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By

PENELOPE KATHLEEN HENWOOD

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Abstract

The purpose of this thesis was to explore the effects of chronic neuropathic pain (CNP) and the process of acceptance of pain as it relates to adjustment to CNP in spinal cord injured (SCI) persons. The participants in two qualitative studies were community-living SCI persons who have CNP. They were currently or had previously received treatment at the out-patient clinic of a regional rehabilitation center. The first study involved a constant comparative analysis of narrative data obtained during three focus groups with 24 SCI persons. The second study involved a grounded theory approach to develop a conceptual framework that describes the process of 'acceptance' of CNP in SCI persons. The data was obtained during in-depth interviews with seven SCI persons with CNP.

In Study 1, four interrelated themes emerged that illustrate the multidimensional impact of CNP in SCI. These themes include 'nature of pain', 'coping', 'medication failure', and 'pain impact'. Participants suggested that learning to live with the pain enabled them to move on with their lives. Learning to live with the pain seemed to be related to acceptance of pain and this construct was explored in depth in Study 2.

In Study 2, the basic social process to describe acceptance of pain was 'moving forward with pain'. This process involved six phases that include 'defining pain'; 'seeking pain resolution'; 'acknowledging pain permanence'; 'redefining core values'; 'learning to live with the pain'; and 'integrating pain'. Two driving forces, 'increasing independence' and 'evolving pain view', were noted to move the process of acceptance forward. The findings from this study suggest that acceptance of pain was beneficial in terms of reducing suffering and facilitating a more satisfying and fulfilling life for these SCI persons. Relinquishing the expectation of a medical cure for CNP and moving toward a self-management approach to pain management led to increased coping with pain for these participants. Further research is needed to examine the process of 'acceptance of pain' and it's relation to adjustment to CNP in a larger sample of SCI persons.

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Chapter One – General Introduction

During rehabilitation, following an acute spinal cord injury (SCI), considerable attention is directed toward maximizing functional capacity, facilitating the learning of new knowledge and skills to maintain health, and supporting adjustment to the disability. The management of pain is subsumed among the many rehabilitation goals that need to be addressed. After discharge, SCI persons experience the stresses of living in the 'real world'. Often, it is at this point that the problem of chronic neuropathic pain (CNP) emerges or escalates.

As nurse clinician at a rehabilitation center, I have noted in my clinical practice the negative physical and psychosocial effects of CNP in the lives of community-living SCI persons. The numerous phone contacts and clinic visits that relate to the issue of CNP led to an increased awareness that SCI persons' have difficulty coping with their pain despite the use of medications commonly prescribed for the management of CNP. SCI persons often expressed their frustration with the inadequacy of medication to alleviate their CNP.

SCI persons rely heavily on the knowledge, expertise and support of rehabilitation nurses and other members of the multidisciplinary team in order to adjust to their disability. Although multidisciplinary chronic pain programs exist to assist chronic pain patients to adapt to their pain, these programs predominately focus on reactivation resulting from deconditioning in response to musculoskeletal pain. These programs are often not considered to be appropriate for SCI persons because functional impairments from the SCI restrict participation in physical activities commonly prescribed. The question of how best to approach the management of CNP in SCI led to an investigation of the literature. The following sections provide a definition of CNP, a brief overview of the prevalence and incidence of CNP, the strategies used in the management of CNP in SCI including their relative efficacy, the biopsychosocial consequences of CNP, and the relevance for conducting further research.

Neuropathic Pain

Neuropathic pain defined as "pain initiated or caused by a primary lesion or dysfunction in the nervous system" (Mersky & Bogduk, 1994, p.212) occurs in SCI persons as a result of trauma to the nerve roots or spinal cord itself as well as changes to the central nervous system that take place over time following the injury (Siddall & Loeser, 2001; Siddall, Taylor, & Cousins, 1995). Clinical symptoms are believed to result from a cascade of neurochemical, anatomical and physiological changes within the spinal cord (Yezierski, 1996). While the pathophysiology of CNP is still largely unknown, several mechanisms are proposed including post-injury alteration in neurotransmitters, the spontaneous continuous and abnormal evoked firing and excitability of ascending sensory neurons in the spinal cord, the activation of alternative pathways in and outside the spinal cord as well as the loss of descending spinal inhibitory mechanisms (Attal, 2000; Eide, 1998; Segatore, 1994; Siddall & Loeser, 2001; Siddall et al., 1995).

The presentation of CNP is related to the level of the SCI and the specific neurologic structures damaged as a result of the injury. CNP may be perceived in a segmental pattern at the level of the SCI, in a patchy distribution, an isolated area such as a hand or foot, or diffusely in all parts of the body below the level of injury (Mersky & Bogduk, 1994; Siddall, Yezierski, & Loeser, 2000), regardless of motor and sensory loss, complete or incomplete spinal cord lesions (Tasker, 2000). CNP that is situated below the level of the spinal injury, commonly referred to as 'central' pain, is considered to be the most prevalent and difficult to treat (Agency for Healthcare Research and Quality [AHRQ], 2001; Tasker, 2000). CNP may present as a continuous burning sensation, a spontaneous intermittent shooting, shock-like, or jabbing pain, or as an area of severe hypersensitivity that is evoked by non-painful stimuli (Tasker, 2000). Other descriptors may include painful sensations such as numbness, tingling, squeezing, throbbing, or cold (Tasker, 2000). SCI persons may experience more than one type of neuropathic pain, in addition to nociceptive pain types of a musculoskeletal or visceