things to think about that you have to watch out for yourself, you got to be really careful and you got to be upfront about things." Maria shares : "my dad scared the shit out of me on that, he's like, 'don't tell anybody what you got (settlement money), guys will be after you'." She continues : "there are things you can do, though, you tie up all your money."

17) Bowel and bladder accidents and related stressors

Altered bowel and bladder function as well as incidents of bowel or bladder incontinence resulting from the varying degrees of loss of control over those functions following SCI were stressors for all participants. Bowel or bladder accidents are embarrassing and humiliating, the fear of them happening can be very stressful and restricts activities, bathrooms not being accessible pose

problems, and plans have to change if accidents happen. Having accidents happen on dates is one of the worst scenarios and was addressed in the section entitled 'dating'.

Rocky uses humour to address this issue : "your unexplained smelly packages, that can be pretty embarrassing." Brody remembers : "my friend jumped into my car and we traveled about 20 minutes to a friend's place – I got out of my car, he gets out, sits down and has this puzzled look on his face and I go, 'what's up ?', he goes, 'nothing's up, something's out', I go 'what are you talking about ?', I am checking his car seat, going 'you better not have', our friend comes out of the house and goes 'what's up ? – ohh (smelling the odor)' and I go 'can you give him a pair of trackpants ?'."

Rocky comments : "drainage can be pretty stressful, too", others agree, "I'm like the blow dome king." A teasing interlude between Brody and Rocky follows and Rocky threatens : "I remember a certain nickname first day in rehab so you just be careful." Reluctantly Brody shares the story : "okay, in a halo (a metal brace which surrounds the head and neck and is anchored with screws to the forehead and back of the head in order to keep the head and neck completely stable), I get transferred to GF (GF Strong Rehabilitation Centre), I sit in the TV room, not bothering [anybody], Rocky comes screaming in, 'hey new guy', and I'm in a halo, I can't turn around, 'what's your name', 'Brody', I respond, 'well we should call you ... (name cannot be revealed because of similarity with real name)' ", "I am not clicking in", Brody explains "they go 'hey buddy, have you checked underneath your seat lately ?' – I got this humangous pool of shit underneath me." Rocky continues : "so guys come in and we're like 'meet ...' ." Brody concludes : "that was my first nickname, not fun, it's like being in kindergarten." Rocky agrees : "ya, you're a baby, a newborn."

Rocky emphasizes : "bowel things can be pretty stressful, embarrassing",

others agree. He continues : "that's probably the worst part of the whole thing for me." Rachel responds : "it's the fear of it happening." Brody remarks : "if I had control over my bowel and bladder, you'd see one happy camper that can't walk – it's out of control is the thing and the hassle of the extra five minutes of putting the bag (drainage bag secured around the calf where the urine from the condom or catheter drains into via tubing) on every morning, and whatever – so it's not like you get up and you leave." Rocky adds : "and you got to plan it – let's say you're meeting some friends and you get there and they have to pack you up stairs to get in there, you can't drink because you can't go to the john or you go to some places and their bathrooms aren't accessible, so again your independence goes, I find that is pretty stressful."

Rachel deals with a slightly different aspect with respect to bowel and bladder issues in that she has control over those functions : "in the morning I get up, go to the bathroom and then I can't go anywhere for one hour, same as go to bed, better expect to be up in an hour – sure I have control, but we're not talking half an hour or an hour 'til I get to the washroom, we're talking 'okay washroom, now would be good, where is it, five minutes, uh, run' and I don't like to go too far from the bathroom on my own, because sometimes pushing your chair when you have to get to the bathroom is not a good thing, you would be surprised what muscles you're using when you're pushing your chair, you really would." She summarizes : "it's still a hassle even though I have the control, so it's 100 times better than I could have ever have hoped for, but it's still a hassle because anything less than normal in that area is not good."

Brody explains his situation : "I have a 10 minute time span before I void, but for me and my hand function to get to the bathroom, get my pants down and void is a totally different matter, it's no fun pulling your pants down in a chair – the amount of laundry I did, even though you got to the bathroom in time, got

your pants down and sit, and you're going, then you jump back in your chair and then 'oh ya, I got to go a little bit more' and then you have a choice of letting the sun dry you up or going home and get changed, or go into your trunk and pull out your spare safety set of clothes and bring them on into the party." Maria adds : "that can be a problem for me too because in getting my pants down they would be rocking and rolling me and then some would come out, so now all my pants have slits in all those hard to reach places and then no one can steal them, also, easy access – now I just have to go on a date."

Chuck comments : "sometimes you just don't want to go out when you don't feel right because you don't want to have that problem and then the feeling ends up going away and you're safe, but sometimes I still worry about it", others agree. "It's really embarrassing, not fun, really embarrassing", stresses Brody. Chuck explains : "that's why I always go in my own van, I never go in someone else's car, never." Brody responds : "it took a long time before I felt strong enough inside, and felt good about myself, confident so that I'd go into someone else's car."

Rachel shares her experience with a bowel accident : "the time it happened to me, I was with friends who didn't have a problem with it, really easy going people, not people who are hung up on that kind of thing – people are taught that those things are taboo subjects, that those things don't happen, that it's not natural, so they are totally uncomfortable with it, same thing with helping someone change, what's the big deal, but it's uncomfortable for other people and all my friends who I hang out with a lot are really comfortable with it, no problem, and I don't have a problem with it either, so I don't have a problem asking someone." She continues : "even in dating I am pretty good at knowing when it's going to happen, so it's usually not a big surprise, if I think it could, I'll call things off first or stick close to home where it's easy for me to get changed."

Rocky comments : "for me it's not so much it happening or not, but the stress of the potential that it could, I used to blow domes a lot, so if I'm out, I'll be checking, 'am I fine, do I have to go ?' and just the threat of it is worse than the actual thing happening, like the fear of suffering is worse than suffering itself."

18) Challenges of independent living

This section outlines the stressor which the challenges of independent living presented for the participants. Independent living refers to performing activities of daily living without the assistance of others as much as possible. The effort as well as the length of time involved in doing things independently were stress factors.

Everyone agrees with Brody's comments : "people just don't get the grasp of how hard it is for a person to put on his condom when he doesn't have hand function, to have a shower, to put pants on." Rocky continues : "to pick up a fork off the floor", Rachel goes for the ultimate challenge : "to pick a knife off the floor." Chuck adds : "it's frustrating too, when you almost got it and you drop it half way up." "Or you've worked on it for a while and someone comes along and picks it up for you", Rocky comments. Brody mentions one of his pet peeves : "stuff falling behind the toilet where you can't reach it", "that sucks", Rachel adds. Rocky shares his solution : "I get a coat hanger and pull it out." "Oh ya, I do too", Brody responds "but it's still a hassle because you have to go get it, you can't just pick it up", Rachel adds. Brody explains : "and you will sit there and reach for five minutes and then you go 'forget this, top of a toothpaste lid, oh well, it will dry up'." He continues : "there is stuff on the market now, adapted things, that make your life easier, especially in the states." "It's twice as expensive, though", reminds Rachel. Brody concludes : "you pay the price for the convenience." Rocky agrees : "ya, you definitely do, that can be stressful too."

Rachel addresses shopping : "what I find so bad is you get home (with your groceries and), you can't carry four bags, you carry one may be ..., sometimes you have to take things out because you can't carry them in the bag so it takes you twelve trips to the car for four bags." Further emphasizing the aspect of everything taking so much longer, Brody explains : "the time frame, before we used to get up, have a seven minute shower, three minutes put on clothes, and off you go, now it's like a seven minute trying to get into the shower, jumping onto a bed to get dressed, putting on a leg bag, etc. – that's frustrating because you got to do that extra routine every day, so it's not like you get up and you leave, and then if you have an accident it's not like you can be out within five minutes, [rather] half an hour or 40 minutes extra." "And", Rocky adds "if it happens at eight o'clock at night, okay, do I sit here and go to bed or do I put all that effort into going out for another two hours ?"

Rachel shares her experiences with respect to dressing : "it's the socks, and buttons, and zippers, and belts, if no one is around to help, I don't do it unless I have the time, because it does take tons of time and I am not willing to put the effort into it, I'd rather wear a pull over, because I don't like fighting with it, but I do when I have time, like on the weekend, but when I got to leave at 6:45 a.m., there is no way that I am putting tons of time into getting dressed, but what I find frustrating is that you don't just grab something and then you grab something else, you have to organize it all and take extras in case something breaks or rips because you can't just walk over and grab another one when you got one pant leg on." Rocky adds : "or even just jumping onto your bed and realizing that you forgot your socks", "or a button on your jeans – brandnew jeans and you cannot do them up." Chuck admits : "I have given up on buttons, they're just too hard, so I don't wear them."

Rocky remarks : "for me it's getting dressed and into and out of bed – right

now I sleep in my pants, so I can appreciate the frustration, because I am right there learning now, and without a lift it takes me 20 minutes to transfer, get my legs up and get somewhere close to sleeping and one time I forgot a drainage bag, so basically my transfers are equivalent to an able-bodied person changing three spare tires, so I changed nine spare tires that night – I was just pooped, I had a great sleep, though, but it's hell ... and I really banged up one of my kidneys, because in transferring I got stuck, fell sideways off my chair, pissing blood for a couple of days, so not only is it the frustration, but how much will your body take of all that kind of work, that can be frustrating, because you want to get out, yet you are tired and don't want to do anything."

Suggestions : Brody comments on how he deals with some of the challenges of independent living : "you find different ways around it and my mind clicks so fast that it's already thinking of a different route without me even telling it to, it's second nature, the first four or five times my easy over eggs became scrambled, but now I can have my easy over eggs and be happy about it – the more you try, your techniques get better and it's always stressful, but you got to just do it." Rocky addresses another aspect of independent living – picking things up which you have dropped : "there is a real art to it because every shape is different, so your strategy of how you approach it is different for each thing, like one thing I might be able to trap between my two hands, but something I might have to roll into a bag, something else I might have to go to the other side of the apartment and get a coat hanger and hook it." Other suggestions include having discussions on the topic of challenges of independent living with individuals who have a SCI and live in the community and taking week-end passes to the discharge environment in order to have practical experiences with any challenges that arise and be able to troubleshoot them prior to discharge. Brody recommends : "the last week before discharge, try things outside of the

norm that you haven't done before that you might experience."

19) Crowds

Sources of stress related to wheeling among crowds of people included being ignored by people walking, having to physically push people to make themselves noticeable, and being blamed if the person pushing them runs into a person who is walking.

Rocky begins : "crowds are very stressful for me because I don't want to hurt anyone." Rachel takes a more ruthless approach : "I have gotten really good at knowing where to hit a person and what works for who." Rocky prefers a less physical approach : "whistles are good, too." Brody comments : "there is another side, too, because when I bang into girls, I always pat them on the bum and they usually go (Brody mimics them turning around furious), 'hey', and then it's like 'alright' (he mimics a surprised but smiling look)." Rachel agrees : "I hit the girl in the bum too, wack them with the back of my hand, because it's the only way you're going to get them to turn around – if they are bumped in the leg, they just ignore it, you got to bang them somewhere where they are going to notice and then they go 'sorry, I'll get out of your way'." She continues : "I think that people are pretty oblivious, it's not like we are invisible, but you'd swear it." Rachel remembers : "I was at a bar Saturday night and got tripped over and bumped into seven times, it's like you're not even there, or they see you coming and I say 'excuse me', if that doesn't work, I push, and if that doesn't work, I just go for it – you try to be polite but it's not working."

Maria had another experience : "I have had it go the other way, though – when I was in a manual chair and someone pushed me, they pushed me into someone, clipped the back of their leg, and the person turned around and looked at me (Maria mimics an angry face), and I'm like 'I didn't do it, look at the person

behind me and tell them off', and now with this thing (referring to the electric chair), it's so heavy, if I roll over someone's foot, it hurts and once you start rolling, you got to keep going, so I close my eyes and keep rolling, hoping that they are too drunk to notice."

20) Health

This section addresses diet and other aspects of physical well-being such as dental care, pressure sores, bladder infections, and sleeping. Some of the participants' comments refer to the time in the rehabilitation centre, but, as will be evident, they also relate to the time post-discharge.

Rocky states with conviction : "you got to understand that you are what you absorb and if you got bad food, bad air, and bad water in rehab, how can you possibly be healthy and that's a major stressor, too, it's something that is widely overlooked, the quality of food is unbelievably important for recovery no matter how much you are going to get back", others agree. "I never used to eat there", says Rachel. "My mom used to always make me things", remembers Brody. "And, looking down the road", he continues, "the amount of different diets, or aspects of a diet that you got to have, you got to have a certain amount of fluids go through your body every day, got to have the right foods, watch what you eat." Chuck comments : "I wasn't told anything about my diet and when I got out I just pounded on pounds, I just lost about 20 pounds this last year." Brody had a similar experience : "oh ya, when I was on my own the first year I might have cooked a meal twice in one week and that might have been boiling one egg or making hamburger helper and the rest was restaurants, McDonald's – I was looking pretty big, I was looking for a bigger sized wheelchair."

Rocky had a different experience : "I went totally the opposite, when I had the accident, I realized that it all comes down to energy and that would be the big

fundamental factor in how much I would get back, how well I do, what kind of infections I get – it was a real fight especially in the hospital and at the rehab centre to get good food, clean water, clean air – that was so hard, so when I got out on my own, I just kept going with that because it worked, I would have my parents bring in good food, stuff that isn't cooked all to hell, distilled water, purifier, that's just as natural for me as breathing now." He continues : "diet is major, that's what I spent most of my time doing during the first two years being out, finding out what works and what doesn't." He adds : "see, it's interesting that our system is called health care, but it is disease care, and that distinction leads into a whole variety of misconceptions about what health is and either your healthy or you have something wrong with you and that's not true because health is just as many stages as disease and finding that out was major."

Maria comments : "I am very conscious of my teeth, because they are sort of my hands, they'll do all of my closing, moving, mouthsticking, so I am very conscious how often I brush, floss, go to the dentist." Rocky adds : "there is nothing more pathetic than a quad without teeth." Brody agrees : "ya, a quad's hands are his teeth." "They're the only thing you have to grip with", Rocky explains, "oh ya, they can open a lot of things", Rachel adds.

Also representative of this category are pressure sores and bladder infections. Brody remembers : "I bought a pair of shoes that gave me a good pressure sore, so that I couldn't wear a shoe for two months and it only took me three hours of wearing the shoe, and we know how to take care of a pressure sore – stay off it." On the topic of bladder infections, Maria remarks : "I can tell when I have to go (to the bathroom) because my temperature rises, I get spasms, so that helps a lot, but if I have an infection, I can't tell when I have to go and that can be a real pain." Rachel adds : "one of those times when I don't want to leave the house is when I got a bladder infection, so get a movie, because I'm not

leaving."

With respect to the loss of sleep, Brody asks : "who here has had a good night's sleep since their accident ?" Chuck and Maria report no problems sleeping, the others agree with Brody : "I could probably count on one hand the number of good night sleeps I have had and that was only because I was drunk when I went to bed." He adds : "I had some medical complications so I had to tune in when I voided at night, knew the symptoms of it, therefore my body got used to waking up each time I voided which would be three or four or five times at night, and I just got into the routine that each time I woke up I used to drink a liter of water." Rocky shares his experience : "only the last couple of months have been good for me – usually I woke up at least twice and part of that is expecting someone to come in to check your drainage, in the hospital and rehab centre there would be someone in there every night with a flashlight and you get conditioned to that." Rachel remarks : "I found that as soon as I ended my chronic pain last month, I got a good night sleep, before that I hadn't had a good sleep for four years, I woke up at least seven times a night just from pain, some nights I was awake all night and nothing helped – special diets, sleeping pills, sleep schedules – nothing until a month ago I finally got rid of the pain and now I sleep so well." Maria's cure : "three months in the acute care at Children's and you're sleeping like a log, you're waking up there every minute with alarms and babies crying and ever since then I have slept like a rock, I can sleep anywhere."

21) Having children

Another source of stress was related to thoughts of parenting and, for women, the experience of pregnancy. The aspects included in this category are : a) the uncertainty regarding the effects of pregnancy; b) the inability to care for their baby on their own; c) the inability to do some activities with them, or physically

teach them sports; d) their partner having to do a lot more; and e) the restriction on the number of children they have because of physically not being able to help their partner. All of the participants found this issue to be a stress factor.

Rachel starts us off : "something that I stress out about all the time is kids, having my own or not, and what that would entail, everyone who I consult about this is really indecisive, 'well it probably wouldn't be a problem, well you probably would have to take a year off work, well you probably would have to lie in bed for six months' – well, what is it going to be, and I've talked to people who have had them and with every injury things are different and nobody can tell you how things are going to be like for you, so it's awkward and I worry about it because it's something I want to do, but now I don't know how it's going to affect me." Brody adds : "or even being a parent", Rachel disagrees : "no, it's not that so much, but it pisses me off, though, that I won't be able to take care of the baby, that I won't safely be able to pick up a baby or change them or feed them – I am angry that I won't be able to take care of the kid on my own, once they are running around it's no problem, but for the first couple of years." Brody interrupts : "I wouldn't say running around because the kids would probably take advantage of you, too." Again Rachel feels differently : "I don't think so, I worry about whether or not I am going to be able to have kids and how it's going to affect me, and I am angry about the fact that I won't be able to take care of the kid on my own, that's going to really piss me off, it's going to really bother me having someone there 24 hours a day looking after my kid – I wonder, am I going to want to do this to myself or am I going to want to look at other options."

Rocky has an interesting comment : "for women it's a biological thing, for us it's more like an intellectual challenge." Brody remarks : "having kids may be frustrating in that we can't do the activities that you would normally do with them." Rachel agrees : "can't take them to the beach, can't go into the sand, can't

go into the water." Rocky supposes : "I think we probably stress out more about that than our kids would, because our kids they grow up with that, we didn't, and the whole set of rules are totally different." Brody asks : "but are the kids actually missing out or are they..." Rocky interrupts : "of course not, compared to this world of able-bodied people, some people might judge that, but I don't think so, I think that every family has it's own dynamics and culturally you look all over the world and each family is different in various aspects and is anyone truly deprived, no, it's just different." Rachel agrees : "I don't think it would be stressful for the kid, I don't think it would be a bad thing, I think it would be frustrating that you might want to do things and not be able to, that's what I think is going to be frustrating", others agree. She continues : "you want to go and hit that ball around with them, but it's going to be different, difficult, and some things are not going to be possible, I think that's going to be a major hurdle to overcome and I think it's going to affect a longterm relationship, too – we can have kids, whether we have them biologically or adopt, or whatever, but that's only one issue, the next one is that I can't do the motherly things that mothers do for so many years and that's going to affect everybody in the family, not just me." Brody adds : "you depend on your parents to do things for you and may be even hire someone."

Maria remarks : "well, right now someone else is my hands and arms already, I won't have to adjust to a third person in the picture." She continues : "I have never really worried about missing out on throwing the ball around with my kid and I guess I have always figured as long as I'm there it doesn't matter and what I would be teaching my kid is how to pick the position in softball that you would have to run the least in – I was never good at sports." After a pause, she adds : "my brother and I are always joking because we both want to have kids, but we are saying I guess we have to have a date first, so there are a few

other things that have to happen first, and I don't know whether I would want to have kids physically because I would be afraid that it would put too much stress on my body and I might die, and not that I would care that much, but I wouldn't want to bring something into the world and not be here to take care of it." Rachel identifies with Maria's comment : "same kind of thing, like, 'what will it do to me', right now I wouldn't be able to because of the medications I am on and it would depend on whether we can train my body to be without them and for the last four years we haven't been able to, but we are going to hope." Maria explains : "it's very hard on your kidneys, it's very hard on your bladder, it really becomes a big problem, and I had a fair amount of internal injury when I was first injured and I don't know whether it would affect that."

Chuck shares his feelings : "the most frustrating thing for me would be not being able to teach him things like to play Lacrosse, like I did, or soccer, kick around the ball together, plus the care too, you'd have to think about your wife, I couldn't help change, she would be doing all this work and you would feel useless just sitting there watching." Rocky elaborates : "you wouldn't want a big family because your wife would be bald by the time she was 30 or at least have white hair, so you concentrate on a small family of four including the parents and that's about as far as I would put my wife into a stress factor and myself, too, I mean, I see it with my sister now, it's bedtime, the kids hide behind the couch, ripping the couch apart and what would you be able to do ?" Rachel adds : "a small, happy family instead of a big, happy family."

22) Employment

This section represents the last category of stressors. It describes factors brought up by the participants around earning wages. Included are : a) the difficulty in finding part-time summer employment; b) motivating factors and

resources, c) the lack of knowledge and training with respect to suitable employment choices, and d) restrictions in employment choices. Only two participants found this to be an issue.

Brody remarks : "age [is] a factor, if you're 52, break your neck and you can't go back to what you were doing before, you've got to find out what you're capable of doing now, then you've got to find an employer who is willing to accept you, but if you're young and gung ho, then it's fairly easy for us to find employment." Rachel disagrees somewhat : "although it is hard to find young part-time employment, like while you're going to school, because everybody is couriers, McDonald's – like we can handle change and a cash register." She adds : "that was what I was doing before my accident – I was working at a paint store, but it's not like I was going to be able to carry five gallon cans of paint around now, so I found it hard and I was bored, I couldn't work part-time and that bugged me." Rocky considers : "it depends on your coverage too, if someone is on compo, there are a couple of factors that aren't even going to encourage a person to go back to work, first of all the money is good, you get everything done for you, so you don't need to work another day in your life, so I think motivating factors are really important." Chuck agrees : "I found it hard to get motivated because I was always a laborer, doing the dirty work, I didn't want to sit in front of a computer and punch buttons all day, that's what I always thought I had to do now, that that was going to be the rest of my career, being in front of a computer, and I didn't want to do that so I didn't look for work right away, and then I took a career planning course for people with physical disabilities and that helped me quite a bit."

Rocky shares his situation : "my coverage is pretty good, so I didn't really need to work, but you look in the paper and it's just a slice of what you can do and what's out there, so that's why I got my own business going, I didn't like

what I found, so I made my own, so it does really depend a lot on motivation and what resources you have." He continues : "plus, there is no encouragement for people on Ministry funding to get a job, because the Ministry chops your money in half right away – where is the transition ?" With respect to transportation, Rocky comments : "finding a job is really hard if you just have the handyDART to work with, because each day it takes you forever just to go for interviews, but then once you got the job, how do you get to the job on time, efficiently – you don't have a life, your life or your schedule is entirely dependent on everyone else's schedule."

Maria shares her feelings : "for me that's been something I've been avoiding – I'm in school all the time, even in the summer, but I have tutored a lot and I do a lot of talks for schools and kids and teachers that are dealing with integrating people in wheelchairs into their classrooms and that pays pretty well, talk for one hour and get paid $200, and it doesn't feel like a job because it's stuff that you know, I just tell my story and let them ask questions which I love", "and", she adds "I am a painter and drawer now, so I have done a few pictures on commission."

Rachel addresses the aspect of restricted employment choices : "I do find it stressful occasionally when I think 'oh, I really would have liked to have done that' and it's something that [I] just physically cannot do now, I don't think that now, because I have found what I like and I probably would have done that anyway, but if you had your heart set on being a police officer, you got to think again." She adds : "I was doing some modeling before and I could do that now, I have an offer back east, but there is no way that I could [do] that here, slam the door in your face here." Rachel emphasizes : "the motivation thing is major, I don't necessarily think it's the financial thing – I don't have to work, but I do because I want to, I want to earn my own way and I want to be bigger than I ever

was before."

Additional stressor added in the last meeting

During the meeting for the verification of the categories and themes identified, one stressor that the participants indicated they had forgotten and wanted to add was spasms (involuntary muscle contractions which, if severe enough, can even throw the person out of his/her chair). Participants commented that it was embarrassing to have spasms in public – "you get the impression that people think you are possessed, and they are so unpredictable."

Overarching themes :

The following paragraphs will outline each of the five overarching themes identified in the study. These themes are made up of the participants' comments that were repeated in a minimum of five of the categories of stressors described earlier (see Appendix G for overarching themes and their definitions).

A) Insufficient preparation for various issues prior to discharge from rehabilitation

One theme which permeates many of the categories is the stress factor related to the insufficient preparation for life in the community prior to discharge from the rehabilitation centre. For example, the participants felt unprepared for some of the difficulties with attendant care and for the lack of information regarding hiring their own attendants. They also felt unprepared for the frustration they experienced with respect to frequently having to train, or explain the disabilty to, someone new, including attendants, friends, and dates. The comments and reactions from others were also overwhelming and unexpected. The participants did not feel prepared for the change from a rigid schedule during rehabilitation to unscheduled time and the resulting boredom

at home. They commented that there was very little information, if any, given on financial help, transportation, recreation activities, and other resources for people with a SCI. With respect to the current zero tolerance policy on alcohol, the participants felt that clients are at risk because they have no experience, prior to discharge, with the possible reactions to alcohol, or the factors which they should be aware of when consuming alcohol.

In a more general manner, the participants commented that they would like to have been prepared for the impact of SCI on their life which they returned to postdischarge and to have had opportunities to develop or enhance skills in dealing with this impact in various aspects of their life. They felt that the rehabilitation centre was isolated from the community, yet it is the community where they would spend the rest of their life. The participants pointed out that the lack of preparation for life in the community after discharge slowed down their transition from institutional to community living and made it more overwhelming than it might have been, if they had had an opportunity, prior to discharge, to be aware of and address some the the potential difficulties and experiences they encountered postdischarge. They also found that they were not prepared for the change from the lack of opportunities for self-determination during rehabilitation to the need for it post-discharge.

Quotes which are representative of this section include : "I would like to see the centre better prepare people before you get out – you learn 10% at the centre and 90% when you get out" and "you're so protected in the rehab centre, everyone there is going through similar circumstances, everything is accessible and level."

B) Chronic hassles

This theme refers to the ongoing, frustrating aspects of living with the implications of a SCI. Specifically, this theme includes training new attendants, friends, and dates as well as the extra tasks and time requirements involved in doing things independently. Other hassles involved being dependent on someone else, facing uneducated comments or reactions from others, and the fight for independence with their family and insurance or social service agencies. The fight for necessities with financial agencies was also included. Accessibility and transportation were further nuisances. The extra financial expenses associated with a SCI represented another chronic stressor. The weather which can restrict activities was also an ongoing stressor. Further on the list of chronic hassles were clothes, including aspects ranging from the frequent replacement of clothes to dressing itself. Shopping and having to rely on help also fit under this theme. The lack of privacy, having people involved in many aspects of their life, and the lack of spontaneity were ongoing stressors. Finally, aspects involved in the topic of dating and intimate relationships met the description of chronic hassles. Rachel sums it up well : "we've got all those (stressors that able-bodied people have) and then we got all those other ones, so it makes everything seem a little bit worse." The aspect common to all of the above-mentioned areas and representative of the theme is the chronicity. These stressors were not transient, or of short duration, but many of them were long-term stressors that the participants were facing on a daily basis.

C) Issues of control and having choices

'Issues of control and having choices' was apparent as a theme throughout many of the categories of stressors. Inherent are : a) the restrictions and losses of choices, options, as well as experiences; b) having to do things differently

compared to pre-injury; and c) the reduced degree of control over aspects of daily life.

The assistance required from others seemed to affect the participants' sense of control over their independence and privacy and restrict their sense of spontaneity. Rachel's comment applies : "there is always someone there, because they have to be there to help." The lack of accessibility also appeared to result in restrictions of choices and experiences. The lack of accessible and affordable transportation seemed to reduce their sense of control and restrict their options with respect to attending appointments, as well as vocational and avocational activities. The enormous financial expenses encountered following a SCI and the necessity to deal with insurance companies or government agencies appeared to yield a reduced sense of control over financial matters and limit options and plans made pre-injury. All participants seemed to experience the lack of an individual approach during rehabilitation as a reduced sense of control over meeting their needs as well as goals and as restrictions on choices and experiences. Brody's quote illustrates this point : "someone else is making your decisions, you're told how your programs run and why – they don't listen to what the client is trying to tell them." Also representative of the theme of 'issues of control and having choices' were restrictions on viable choices in vocations and avocations. With respect to intimate relationships and sexual relations, some aspects were no longer possible, others required a different approach. For Maria who is ventilator dependent even going out on a date was not possible without it being a threesome unless the date has medical training. For both women, the option of becoming pregnant seemed affected. Restrictions on the decision of how many children to have applied to both men and women. According to a traditional parenting role, some of the aspects involved such as not being able to care for their children on their own or physically teach them

sports were no longer possible, others were different.

D) Feeling isolated in the experience of disability

Because quadriplegia is not a shared experience with everyone, one of the inherent issues for the participants was continuously having to explain their disability to others. Also, by dealing with difference everyday, whether through the reactions from others, the hassles of transportation or accessibility, personal care issues, or the many others aspects of daily life which they approach differently compared to pre-injury and compared to able-bodied people, the feeling of isolation was an evident consequence. This feeling of isolation seems to be at the basis of the participants' comment that talking with individuals who are going through a similar experience is invaluable. The theme of feeling isolated in their experience of disability is described by the participants as "they (the general public) see you outside of the group of normal people", "people are scared of me", and "other people don't know what it's like."

E) Obstructions to independence

The last theme inherent in many of the categories of stressors presented earlier outlines the obstructions the participants encountered to their sense and pursuit of independence. The frustration regarding the lack of respect for their independence was evident in the attitudes and behaviours of strangers, attendants, and family members : "they want to help too much and don't seem to understand the meaning of the word 'no' – you waste so much time saying 'no, no, I can do it, don't' and they don't listen or respect it." The lack of accessibility of the environment also represented an ongoing frustration in their pursuit of independence : "some places and their bathrooms aren't accessible, so again your independence goes." The deficiency in accessible public transportation and the exceptional expenses involved in obtaining their own transportation were

further obstacles. The involvement of government and insurance bodies in the participants' lives as well as the agencies' lack of an individual approach also compromised the participants' independence.

Items of clothing such as belts, zippers, and buttons also restricted their independence for some participants. Store merchandise being too high up or too heavy hindered the participants' independence in shopping. A compromised sense of privacy and spontaneity also appeared to undermine their sense of independence. The participants' comments regarding the lack of an individual approach during rehabilitation evidenced obstructions to their independence. Included were the health professionals' restricted view on abilities, the lack of opportunities for self-determination, and the deficiency in community based skills training and information on community resources. Differences in the approach to dating and intimate relationships also seemed to undermine their sense of independence. The participants' comments with respect to alterations in body functioning and control evidenced an influence on their independence. Finally, health issues, including medical complications which may require the need for involvement of medical professionals at various times appeared to have the potential for compromising their sense of independence.

In summary, this chapter outlined the results of the study in 22 categories of stressors (ordered according to the sequence in which they were discussed by the participants) and 5 overarching themes. The narrative format of focus group reporting was utilized, relying heavily on direct quotes from the participants. The participants' suggestions of how stressors could be alleviated were presented at the end of each category of stressors.

Chapter V

DISCUSSION AND IMPLICATIONS

This chapter addresses some of the methodological issues inherent in obtaining the study's results. The results are then related to the theory of stress employed in this study. Next, the results and their implications are discussed and compared to previous research. Finally, directions for future research are proposed.

Focus Group Process Issues

The following section will examine some of the process issues of the focus group methodology used to obtain the study's results. As discussed earlier, one of the methodological issues in the measurement of stress with the traditional checklist format is its susceptibility to retrospective bias which involves the number and quality of events recalled, with the number found to diminish over time due to forgetting (Jenkins, Hurst, & Rose, 1979; Monroe, 1982; Uhlenhuth, Haberman, Balter, & Lipman, 1977). Also cited as a problem area is the failure of the participants' mood state at the time of the measurement to precipitate the recall of stressful events or situations (Bower, 1981; Clark & Teasdale, 1982). Both of these problems appear to have been alleviated through the use of the focus group methodology as the participants, through their comments, triggered in each other, issues that each person might not have remembered, or thought of, if questioned alone. Furthermore, a closely related factor to the issue of the mood state of the individual at the time of measurement affecting the recall of stressful events, involves the assumption critiqued by Bargagliotti & Trygstad (1987), that participants are aware of their stressors. Bargagliotti's and Trygstad's critique points out that some stressors are considered taboo subjects, others involve

chronic stressors which may not be readily accessible for recall. Both aspects hinder the spontaneous expression of stressors. The approach followed in this study elicited discussion on sensitive subjects as a result of trust building and homogeneity factors. The awareness of chronic stressors was facilitated by the fact that the participants triggered in each other issues which they might have not remembered on their own. This dynamic was verbalized frequently by participants commenting "that makes me think of", "that reminds me of", "yes, I had forgotten about that."

Another aspect of employing the focus group methodology which is noteworthy addresses a previous finding that the sources of stress delineated with quantitative versus qualitative methodologies differed (Bargagliotti & Trygstad, 1987). While the quantitative study identified discrete events as the sources of stress, the qualitative study described sources of stress related to interactional processes of events occurring over time. In the present study, both of these sources of stress were identified with the focus group methodology rendering the result more integrated and potentially more useful.

It is also noteworthy that the approach taken in this study with respect to the dynamics of interaction dissipated the potential detrimental effects of 'groupthink'. That is, the participants were asked to each address each issue that was raised and indicate whether the particular issue was stressful for them or not, which they all did quite autonomously as could be judged by the variability in the responses. This format is considered to have diminished, if not eradicated, any pressures felt by the participants to agree with the majority. This format also ensured more opportunities for equal input among the participants than would a format where participants respond in an arbitrary manner and not necessarily to each issue.

Finally, the depth and richness of the results, as well as the openness of

the participants and the intimate nature of the topics discussed, attest to the effectiveness of the focus group methodology, the participants as co-researchers, and the researcher as moderator.

Results Related to the Theory of Stress

The following paragraphs examine the results with respect to Lazarus' and Folkman's theory of stress (1984) employed in this research as well as with respect to some of the methodological problems encountered by previous stress researchers.

This study identified contextually meaningful categories of stressors, the lack of which was one of the methodological problems in the measurement of stress. Thoits (1987) attributed the inability to identify contextually meaningful categories of stressors to the restricted pool of event checklists where most checklists contain a common set of stressors generalized across population groups. Thoits also seriously questions the validity of such a generalization. This study responded to Thoit's calls for the generation of a 'unique stressor model' where specific experiences that define the type of stressors encountered by different groups of individuals are examined. The present study has generated a preliminary list of 22 categories of stressors experienced by individuals with quadriplegia living in the community.

With respect to Thoit's (1987) call for the generation of a 'unique stressor model', this pursuit, however, has to be addressed with caution. While such a model may serve well as a tool to promote an understanding of some of the stressors experienced by a specific group, for example, it should not be taken as an inflexible tool which is regarded as complete, or 'the way it is for everybody'. These words of caution address the model of stress employed in this study, namely that the stressfulness of an event is mediated by the meaning the

individual attributes to the event and that the same event may have different meanings to different individuals and to the same individual in different situations and at different times (Lazarus, Delongis, et al., 1985; Lazarus & Folkman, 1984).

With respect to Lazarus' and Folkman's (1984) theory of stress, the results of this study support the process of appraisal of stressful events as being affected by a series of person and situation variables. The following is an example of how beliefs and commitments, the main person factors, affect appraisal. Maria did not find it stressful to think that she would be unable to throw the ball around with her children or physically teach them sports. Chuck and Brody, however, found this thought stressful. Maria believed that the most important thing would be for her to be there and teach her children how to pick the position in which they would have to run the least. For Chuck and Brody the importance resided in the physical teaching role. Another example of commitments affecting stress appraisal is illustrated by Rachel's comment on employment choices. Rachel mentioned that if she had had her heart set on being a police officer and then suffered a SCI, rendering this career impossible for her, she would have found that quite stressful. Rachel also indicated that earning her own money during school was very important to her and not being able to do that because she could not return to her pre-injury part-time job and could not find other part-time work, was quite stressful for her.

In line with the beliefs about control regarding outcomes having the greatest effect on stress appraisals when situations are novel (Archer, 1979; Rotter, 1975), the following is noteworthy. For the participants of the present study, one of the factors which added to the stressfulness of certain situations was the lack of preparation for these situations prior to discharge from the rehabilitation centre. It can be hypothesized that if the participants had felt more

prepared for certain situations, the stressfulness of these situations would have been reduced by virtue of the fact that they would have expected them, been able to prepare for them, and thus also had more control over them. A number of issues which the participants found stressful were also those that were out of their control. Examples include the deficiency in a flexible, client-centered approach during rehabilitation, the perceptions of other people, some personal care issues, accessibility factors, and the dependence on others, including the lack of privacy in certain daily activities. These results which emphasize the importance of the role of control in determining the stressfulness of a situation are supported by disability research. Researchers examining the elements of the environment which most obstruct as well as most facilitate independent living according to individuals with physical disabilities found that the issue of greatest importance was control (Acheson Cooper & Risteen Hasselkus, 1992). The factors which were identified to enhance the sense of control over the environment in that study were attendant services, a barrier-free design, and technology. The results of the same study also outlined that with respect to independent living, having privacy contributed to the participants' sense of control. Moreover, a flexible environment with choices and opportunities for decision making affected the participants' sense of control. These researchers conclude that choice enhances well-being. The importance of control is also supported by an early study on productivity, an index of overall adjustment, which determined that individuals with a SCI who had active control over their lives were more productive as defined by activities of a constructive nature, including employment, avocational pursuits, and family responsibilities (Kemp & Vash, 1971).

Discussion and Implications of Results

This section analyzes and interprets the results, elaborates on their implications, compares them to other research, and presents some recommendations of how the stressors might be addressed. As encouraged by my discipline of study, I will, at times, interject my reactions and comments in this section. Where relevant, the findings of the present study will also be related to the programs at the local rehabilitation centre.

1) Attendant care

The first stressor identified by the participants of the present study was attendant care. The frequent turnover and potential unreliability of attendants seemed to translate into unpredictability and lack of control over attendant care and thus represented a source of stress. Another aspect seemed to be feelings of vulnerability as new attendants come into the lives of people who have a SCI and perform very private aspects of personal care. Initially this dependency on others may involve feelings of helplessness, panic, and desperation. It appears to be a challenge to work this other person into the perception of one's life. A good personality match between the individual with a SCI and the attendant seemed to be crucial in reducing the stress factor which attendant care can represent and be crucial to fostering a trusting, comfortable relationship.

Based on the participants' comments, the control that is lost by having to have another person involved in their personal care seemed to be regained somewhat by the practice of hiring on their own, rather than receiving care through attendant care companies. As was advocated by the participants, to maximize positive client attendant relationships, and to reduce the stress factor which attendant care presents, it seems crucial to offer relevant skills workshops prior to discharge from the rehabilitation centre. With respect to such

preparation, the BCRS, GF Strong site, does in fact offer workshops on attendant care, but only on the High Lesion SCI Program. Considering the fact that individuals sustaining a SCI are likely to have no prior experience with attendant care issues, workshops dedicated to this topic seem essential to everyone who has sustained a SCI and will be utilizing attendant care. The participants of the present study also regarded opportunities to interact with speakers with a SCI who live in the community and have personal experience in this area as crucial elements. Previous research supports the findings of the present study with respect to the difficulties that attendant care can present and emphasizes the need for training and the acquisition of relevant skills (Acheson Cooper & Risteen Hasselkus, 1992; Bach & McDaniel, 1993).

With respect to the issue of attendants having a hard time to change a routine or of wanting to help when they see their client struggling, the writer has the following comments. Such a reaction from attendants would seem to evidence the need to remember that what they are hired for is to be the hands or legs of the person with the disability. That is, to be there for the client, without an agenda of their own, even if that agenda is their own definition of how to be helpful. Inherent in this challenge to attendants is also an awareness of their own dynamics and motivations with respect to being an attendant. Being an attendant myself, I have become more aware of some of the aspects of my own agenda. For example, independence holds an important value to me. Hence, in assisting individuals with a SCI, I quite unconsciously promoted in my actions or words the pursuit of my own definition of independence until I realized that this was my own agenda and not at all that of one of the individuals with whom I was working, or, more accurately, this person had a different definition of independence.

2) People's looks, comments, and behaviours

Another finding of this study was the stressful nature of the attitudes of non-disabled individuals. One of the aspects which rendered the comments and behaviours of strangers as well as family members stressful was the apparent lack of respect for the participants' 'no, thank-you' to offers for help. The message from the participants of the present study seemed to be that able-bodied people need to be able to accept a decline to their offer for help, be able to see individuals who use wheel-chairs struggling and respect that as part of their independence.

As evidenced by the results of the present study, resisting the helping and caretaking role seems to prove especially challenging for parents who may feel that their caretaking role is enhanced following a SCI of their daughter or son. From the participants' perspective, having comments such as "if I want help, I'll ask" not respected and continually having to say "no, no, I can do it" is frustrating and leaves them feeling helpless. Thus, workshops for parents or other family members addressing their feelings, reactions, and ways of interacting with the individual who has sustained a SCI would seem especially important in reducing the stressfulness of these interactions. Of course, outside of the suggestion for workshops addressing the family's interactions with the individual who has a SCI, creating an opportunity for family members to share their feelings with respect to the SCI is important in its own right and has previously been advocated (Vargo, 1982).

Another stressful aspect of the reactions encountered from the general public was when the participants felt they were treated differently because they were sitting in a wheel-chair. Being judged, labeled, and confronted with difference daily can be isolating and affect their self-worth. In some situations involving the general public, the disability appeared to represent a license to invade the personal space of the participants by asking personal questions they

likely would not ask other able-bodied individuals. If individuals with a SCI do not feel prepared and skilled to handle such questions and reactions from others, feelings of being public property may result.

Previous research supports the finding of the present study with respect to the attitudes and behaviours of the public (Curcoll, 1992; English, 1971; Povolny, Kaplan, Marme, & Roldan, 1993; Ray & West, 1983; Rothschild, 1970; Wright, 1983). Wright (1983) offers one explanation for the focus on the disability being central to interactions with strangers :

> The situation where little is known about the person with the disability appears especially conducive to negative-spread effects ('the power of a single characteristic to evoke inferences about a person' [p. 32]). The fact that content is so sparse provides few constraints against perceiving the person as generally less endowed and less fortunate in an overall sense than the able-bodied. Such is the case between strangers. In the stranger relationship, the obviousness of a disability becomes the outstanding characteristic. (p. 73)

With the exception of the impact which education has, the reactions or inferred attitudes of others cannot be controlled. What individuals with a SCI can control, however, are their responses and reactions to those of the general public. Here, sessions devoted to skills of dealing with the various reactions which individuals with a SCI may encounter might serve to reduce the stressfulness of this factor. Role playing, for example, to develop a repertoire of answers with which to respond to some of the reactions from the general public may be one effective intervention. Also, speakers from the community who have a SCI were considered essential resources by the participants.

3) Accessibility

Another stressor identified by the participants was the lack of accessibility, restricting the activities and daily lives of individuals who use a wheel-chair. These restrictions involved not being able to get into some restaurants, stores, offices, houses, or to move about freely on sidewalks, trails, and the rest of the environment. Also involved was the extra planning ahead by phoning to make sure that a certain place is accessible. The fact that individuals who use a wheel-chair cannot take accessibility for granted seemed to represent a source of chronic stress. Feelings of segregation, isolation, and devaluation may all be consequences of the lack of accessibility. As demonstrated by the participants, accessibility also influenced their sense of spontaneity and independence. Increased awareness, education, and advocacy appears to be needed in order to continue to ameliorate this barrier.

The participants' comments with respect to accessibility are congruent with the perspective of the Independent Living Movement (social movement which supports the rights of individuals with physical disabilities to live outside of institutions) as well as the perspective of the author that the environment, including attitudinal or societal influences, contributes to the creation of a disability (DeJong, 1979). Moreover, Bach and McDaniel (1993), in conducting a focus group study on quality of life issues of adults with quadriplegia, have also delineated the problem which the uncertainty of whether places are accessible presents for individuals who have a SCI.

4) Transportation

Closely related to accessibility are the challenges of inadequate transportation identified by the participants. This deficiency in accessible, affordable means of transportation, restricting the lives of individuals who have

a SCI has also been previously reported (Yerxa & Baum Locker, 1990). Accessibility of the environment and accessibility with respect to transportation represent crucial elements in equaling the opportunities available to individuals who use wheel-chairs to those available to able-bodied individuals. Some of the potential implications of the lack of accessible, affordable transportation are feelings of isolation, inactivity, having a restricted social or leisure life, lack of spontaneity, freedom, and independence.

5) Finances

The multiple expenses resulting from a SCI represents another stressor delineated by this and other research (Bach & McDaniel, 1993; Dew et al., 1983; Yerxa & Baum Locker, 1990). As indicated by the participants of the present study, the type of insurance coverage determines the degree of problem which finances will present. Some of the potential psychological consequences of having to fight for necessities and being financially dependent on government or insurance services can include feelings of degradation and humiliation. According to the participants, it can also be very exhausting and chronically stressful to have to fight for necessities. Another aspect was that pre-injury plans and dreams may be lost to the extraordinary expenses encountered following a SCI.

6) Insufficient focus on the mental and emotional aspects during rehabilitation

With respect to the time during rehabilitation, the participants reported that it was stressful not, or very rarely, to have their emotional needs acknowledged or addressed. According to the participants, the rehabilitation program was 'physical' as opposed to 'mental' rehabilitation and thus left a significant gap in the rehabilitation process. This lack of opportunities for emotional expression, support, and the development of adaptive coping strategies can result in emotional and mental issues being 'shelved' and

maladaptive coping strategies being engaged. It is paradoxical that, according to the participants, the mental health and attitudes of individuals with a SCI are frequently criticized during rehabilitation, yet they are not addressed.

Simply put, there seemed to be no attention given to the impact of the SCI on the person's life. The fact that individuals who sustain a SCI likely come from an independent, active life, as did most of the participants, and are faced virtually overnight, at least initially, with the loss of that life, possibly with the loss of their self-definitions and roles, and with physical dependence seemed not acknowledged. There appeared to be no opportunities for support in negotiating a new or different self-identity, self-concept, and self-image, or for the impact of the SCI on self-esteem or sense of purpose. The mental tools that are needed to cope with their own reactions to the SCI as well as with the various reactions from family and friends, the rejection and alienation from society, and with the subtle message that society has rights which supersede those of the individual with a SCI seemed unexplored. Yet, it is the mental, emotional, and perhaps spiritual resources which the persons with a SCI utilizes in living in a society designed for, and dominated by, able-bodied individuals. According to the participants, the ability to see the numerous opportunities and challenges that are still possible and the fact that, as Chuck said, "you can lead a productive, active, and fulfilled life would have been important to be aware of from the beginning."

Another aspect of the lack of attention paid to mental and emotional aspects following SCI is the fact that an opportunity or support for the initial explorations of meaning attributed to the injury is not provided. The psychological and spiritual development which an event like a SCI may foster and which serves, for some people, as a way to transcend the injury, may also be hindered by the lack of an opportunity and support to engage in this process.

In the suggested focus on the mental and emotional factors following SCI, an individual, holistic approach, including consideration given to the collective pre- and post-injury experiences, goals, values, and attitudes of the individual is indicated. As identified in this study as well as by Carpenter (1991) there is a disruption post-injury between the inner self being the same and the outer self being radically altered ("you're the same, but") which may need to be addressed in order to facilitate integration. As was evidenced in the present study, family and friends can play important roles in connecting the past with the present and future as well as in reinforcing the individuals' self-concept by thinking about, and treating them, as Brody said, as "the same old prick, just shorter and more demanding." It is also noteworthy that in changing perspectives and in making meaning, individuals are confronted with our North American society placing high values on physical attractiveness and independence, assessing difference as inferior, and as Phillips (1990) describes, regarding individuals with a SCI as 'damaged goods'.

In terms of recommendations, all participants called for more sensitivity on behalf of health professionals with respect to "what the client with a SCI is going through." The participants strongly agreed that the presence of a staff member who also has a SCI is invaluable. While the BCRS, GF Strong site, does have a staff member as part of the High Lesion SCI Team whose role is a peer mentor, it is only on that team and not on the general SCI Team that this resource exists. The participants also emphasized that guest speakers with a SCI who have lived in the community for some time were extremely beneficial in gaining knowledge, understanding, and a feeling of support.

The importance of opportunities for communication with individuals who have been through the experience of SCI and its emotional and mental rehabilitation or with professionals who are trained in this area is evident when

one considers the following : as a standard part of living we may not have had to make meaning or sense of an injury such as a SCI, nor may we be aware of, or have reflected on, our assumptions or attitudes, their underlying reasons, or have done in-depth investigations into the make-up of our self-concept, our values, and goals – these aspects seem to be intrinsic parts of life that we ordinarily may not have put under a microscope, but this is exactly what individuals with a SCI may be engaged in at some point following the injury. The proposed interaction and support gained by talking about their experience of SCI may aid in assembling the disability as part of the individuals' life continuum, rather than leaving it as a focal point. This contact and support may also ease the potentially quite unsettling and emotionally charged process of challenging long-held assumptions which may have important connections to the very nature of who an individual is. Due to the shared nature inherent in this contact, it may also add significance to the process of reassessment and growth.

In support of the importance of opportunities for emotional and mental rehabilitation, several researchers suggest that attention to emotional and mental issues such as self-perception and self-acceptance have a far greater impact on personal and social adjustment than physical ability (Carpenter, 1991; Trieschmann, 1988; Zola, 1981). While important foundations can be laid by addressing the mental and emotional aspects following SCI during rehabilitation, it seems equally important and perhaps even more so that opportunities to continue this process after discharge exist.

7) Lack of individual approach during rehabilitation

Another stress factor identified in the study was the lack of an individual approach during rehabilitation as well as in dealings with insurance companies,

or the Ministry of Social Services. During rehabilitation, the attitudes of health professionals, being told 'you can't', and having unnecessary limits set on them seemed to foster a lack of belief in the participants regarding their own abilities and resulted in restrictions on their capabilities. Also, someone else was making their decisions, the participants reported. Implications of this lack of an individual approach during rehabilitation involved the loss of independence and self-determination as well as depersonalization and devaluation. The lack of respect for the uniquely adult characteristic of self-determination suggests that the participants were no longer regarded as adults, but as inferior, and according to them, as "kids" and "paras, quads, apes, that's about how you are treated."

Thus, during rehabilitation, the participants were not only dealing with the insult on their sense of control over their body and lives, but also on their autonomy and self-determination. The participants stated that any deviations in their actions, feelings, or attitudes from the expectations of rehabilitation professionals resulted in being labeled 'non-compliant', 'difficult', 'unmotivated', 'not adjusted', or 'in denial'. In support of the importance of a client-centered, individual approach, Carpenter (1991) stated :

> Terms such as adaptation, coping, and adjustment ... are defined differently by each individual who sustains a SCI and failure to recognize these differences leads health professionals to develop preconceived ideas about the psychological reaction to SCI, and the roles patients should adopt during rehabilitation. (p.30)

The lack of an individual approach and treatment in accordance with preconceived ideas of acceptable client roles and reactions seems to imply that individuals who have sustained a SCI are suddenly required to separate themselves from their defining characteristics, their experiences, history, attitudes, values, and goals which made them who they are and all that is

relevant and by which they are now defined is the physical injury. By focusing all attention on the injury, the initial and more in-depth incorporation of the event of SCI into the context of the person's life, where the disability is part of the picture, rather than the whole picture, seems hindered. Carpenter (1991) stated :

> This emphasis [on] overcoming physiological and physical disability reinforces the success-as-normalization perspective inherent in current rehabilitation programs... Those who continue to strive for the goal for social 'norm' and to some degree achieve that goal are viewed as 'supercripples' and singled out as having exceptional courage. By implication this devalues other people with a disability who are unable, or do not have the desire, to define their lives in terms of society's 'norm'. By acquiescing to the perspective of 'normalization' the individual's learning processes become blocked by the traditional and stereotyped definitions of success inherent in it. (p. 94)

Carpenter (1991) emphasized that "the concept [of normalization] also denies the validity and value of the disability experience as a significant life event which is assimilated into an individual's life, and which may trigger transformative changes and psychological growth" (p. 179). This focus on physical aspects and on 'normalization' may also translate into viewing situations and life from the perspective of what individuals with a SCI cannot do versus what they can do and may result in feelings of inadequacy, loss of self-esteem, and self-worth. Carpenter's (1994) findings regarding the frustrations with respect to the limiting consequences of the approach by rehabilitation staff, focusing on expected accomplishments related to injury levels, are mirrored by the findings of the present study. Carpenter's interpretation of the consequences of this outlook apply : "this narrow view of individual potential subtly undermined the subjects' own sense of competence and ability to make decisions

in the new context of their lives" (p. 620).

The comments from the participants of the present study also evidenced their challenge of the perspectives of health professionals : "some people you say 'can't' to and they go, 'okay', but other people they go, what do you mean 'can't' and prove them wrong." This dynamic of addressing the attitudes of rehabilitation staff has also been identified by Carpenter (1994) which she presents as part of the theme of 'redefining disability'. Such findings illuminate the discrepancy that exists between the perceptions of rehabilitation professionals pertaining to SCI and its implications and those of individuals who have sustained the SCI. These findings also support the importance of addressing this discrepancy especially considering the fact that the attitudes of health professionals can have a powerful impact on the newly-injured individual who may be especially vulnerable to these attitudes.

The findings of the present study as well as those of Carpenter (1991) identify a paradox : during rehabilitation attitudes of dependence and paternalism seem to apply, yet the goal of rehabilitation is, and community living requires, a sense of independence and control. Resolution of this paradox seems critical in matching the rehabilitation approach with what is needed upon discharge.

It seems evident from the results discussed so far that more empathy and flexibility by rehabilitation staff is required so that the needs and goals of each client are respected and addressed. Numerous researchers have identified these deficiencies in a client-centered approach to rehabilitation and called for changes in approach (Acheson Cooper & Risteen Hasslekus, 1992; Carpenter, 1994; Trieschmann, 1988; Vargo, 1982). Researchers in occupational therapy remark that "as a profession, we are still learning how to manage the delicate balance between the use of our expertise, training, and experience, and clients' rights to

set and meet their own priorities in treatment" (Acheson Cooper & Risteen Hasselkus, 1992, p. 7). Vargo (1982) has identified rehabilitation programs to be mainly concerned with the client being co-operative with respect to the goals and policies of the rehabilitation centre. He has also advocated the need for "a philosophy of client as co-manager" (p. 2). Richmond and Metcalf (1986) have emphasized the need to approach individuals with a SCI as "having individual needs, desires, hopes, coping strategies, and intellectual capacity" (p. 183). Carpenter (1991) suggested that "in acknowledging the individual with the disability as ultimately the most knowledgeable person, researchers could assist in the integration of the physical, psychosocial and personal dimensions of rehabilitation to the benefit of both the individual and rehabilitation practice" (p. 44).

8) Change from a schedule to no schedule

The lack of preparation for the transition from institutional to community living has also been previously documented (Dew et al., 1983; Trieschmann, 1988). For the participants of the present study who did not return to school following their discharge, the effect of the loss of a routine such as boredom, the feeling of loss of control over their life and the uncertainty of what to do with their time day in and day out seemed to be felt strongly. Coping strategies such as alcohol abuse were frequently engaged by some. In order to ease the transition from the rehabilitation centre to community living, it seems especially important, at the point of discharge, to have access to support from other individuals who are going through similar experiences or have gone through them in the past. Group support sessions for individuals with a SCI making the transition to community living may be beneficial here. In addition, exploring and planning what individuals would like to do with their time prior to

discharge is also indicated.

9) Insufficient information on community resources when leaving rehabilitation

As did the previous section, this section also addresses the lack of preparation for community living. In addition to the importance of knowledge of community resources in its own right, information can also enhance the individual's sense of control and security which seems relevant following a life-changing injury such as SCI. A manual with the various community agencies and contact people relevant to individuals with a SCI would seem to be a useful resource.

10) Approach to alcohol and drugs during rehabilitation

The participants also identified the lack of resources for alcohol and drug problems during rehabilitation as well as the rehabilitation centre's zero tolerance policy as sources of stress. The need to address alcohol and drug abuse at the rehabilitation centre and thereafter is emphasized by the participants' comments regarding the connection between alcohol as well as drug abuse and SCI. This connection is supported by other research documenting high percentages of pre-injury and post-discharge substance abuse (Heinemann, Donohue, Keen, & Schnoll, 1988; Young, Rintala, Rossi, Hart, Fuhrer, 1995). For example, among 75 individuals with a SCI assessed at a rehabilitation centre, 91% reported drinking prior to the injury, 53% reported drinking at 6 months post-injury, and 67% reported drinking 18 months after the injury (Heinemann, Doll, & Schnoll, 1989). While the prevalence rates of alcohol abuse among men with a SCI are reported to be higher than those of the general population, estimates vary from 23% to 73% compared to 16% among men of the general population. For women with a SCI, prevalence rates were 13% compared to 5% among women of the general population.

Among the variables related to alcohol abuse were that participants experienced more stress, were more depressed, and perceived their overall health to be worse than those who did not abuse alcohol (Young et al., 1995). Young et al. emphasize that prevalence rates of alcohol abuse of one in five individuals with a SCI living in the community necessitates screening, treatment, and referral as part of rehabilitation programs.

With respect to the rehabilitation centre's current zero tolerance policy, the participants of the present study had numerous comments. They felt that it implied the lack of a "normal life" during rehabilitation, not being treated as adults, someone else making their decisions, and the lack of experience and knowledge of how to deal with the reactions to alcohol after SCI. Linked to the fact that the rehabilitation centre's approach to alcohol does not recognize their clients as adults is its inherent degrading and punitive response. This approach also does not appear to foster independence, or a sense of control, or to be helpful in preparing for 'real life' with respect to alcohol after discharge from the rehabilitation centre.

11) Weather

Weather represented another source of stress for the participants. This is an example of an issue which can be a nuisance also for able-bodied individuals, but is exponentially more so for individuals who use a wheel-chair. Snow, for example, may imply that individuals with a SCI, are unable to be mobile in their chairs. Rain can also restrict activities as it is difficult to wheel with wet hands and wet tires and, it is uncomfortable to be wet. An umbrella cannot be held, rain-capes are bulky and may impede pushing the chair, or be avoided for esthetic reasons. Even high temperatures posed problems for some individuals with a SCI as they can lead to medical complications.

12) Clothing

An issue related to weather is that of clothing. Participants described the problems they have in shopping for and wearing clothes. In shopping for clothes the nuisance of being dependent on someone to come along was a potential issue. Other problems included the lack of opportunities to try clothes on, the need to be aware of and select clothes with the danger of pressure sores in mind and, for some people, with the ease of being able to dress oneself independently in mind. Restrictions in the choice of clothes can be a consequence of the latter two aspects and may require some creativity and problem solving.

13) Grocery shopping

Grocery shopping was another stressor for the participants. As applied to the last section on clothes, one of the frustrating aspects was the dependence on others for assistance.

14) Lack of privacy

The lack of privacy in various aspects of their lives was stressful for the participants. Whether restrictions with respect to privacy were a result of the personal care required or due to government or insurance bodies prying into all parts of their lives, or due to other factors, this was an ongoing stressor experienced by all participants. Closely related to the lack of privacy seemed to be the lack of physical independence. Dealing with the lack of privacy and finding ways to reduce its stressfulness could be part of the proposed attention given to the emotional and mental aspects of SCI.

15) Lack of spontaneity

Related to the lack of privacy, the lack of spontaneity also represented a source of chronic stress for the participants. Restrictions on their ability to be

spontaneous may exclude individuals with a SCI from plans made by friends on short notice. The need to plan many activities of daily life and personal care may not have been an area of strength pre-injury, can be annoying, and seemed to restrict their sense of freedom and creativity. If individuals with a SCI value their sense of spontaneity, they may need to find different ways to satisfy this preference and attribute. As did the lack of privacy, the lack of spontaneity also seems to fit under the suggested focus on the emotional and mental aspects of SCI.

16) Dating

All participants agreed on the stressfulness of initiating and sustaining intimate relationships. With respect to the last section on spontaneity, one of the aspects of intimate relationships which was stressful for the participants was the lack of spontaneity. Also, in communicating the details of the disability with respect to an intimate relationship to someone with no prior knowledge, the onus is on the individual with a SCI. This can be challenging, stressful, and represents "just one more step in the extra things we have to do." The fear of the person's reactions to the details of what the disability involves in an intimate relationship was another stressful aspect addressed by the participants. One of the reactions, rejection, may be experienced more frequently post-injury than pre-injury and may warrant the need for skills and tools of dealing with it. As mentioned by the participants, for some able-bodied people the visibility of the physical disability may be perceived as dependence, care-taking, and being needy to the exclusion of an appreciation of the ways in which the person with a SCI is independent.

For the person with the SCI intimate relationships may involve losses and changes in experiences such as feeling touch, reciprocating hand-holding, even

sitting on a couch may be affected. The way love is expressed and felt may change both for the individual with a SCI and for his/her partner. Making love likely needs of be approached differently than pre-injury and the need for tools as well as the lack of control over body functioning and movement can be humiliating and affect the person's self-esteem and body image. In an intimate relationship the separation between the care-taking role and the role as partner and lover may present challenges for the able-bodied partner. The additional challenges faced in this area by individuals with SCI and their partners evidence a need for exploration, support, and the development or enhancement of personalized skills in dealing with the aspects involved in dating and intimate relationships. Good communication skills would seem to play an important role.

The findings of the present study with respect to the difficulties dating and intimate relationships can present are also supported by previous research (Carlson, 1979; DeVivo & Fine, 1985; Dew et al., 1983; Povolny et al., 1993; White et al., 1992). For example, in equating dissatisfaction with stress, the findings of Carlson as well as White et al. who assessed the life satisfaction of 54 and 79 men with a SCI, respectively, indicated that the respondents' dissatisfaction, or stress, was greatest in the area of intimate relationships. Researchers investigating the impact of SCI on marital status have also found fewer marriages and more divorces compared to the general population (DeVivo & Fine, 1985; DeVivo, Hawkins, Richards, & Go, 1995; DeVivo & Richards, 1992; Dew et al., 1983).

17) Bowel and bladder accidents and related stressors

Body functioning was another source of stress for the participants. This issue seemed to affect the participants in a number of ways. First, there was a need to be closely aware of and monitoring the state of their body which seemed to translate into being at its disposal to a certain degree and meant that planned

activities might have to be changed on short notice. Second, the fear of an accident happening was very stressful and often lead participants to cancel plans if they "didn't feel right." Third, other people being involved in these private aspects of personal care "takes some getting used to." Forth, the inaccessibility of public washrooms affected the participants' independence. Fifth, socialized attitudes that this subject is "taboo and not normal" may foster feelings of humiliation and degradation in the individual with a SCI.

18) Challenges of independent living

The challenges of independent living were described as another stress factor by the participants. The effort and time factors involved in doing aspects of daily living independently were, at times, exhausting to the participants. This issue seemed two-sided, though, in that the participants reported that doing things independently made them feel better about themselves, but at the same time, the extra time and effort involved was also draining. The participants felt that some preparation for aspects of independent living prior to discharge would and did alleviate their stress factor. An important part in this preparation were discussions with individuals who have a SCI and live in the community.

19) Crowds

One of the aspects which made crowds stressful for the participants was not being noticed by virtue of the fact that they are not at the same height as able-bodied people walking. An extension of this dynamic is the fact that individuals who use wheel-chairs are always being looked down to when interacting with people who are standing. Potential feelings of frustration and anger with respect to not being noticed, being insignificant in crowds may have lead to some of the assertive and perhaps even aggressive ways of dealing with crowds described by the participants.

20) Health

Further on the list of stress factors addressed by the participants are health issues. In support of this finding other researchers (Dew et al., 1983) have determined that recurrent physical problems are frequently experienced by individuals who have a SCI. For example, individuals with a SCI are at a higher risk for certain medical conditions and are prone to bladder infections and pressure sores (Zejdlik, 1992). More care needs to be invested in maintaining health than pre-injury which can represent a source of chronic stress. Health has also been delineated as an important factor with respect to quality of life issues (Bach & McDaniel, 1993) and ill health has been identified as a fear and worry of individuals with quadriplegia by Yerxa and Baum Locker (1990).

21) Having children

Thinking about and exploring the possibility of having children was another stressor experienced by the participants. For the two women the fear and uncertainty of the effects of pregnancy on their bodies were stressful. If the choice is made not to become pregnant there will be the loss of this experience to face. In the area of parenting there are further losses and changes of experiences and activities. The challenges faced by individuals with a SCI in this area support the need for an exploration and focus on this topic at the rehabilitation centre and post-discharge.

22) Employment

A surprising finding of the present study pertained to employment. With the exception of the comment that it was hard to find part-time, student employment during the summer, and that age played a role in the ease of finding permanent employment, the participants were quite optimistic with respect to finding employment. This finding seems to contradict that of previous

research (Dew et al., 1983; Yerxa & Baum Locker, 1990) which has identified the lack of finding employment as a frequent problem among individuals who have a SCI. However, as the age of the participants in the study by Dew et al. ranged from 20 to 83, conclusive comparisons between the findings of the present study and their study cannot be drawn. It is interesting to note, however, that in the study by Dew et al., among the major problems cited in preventing the participants from obtaining or maintaining employment were the loss of financial benefits and transportation which are also supported by the results of this study. Moreover, it is interesting that, with 20% of the participants in the same study being employed, only 43% of those who were unemployed were interested in working if any identified barriers were removed. This finding stands in contrast to that of the present study where all participants wanted to work and either did work or were in the process of seeking employment.

In the study by Yerxa and Baum Locker (1990), the ages of the participants were also substantially higher than those of the present study, rendering comparisons inconclusive. Contradictory to the results of the study by Dew et al. (1983), indicating a low interest in work by individuals who have a SCI, and in support of the findings of the present study, Yerxa and Baum Locker found that individuals with a SCI had more vocational goals, including earning a living or finding a new job, compared to non-disabled individuals.

One of the implications of the inability to physically perform a certain job mentioned by one of the participants was the loss of a dream or planned career. Furthermore, since society puts a high value on work and many people define themselves by the work they do, having difficulties or being restricted in this area can have repercussion on the individual's self-esteem and self-worth.

<u>Overarching Themes</u>

The following comments address the overarching themes outlined previously by elements that are common to several of the categories of stressors. Participants' suggestions as to how the stressors could be ameliorated will be included as will literature which addresses the findings of the present study. As in the last section on the categories of stressors, the author will comment on the themes as well as on the suggestions of how the stressors could be addressed.

<u>A) Insufficient preparation for various issues prior to discharge from rehabilitation</u>

The first overarching theme which appeared in many of the categories of stressors describes the participants' feelings of being unprepared for many of the experiences they encountered upon discharge to the community. This lack of preparation implied that many aspects of community living were unknown. This lack of knowledge seemed overwhelming and, at times, to be accompanied by feelings of a loss of control over the environment. Skills to deal with the impact of the transition from institutional to community living are needed both on an emotional and mental level as well as on a practical level. However, in addition to a more comprehensive, real-life preparation for community living, the philosophy that rehabilitation ends with the discharge from the rehabilitation centre may need to be examined. According to the participants' comments as well as other research (Carpenter, 1991) some of the greatest difficulties and opportunities for growth were experienced upon return to their life upon discharge. This may also be the time when individuals are engaged in addressing mental and emotional issues following SCI in more depth and dealing with the impact of SCI on the various aspects of their lives. For example, the loss of, or need to modify their sense of purpose may be faced as may be the

process of re-defining their self-concept, self-identity, goals, values, priorities, and making meaning out of the injury perhaps by renegotiating society's definition of normality and establishing their own criteria.

As mentioned earlier, group meetings for individuals with a SCI making the transition to living in the community would be one resource that may be beneficial at this time. An important part of these meetings would be speakers with a SCI who have lived in the community for some time. These meetings could serve functions of support and gaining skills as well as knowledge of resources and thereby ease the transition. This resource may also serve to narrow the gap identified between the end of the official rehabilitation process as experienced in the rehabilitation setting and the beginning of the real-life, life-long process of learning engaged in when living in the community. The proposed meetings may further aid in narrowing the gap between what was taught in the rehabilitation centre and what is necessary upon living in the community.

Among the specific issues which, according to the participants, are in need of enhanced preparation and skills at the rehabilitation centre are as follows. First, the need to "explain it all every time" they met new attendants, friends, and dates was a stress factor for which they did not feel prepared. Here, communication skills, possibly assertiveness skills, and role plays to develop a repertoire of answers or approaches might be beneficial in better preparing clients for this stressor. Second, the participants indicated that they were unprepared for the stressor entitled 'change from a schedule to no schedule' and to boredom. Here, an exploration and planning of what the individuals would like to do with their time may be appropriate. Similarly, the participants felt unprepared for the change from the lack of opportunities for self-determination during rehabilitation to the need for it post-discharge. Third, the participants did not feel

adequately prepared with respect to information on community resources such as financial help, transportation, recreation, and other resources available to individuals with a SCI. The participants' suggestion here as well as with respect to the experience of SCI in general, was to bring in speakers from the community during rehabilitation and, upon discharge, to be connected with someone who lives in the community and "has been through it", "like a buddy system, who can give helpful hints, and knows what it's like." Forming such links to ex-clients has also been advocated previously by Vargo (1982). The invaluable nature of such a connection is also supported by the comments of the participants in Carpenter's (1994) study. Although this role is intended to be fulfilled by a BCPA counsellor and the participants agreed that the concept of such a counsellor was a good one, most did not find the liaison effective. The participants attributed their assessment of this lack of effectiveness to the lack of a similar injury, the lack of a personality and age fit, and the lack of knowledge of resources and relevant information.

With respect to the lack of information on community resources identified in this section, this seems to be an aspect where some progress has been made since the participants' experiences. For example, the author is aware that the High Lesion SCI Team at the rehabilitation centre does hold education sessions on community resources and gives out relevant written information. In addition, I am told that the BCPA now gives out a booklet on community resources (Gursh Sall, personal communications, August 23, 1995).

The results of the present study with respect to the participants' feelings of being ill-prepared for life in the community are representative of findings from previous research. Numerous researchers have indicated that a large proportion of rehabilitation was accomplished after discharge and that rehabilitation programs did not teach the necessary practical skills which could ease adjustment

(Carpenter, 1994; Dew et al., 1983; Felice, Muthard, & Hamilton, 1976; Morgan, Hohmann, & Davis, 1974; Trieschmann, 1988). Carpenter and Trieschmann support the findings of the present study by regarding the rehabilitation program as deprivational where individuals are cut off from their social life. As was advocated by the participants of the present study, as well as by Carpenter (1994), targets of education programs involving individuals with a SCI as educators need to include health professionals and, among them, both those working in direct client care as well as those working in policy and decision making capacities. Such course of action is expected to result in the development of "more relevant programs in which content and instruction are directed by the goals identified by the clients, reinforced by those who have experienced the injury, and provided in the real-world setting" (Carpenter, 1994, p. 627).

Craig and Hancock (1994) assume a preventative standpoint in advocating the importance of psychologically preparing individuals with a SCI for challenges that may be encountered in the community. Furthermore, a study by McHugh Pendleton (1990) identifies independent living skills training ("specific abilities broadly associated with home management and social/community problem solving" [p.94]) during rehabilitation, for those individuals who have not yet achieved them, as the most needed and valued (by the consumers), but least addressed factor. Interestingly, the same study found a statistically significant relationship between the occupational therapists' time spent providing independent living skills training and their self-perceived locus of control measure. The more individuals felt controlled by external circumstances, the smaller the amount of independent living skills training they provided to their clients with physical disabilities at the rehabilitation centre. Even the clients' diagnoses were found to be significant predictors of the amount of independent living skills training provided. While individuals with a SCI were

not among the predictive client groups, individuals with cerebral palsy served as positive predictors for independent living skills training whereas individuals with diagnoses including cerebral vascular accident, fractures, and other medical problems were negative predictors of independent living skills training. These results illustrate the importance which personality factors as well as perceptions play in our interactions with clients.

With respect to feeling insufficiently prepared for various issues prior to discharge, the participants of the present study acknowledged, though, that it is impossible to address all potential stressors, obstacles, or problems at the rehabilitation centre. Thus, a general approach that addresses individualized strategies of how to deal with chronic stressors, using commonly encountered examples, seems appropriate and would teach skills, such as stress management, communication, planning as well as problem solving skills, and the like that are applicable or generalizable to a wide variety of situations. With regard to communication and other social skills, Charlesworth and Nathan (1984) identified that the lack of interpersonal skills contributes to stress in work, family, and social encounters. Furthermore, assertiveness skills, including speaking up for oneself, asking for assistance when necessary, and directing others in their care, have been identified by Bach and McDaniel (1993) to be important to the quality of life of individuals with quadriplegia. The same researchers also point out that assertiveness is not a characteristic or skill which is generally supported by rehabilitation staff.

McHugh Pendleton (1990) also advocates the teaching of generalizable skills such as problem solving at the rehabilitation centre so that these skills can be applied to new problems that arise when living in the community. She further promotes the development of community based programs so that the needs of individuals with physical disabilities could be more adequately

addressed. Vargo (1982) has also called for the development of a system that helps the individual adjust from institutional living to living independently in the community. This should, according to Vargo, include a resource centre for information, assistance with independent living skills, and counselling at any stage of the adjustment process, including personal and family support services.

The interpretation of the above-mentioned comments regarding the theme entitled 'insufficient preparation for various issues at the rehabilitation centre', needs to be addressed with caution, however. This comment refers to the need of a rigorous discussion to take into consideration alternate explanations for some of the findings (Krueger, 1994). For example, with regard to some of the topics raised in this section, health care professionals may have addressed certain information and taught certain skills, but the timing of this interaction or the number of repetitions, if repetition did occur, may have not been appropriate for maximal uptake and retention and hence not have been remembered. This comment does not, in any way, affect the credibility of the comments from participants of the present study or from previous studies, but simply points out that there are effective and ineffective timing and ways to present information or teach skills. Further investigations into what information or practical skills are taught, when, how, and how much of this information is retained seem needed. Such investigations would appear to be crucial steps in rendering the rehabilitation program maximally effective and thus making adjustment easier for clients. An assessment of the learning style of each client and the presentation of information in line with this style would also appear to be most useful.

Next, the author wishes to address her personal experience with two aspects of the participants' suggestions. First, the participants' recommendation was to invite guest speakers for group discussions on various relevant issues.

Having organized such meetings at the rehabilitation centre, it proved very difficult to get people interested and often only one, two or three people would participate. It was interesting, though, that on one occasion when I had organized a meeting with a guest speaker, only one person agreed to attend the discussion, but when the guest speaker was ready to leave and sat in the hallway talking to the other participant and me, three other people came and joined us and continued the discussion, covering the intended topics, on their terms. Possible explanations for this occurrence are that when approached initially, the group meeting represented yet another meeting scheduled by staff and thus was not appealing to clients. When the three clients joined, it was on their initiative and on their terms (i.e. not in a designated room, but casually in the hallway). I also hypothesize that more participants may have attended such a meeting if one of the clients had organized it. Other researchers (Craig & Hancock, 1994) also support this finding of low attendance in SCI group programs and have delineated some of the factors involved as well as possible solutions which are described in Appendix H. It is noteworthy, however, that while high attendance is an ideal goal, this should not be at the cost of disregarding the importance of only one or two clients benefiting from a discussion who may, in fact, then advocate the program to other clients (Marjorie Griffin, personal communication, June 7, 1995).

The second aspect regarding the participants' recommendations which I wish to address is the widespread problem affecting suggestions for programs at the rehabilitation centre – staff constraints. Provisions for sufficient numbers as well as appropriately qualified staff are thus fundamental issues in need of being addressed.

B) Chronic hassles

The second overarching theme, 'chronic hassles', identified in the current study illustrates the fact that many of the categories of stressors are interrelated. For example, in the present study, the lack of spontaneity which can be regarded as a chronic hassle, relates to accessibility, transportation, weather, attendant care, body functions, and intimate relationships. The overarching themes and in particular the theme entitled 'obstructions to independence' also evidence connections between several stressors as will be identified in a later section. This finding reinforces the need to view the approach to disability with multiple perspectives.

The theme entitled 'chronic hassles' also emphasizes the importance of having personalized, effective ways of dealing with chronic stress and, as did previous research, advocates the need for opportunities for support and counselling both during rehabilitation and thereafter (Craig & Hancock, 1994; Miller, 1993; Richmond & Metcalf, 1986; Trieschmann, 1988; Vargo, 1982; Zejdlik, 1992). Numerous researchers called specifically on the use of group counselling for interpersonal support and skills training (Craig & Hancock, 1994; Kemp & Vash, 1971). It is important to note that provisions for psychological services are advocated by the participants of the present study and other consumers (Lightpole, 1991; Pelletier, Rogers, & Thurer, 1985). The results of this study and other research which demonstrated that the passage of time since injury did not allay the distress experienced by 53 individuals who have a SCI (Frank & Elliot, 1987), further emphasize the significance of fostering in clients the development of skills to deal with chronic stress. The view of adjustment as a life long process (Trieschmann, 1988) and reports from researchers who have indicated there to be a substantial psychological and health cost to dealing with chronic stressors also support the critical nature of possessing skills to deal with chronic stress.

C) Issues of control and having choices

Losses of, or restrictions on choices, experiences, and control as a result of SCI were frustrating, infuriating, and upsetting for the participants. Dealing with these issues may be challenging and involve negotiations with respect to the individual's sense of self. As was identified earlier, the participants felt that restrictions on their self-determination, choice, and control began at the rehabilitation centre. Another aspect of the lack of choice was that upon injury individuals may suddenly be confronted with the fact that another person is permanently involved in very personal aspects of their life and is part of their life. Furthermore, dealings with insurance companies or government services may now also be part of their life and financial coverage can determine their lifestyle. Independence, privacy, spontaneity all may take on new definitions. The environment poses restrictions on access to places and participation in activities. Some vocational and avocational activities are no longer possible.

In Carpenter's (1991) study, one of the themes identified in her interviews with individuals with a SCI which relates to the theme 'issues of control and having choices' of the present study is 'redefining disability'. This was achieved according to Carpenter by a) becoming aware of their world, and self view which was seen as the first step toward gaining a sense of control and choice over their lives; b) challenging the attitudes and stereotypes held by rehabilitation professionals as well as society; c) attributing meaning to the injury; d) expanding the range of options and possibilities; and e) developing a modified sense of identity, goals, and values which was also evidenced by the comments from the participants of the present study. The components of the theme 'rediscovery of self' identified in Carpenter's study is also represented in the present study. They include achieving knowledge and control regarding the injury and its implications, ignoring the limits imposed by the expectations of rehabilitation

staff, determining their own definitions of "what's possible" and charting their own life course. Part of this process seemed to be also self-actualization which was evidenced in the comments from the participants of the present study by "being bigger and better than I ever was before."

D) Feeling isolated in the experience of disability

The need to do things differently compared to pre-injury and compared to able-bodied people reinforced by environmental, societal, and attitudinal barriers can lead to feelings of isolation. In this regard the results of the present study as well as those of other research (Carpenter, 1994) have emphasized the importance and essential nature of the support from, and connection to, peers who "have been through it." Despite the identified importance and benefit of peer support as well as the willingness of individuals with a SCI to serve as resources to newly injured individuals and health professionals, this resource seems underutilized. The underutilization of resources deemed essential by the participants of the present study and previous research indicates that rehabilitation professionals are important targets of educational programs. The goals of such programs, containing the perspectives of individuals with a SCI, would be to promote greater understanding of the experience of SCI and greater awareness of the approach and resources deemed essential and effective by individuals with a SCI.

Another aspect inherent in the feeling of isolation in the experience of disability pertains to elements of the present study which Carpenter (1991) has labeled 'rediscovery of self', 'redefining disability', and 'establishing a new identity'. By their very definition, these themes imply a very private, personal process. Also, the process of making meaning of the experience of SCI involved in these themes is intensely personal and seems to implicate a certain degree of

isolation as part of these endeavors following SCI.

E) Obstructions to independence

According to the participants, obstructions to their independence were evident at the rehabilitation centre where self-determination was neither encouraged nor supported and skills as well as information fostering independence were lacking. It continued with the attitudes of family members who had difficulties respecting the participants' decline to their help. The consequences of the injury itself of course also restricted independence and may change how independence is defined. The participants' compromised sense of privacy and spontaneity affected their sense of independence. Changes in independence surfaced prominently in dating and intimate relationships. Environmental obstructions such as the inaccessibility of buildings and other parts of the environment, the inaccessibility of methods of transportation as well as societal obstructions such as the attitudes and services provided by government and insurance agencies represented further obstacles.

In addressing these obstructions to independence, individuals with a SCI and individuals interacting with them, including professionals, family and friends, as well as the environment need to be considered. With respect to the individual with a SCI, opportunities to, and support in, redefining independence may be needed. With respect to individuals working or interacting with individuals with a SCI, raising their awareness and knowledge around obstructions to independence seems indicated. The latter could involve in-services, workshops, one-to one education, and in the case of family members, be part of the family education and support proposed at the rehabilitation centre and in the community. In terms of the environment, continuing to reduce architectural and attitudinal barriers would seem to contribute to ameliorating

the obstructions to independence described by the participants.

In review, this chapter covered a discussion of the methodological issues in obtaining the study's results. It related the results to Lazarus' and Folkman's (1984) theory of stress. It presented a discussion of the 22 categories of stressors and 5 overarching themes, including their implications, suggestions for how the stressors could be addressed, and comparisons to previous research.

Conclusion

In the present study 5 individuals with quadriplegia identified 22 categories of stressors and 5 overarching themes, the latter containing elements that were repeated in many of the categories of stressors. Some of the stressors related to the participants' experiences in the rehabilitation centre, others were representative of experiences while living in the community. Numerous stressors related to feelings of being unprepared for stressors and experiences encountered upon discharge to the community. Several stressors could be identified as chronic hassles. The theme entitled 'issues of control and having choices' was representative of several categories of stressors ranging from the approach during rehabilitation to accessibility issues. The participants' comments in several of the categories of stressors also evidenced feelings of isolation in the experience of disability. Finally, the environment and the obstacles faced in the pursuit of an independent lifestyle were commonly encountered stressors. With respect to the focus group technique employed to achieve the study's results, it was critical to obtaining the depth and richness of the findings as was the participants' openness fostered by this technique and the researcher.

It seems important to note and remind the reader that the purpose of this study was to identify stressors and that this focus may have drawn a 'negative' or 'overwhelming' picture. Therefore, it is important to remember that the other

part of the participants' lives, their joys, satisfactions, and accomplishments were not described, but very much existed as supported by comments such "I'm bigger and better than I ever was before", "leading a productive, fulfilling life." The reasons for the inclusion of these comments are a) to call attention to the fact that the study's focus, by its very design, did not paint a holistic picture of the lives of the participants and to call attention to what is missing; b) to avoid contributing to the 'tragedy' view of disability which regards the life of the person with a disability to be essentially over, devalued, or inferior and ignores the multiple possibilities, opportunities for growth and an equally or perhaps even more satisfying, productive, happy life as experienced pre-injury (Carpenter, 1991).

An important feature of the trustworthiness of a study is the consequences for the research participants of the process of data collection and the use of data (Messick, 1989). Among the implications of the findings of the present study are : a) knowledge of the nature of stressors encountered by individuals who have a SCI and live in the community can guide a more comprehensive preparation for potential stressors prior to discharge from the rehabilitation centre, thereby bridging the gap between services offered and perceived need; b) effective out-patient and community-based programs can be designed, guided by the suggestions of the participants, to enhance the resources available to individuals who have a SCI and live in the community; c) as a result of such programs, well-being can be enhanced among individuals who have a SCI on a psychological as well as a physical level; d) finally, the findings of the study may help to raise general awareness as well as understanding of the potential stressors experienced by individuals who have a SCI among the research community, individuals working with people who have a SCI, including counsellors, as well as society at large.

<u>Directions for Future Research</u>

First, a comment pertaining to research where homogeneity among participants is an important issue. As a result of a pilot study, the researcher was aware of the fact that different levels of injury such as paraplegia versus quadriplegia versus high lesion injuries, and even the differences in capabilities within one of those categories could affect homogeneity factors with respect to the different stressors encountered. This was further supported by the results of the present study. Thus, in future research where homogeneity factors play a role in the process of gathering the results, or in the results themselves, it seems important to be aware of this factor.

One suggestions for future research includes an investigation of how the nature of stressors evolve over time. Other studies might explore the stressors of individuals who are either longer or shorter post-injury than the present group.

The results of this study also reinforce the need identified by other researchers (Carpenter, 1994; Dew et al., 1983; Frank & Elliot, 1987; Tate et al., 1993; Vargo, 1982) to focus more attention on the experiences of individuals after discharge to ascertain how rehabilitation programs could be rendered more effective as well as to identify their limits and to aid in the development of community programs that could ease the transition from institutional to community living. The results of the present study emphasize the effectiveness, in terms of depth and richness, of the findings obtained through the use of a qualitative research methodology, and specifically the focus group technique. The present study thus further advocates the inclusion of the perspectives of individuals in the target group, the consumers, in research and decision making processes alike.

The present study demonstrated the effect of the attitudes, biases, and perceptions of health professionals who are delivering rehabilitation programs

which should not be overlooked. Thus, investigations into the attitudes of health professionals regarding disability, their motivations for this career choice, and other dynamics that may affect clients is advocated both as a private, self-reflective process and as stimulated by a more formal research process.

With the goal in mind of rendering rehabilitation programs maximally effective and thus making adjustment easier for clients, further research on effective timing and ways to present information or teach skills during rehabilitation needs to take place. One of the recommendations of this study includes an investigation into what information or practical skills are taught, when, and how as well as how much of this information is retained. With respect to the issue of low attendance for psychoeducational group programs, additional research seems needed to explore some of the compromising factors.

Finally, more research by counselling psychologists and other professions investigating related issues, as well as a more practical involvement of counsellors and counselling psychologists in rehabilitation are advocated. The latter is supported by other researchers (Pelletier, Rogers, & Dellario, 1985; Thurer & Rogers, 1984) who have called on counselling psychologists to develop psychological services which address the needs of individuals with physical disabilities as well as by the comments of the participants of the present study identifying the insufficient focus on mental and emotional aspects during rehabilitation and thereafter.

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Appendix A

Recruitment Notice

Appendix B

Initial Telephone Contact Protocol

Initial Telephone Contact Protocol

Introduce yourself. Indicate the purpose of the call – to describe the study. The purpose of the study is to find out from individuals who have a SCI and live in the community what your stressors are, what implications they have for you, and what you suggest could be done to better prepare you for potential stressors at the level of the rehabilitation centre as well as to assist you when you live in the community. These questions will be discussed in a group format with five members per group. There will be three meetings, one each week, each lasting two hours. The days of the meetings as well as the times will be set at a time convenient to all the participants. I will lead the group discussions in terms of posing the questions and facilitating the discussions, but the focus is on discussions among the participants. The discussions will be audiotaped, reviewed by my supervisor, transcribed with the real names of the participants substituted with pseudonyms, and erased immediately following transcription. Complete confidentiality is assured. Every participant will receive a $20 restaurant gift certificate. Ask if they have any questions so far and confirm interest to participate. Ask for possible times to meet (days of the week and times), three times for two hours each and one meeting per week. Set-up the in-person meeting in the week prior to the start of the focus groups and discuss its purpose. The purpose is to introduce myself in person, meet you in person, and answer any questions you may have. You will also be asked to read and sign a standard letter of consent which the university requires me to give to you and states that I have told you about the study in detail and that you would like to participate. There is also a standard 1-page questionnaire which asks your age, marital status, occupation and so on which is used for statistical purposes only. Give them your phone number, thank them for their interest, and indicate that you look forward to meeting them.

Appendix C

In-person Interview Protocol

In-person Interview Protocol

Introduce yourself. Ask if they have any questions about the information given in the phone call. Review the Informed Consent Form, ask them to read and sign it. Introduce the Demographic Form, ask them to fill it out, and help them if writing is not possible or difficult. Ask if they have been involved in a group discussion before and if they feel comfortable talking and sharing in a group setting. Ask them to, at home, think about and write down or make mental notes of the stressors they experience in their life right now as well as when they were first discharged from the rehabilitation centre. Ask them to also think about their suggestions for a better preparation for potential stressors at the rehabilitation centre as well as for how they can be assisted when living in the community. Ask them to bring the list or mental notes to the discussion meeting. Give them an overview of what will happen in the first session : We will all introduce ourselves and share autobiographical information. Next we will discuss what some of your stressors were when you were discharged from the rehabilitation centre and returned to live in the community. Towards the end of the session we will discuss what your suggestions are for a better preparation for potential stressors at the rehabilitation centre. In the second and third meeting we will talk about the stressors you experience in your life right now and what implications they have for you. Towards the end of the sessions we will talk about your suggestions for effective assistance when living in the community. Review time commitments : three 2-hour sessions, one per week with a 10 minute break in the middle. Give them a piece of paper with the dates, times, location of the focus groups, and phone number of the researcher. Ask if dates, times, and location are still suitable. Ask if they have any questions. Thank them for coming and indicate that you look forward to seeing them in the group and will call them one day prior to the group meeting to remind them.

Appendix D

Focus Group Protocol

Focus Group Protocol

Thank the participants for coming and invite everyone to introduce themselves by their name, autobiographical information, including what their life consists of currently such as work, school, where they are living, as well as any other information participants choose to include. The researcher begins and participants follow in a 'Round Robin' format. Next state the purpose of the group meetings. For the first meeting : a) to find out from the perspective of the participants what some of the stressors and their implications were that they experienced when they were discharged from the rehabilitation centre and returned to living in the community, and b) what their suggestions are as to how they could have been better prepared for those stressors prior to discharge. For the second and third meeting : a) what the stressors and their implications are that they experience now, living in the community and b) what their suggestions are for how some of those stressors could be alleviated. Indicate that you hope that this information will contribute to raising the level of awareness and understanding of people who work with individuals who have a SCI as well as society in general. Due to the potentially sensitive and unsettling nature of the experiences shared, indicate that you are ethically required to mention that appropriate referrals are available from the researcher should anyone wish to talk with someone on an individual basis following the group meetings. Emphasize that the focus of the meetings is on the experiences and perspectives of each of the participants and that there are no right or wrong answers – the group leader simply wishes to learn from the members' experiences and perspectives and would like as many different points of view and experiences as possible. Emphasize that if someone's experience is a little different from someone else's, then that is exactly what you would like them to say. Mention that in past groups, someone may say, 'I guess my experience is different from

everyone else's, and then they find out that the same things have happened to other people too, but no one else would have mentioned it if someone didn't start the ball rolling'. Mention that even if they think that their experience is just like everyone else's, don't just say, 'I agree', but ask them to tell you their experience, because there's always something unique in each person's experience. Next, indicate that the role of the moderator is to facilitate the discussion, to make sure everybody gets a chance to speak, to ensure we remain on topic, and to clarify what the participants bring up to make sure you have understood them correctly. Ask if anybody has any questions so far ? Review group norms and ensure everyone's agreement to them : confidentiality, starting on time, letting everybody have a chance to speak, and waiting until the person who is talking is finished before the next person speaks. Clarify what is meant by stressors : anything that causes the participants to feel anxious, upset, uncomfortable, or frustrated. Begin the discussion of the first meeting, break at midpoint for 10 minutes. Thirty minutes prior to the end of the first meeting address their suggestions of how they could have been better prepared for the stressors prior to discharge. Then summarize the stressors, implications, and suggestions that have been brought up to verify correct understanding, accuracy and completeness. End with a 'Round Robin', asking them to address how they found the meeting, anything they would like to add to what was said, and anything they liked, disliked or would like to change about the format of the meeting. Researcher starts. Confirm meeting next week and ask participants to think about what some of the stressors and implications are that they experience in their lives right now, or have experienced while living in the community as well as what their suggestions are as to how they could be alleviated.

Second meeting : As a warm-up exercise, ask them in a 'Round Robin' to talk about how their week was and any stressors they were aware of. Discuss stressors

they are experiencing right now or have experienced while living in the community as well as their implications. Discussion process was changed slightly in this and the next meeting so that a more detailed description of the data was possible. Once an issue is raised, ask participants to address whether they considered the issue raised a stressor for them or not, and if so, to identify an experience they had pertaining to this issue. Break at midpoint. Thirty minutes before the end of the session ask them to talk about their suggestions for how some of the stressors could be alleviated. Complete the rest of the session as in the first session.

Third meeting : Same format as second meeting. Confirm that following transcription and identification of themes, you will phone them to schedule one more group meeting to validate the themes and to confirm that the written information is representative of what the participants had intended to relay. Thank them for participating, distribute gift certificates.

Appendix E

Informed Consent Form

Appendix F

Demographic Questionnaire

Demographic Questionnaire

For purposes of statistical analysis only, please answer the following questions about yourself. Your answers will remain anonymous and strictly confidential. However, this biographical data is crucial to the study.
Please answer the following questions by CIRCLING the most appropriate response unless otherwise instructed.

1. What is your age ? _____ years

2. Are you   male   female

3. Are you :   married/common law   1
                    separated/divorced   2
                    single   3

4. What was the date of your injury ?   _____.

5. What is the level of your injury ?   _____   complete/incomplete.

6. Please list any medications you are taking :

4. Eight months before your injury OR over the last eight months, whichever is more recent, you were a :

A full-time student	1
A part-time student	2
Working full-time	3
Working part-time	4
Other	5

5. What is the highest educational level you have attained ?

Less than grade 12	1
Grade 12 completed	2
College or Technical school (2 or 3 yr. degree)	3
University (4 or 5 yr. degree)	4
Post university degree	5

6. What is your cultural background ?

Appendix G

Categories and Definitions of Stressors and Themes

Categories and Definitions of Stressors and Themes

Categories are listed according to the order in which they were discussed by the participants.

1) Attendant care
– individuals who assist people with disabilities in aspects of personal care

2) People's looks, comments, and behaviours
– reactions encountered from mainly able-bodied individuals

3) Accessibility
– state of the environment as being freely accessible with a wheel-chair

4) Transportation
– wheel-chair accessible methods of commuting

5) Finances
– financial matters including dealings with insurance companies and government agencies for necessary equipment, supplies, and pensions

6) Insufficient focus on the mental and emotional aspects during rehabilitation
– psychological issues following SCI not addressed adequately during rehabilitation

7) Lack of individual approach during rehabilitation
– unique needs of each individual were not addressed during rehabilitation

8) Change from a schedule to no schedule
– transition from a rigid schedule during rehabilitation to no schedule and boredom at home

9) Insufficient information on community resources when leaving rehabilitation
– inadequate information on financial matters, transportation, recreation, and other resources for people with disabilities living in the community

10) Approach to alcohol and drugs during rehabilitation
– no resource for people who wanted help, objections to current zero tolerance policy

11) Weather
– rain, snow restricting wheel-chair mobility, sun causing medical complications

12) Clothes

– problems with respect to items of dress, including financial aspects and dressing itself

13) Grocery shopping

– compromised independence in shopping for groceries

14) Lack of privacy

– deficiency in opportunities to be apart from the company or observation of others

15) Lack of spontaneity

– lack of opportunities to act impulsively, unplanned in their life

16) Dating

– intimate relationships and all the nuances the SCI adds

17) Bowel and bladder accidents and related stressors

– emotional effects and practical issues resulting from the loss of control over bowel and bladder functions

18) Challenges of independent living

– time and effort involved in an independent lifestyle

19) Crowds

– lack of attention of able-bodied people to individuals using wheel-chairs

20) Health

– issues pertaining to diet, dental care, pressure sores, bladder infections, and sleeping

21) Having children

– effects of pregnancy, child care, parenting and partner issues

22) Employment

– difficulty finding suitable employment, restricted choices, motivating factors and resources

<u>**Additional stressor added in the last meeting**</u>

Spasms – embarrassing to have in public, people may think you are possessed

<u>Overarching themes :</u>

A) Insufficient preparation for various issues prior to discharge from rehabilitation

– collaboration of earlier mentioned categories, addressing comments of inadequate preparation for various issues prior to discharge from rehabilitation

B) Chronic hassles

– collaboration of earlier mentioned categories, referring to the additional tasks, time requirements, and nuisances encountered following the SCI

C) Issues of control and having choices

– collaboration of earlier mentioned categories, representing restrictions over choices and a reduced degree of control over physical, personal, environmental, and financial aspects

D) Feeling isolated in the experience of disability

– collaboration of earlier mentioned categories, addressing the daily dealings with difference which can summate to feelings of isolation

E) Obstructions to independence

– collaboration of earlier mentioned categories, delineating the various aspects which impede the enhancement of autonomy

Appendix H

Craig's & Hancock's Discussion on Low Attendance in SCI Groups

Craig's & Hancock's Discussion on Low Attendance in SCI Groups

A discussion on some of the factors involved in low attendance for psychosocially oriented SCI group programs and possible solutions identified by Craig and Hancock (1994) follows. Although this section represents a digression from the results of the present study, it is warranted as it relates directly to many of the suggestions for programs and services raised in this study. First, the majority of individuals who were approached declined to participate in a group cognitive behavioral therapy aimed at providing cognitive and behavioral skills to cope with the psychosocial challenges encountered upon discharge from the rehabilitation centre. However, by the end of the program 90% of the 20 participants agreed or strongly agreed that it was effective in helping them adjust to their injury. Craig and Hancock suggest that client characteristics are among the factors responsible for the difficulties in recruitment. A minority of men seek psychological services perhaps as a result of socialized pressures to be self-reliant and present as being 'in control' combined with the fact that the majority of individuals sustaining a SCI are men. Craig and Hancock suggest that the typical individual with a SCI being young, male, and more action than verbally oriented may be another complicating factor. Another aspect which the researchers identified they labeled denial/avoidance. Sixty percent of their participants, they determined, believed that they would walk again despite medical contraindications. Although the researchers acknowledge that denial or avoidance can be an adaptive coping strategy in some contexts, it is their opinion that it proved counterproductive with respect to participation in a program aimed at learning problem solving skills with respect to an injury which they did not believe was permanent. Another factor they related to low participation was that of information overload or 'too much, too soon'. Furthermore, Craig and Hancock suggest that it proved difficult for clients to anticipate the relevance of

the intervention, likely due to the limited experience with future challenges of independent living. Other complicating factors were those of a busy rehabilitation schedule with priority given to physical rather than psychological therapy. Finally, medical complications such as dysreflexia, infections, and pressure sores also accounted for some of the problems of low attendance.

Some of the strategies suggested by Craig and Hancock (1994) to ameliorate the difficulties discussed are getting to know potential participants prior to recruitment to therapy, having all rehabilitation staff support the importance of the group sessions on an ongoing basis as well emphasize the skills based rather than insight oriented focus. Participants, the researchers suggest, should also be reassured that they do not have to speak if they do not wish and feelings of initial reluctance, if detected, should be normalized with an added comment that previous participants, upon completion of the group sessions, judge them to be very beneficial and effective. Furthermore, Craig and Hancock stress that the involvement of a co-therapist who has sustained a SCI may also enhance participation and credibility. Use of lay language rather than psychological jargon was also cited as important. Finally, to allay schedule or priority conflicts, the same researchers suggest that organizers of the group sessions liaise and set up meetings with other rehabilitation staff to explain the elements and importance of the program, dates and times, and to generate support.

Appendix I

'The Adventures of the Disabled Village'

'The Adventures of the Disabled Village'

Imagine a town full of individuals who have a physical disability
(physically impaired people changed to reflect proper language) and use
wheelchairs. They run everything. They run shops, the factories, the
schools, the television studio, the lot. There aren't any able-bodied people,
so naturally, when they built the town the community decided that it was
pointless to have ceilings ten feet high and doors seven feet high. "It's just a
lot of wasted space that needs heating, " they said. So the ceilings were built
at seven feet and the doors at five feet. In every way they designed the place
the way they wanted it, and these proportions are now standardized by
regulation. Everyone is happy. Years go by. One day a few able-bodied
people come to stay. One of the first things they notice is the height of the
doors. And the reason they notice is because they keep hitting their heads.
They come to stand out by their bruises they carry on their foreheads. Some
doctors, psychiatrists and social workers all become involved. The doctors
do extensive research and conclude in their learned reports that the
disabled able-bodied suffer from 'loss of reduction of functional ability' and
the resulting handicap caused 'disadvantage or restriction of activity.'
Committees are formed. Many people are worried about what becomes
known as the 'problem of the able-bodied.' Throughout the town there is a
growth of real concern. Specially toughened helmets are handed out free to
the able-bodied to be worn at all times. Braces are designed which give
support and relief while keeping the able-bodied wearer bent to a normal
height. Getting a job is a major problem for the able-bodied. One man, for
instance, applies to become a television interviewer. But first he must be
examined by a doctor. There is this regulation that states that all able-bodied
people (people added) must be given a special medical examination when

they apply for a job. And the doctor, perfectly naturally, points out in his report that it would be rather strange to have a television interviewer with a bent back who wore a helmet all the time. He doesn't get the job. Money, of course, becomes a major problem. Various groups of compassionate wheelchair users get together and form registered charities. Every quarter they have a collection day. Upturned helmets are left in pubs and shops for people to drop their small change into. There is a heartening support for organizations such as 'The Society for Understanding the Disabled Able-Bodied.' There is talk of founding special homes. But then one day it dawns on the able-bodied people (people added) that there is nothing actually wrong with them, just that society excludes them. They form a union to protect themselves and to campaign against segregation. They argue that if ceilings and doors were raised, there would be no problem. But this is, of course, a foolish suggestion. After all, there are regulations which govern the height of ceilings and doors. (page number unknown).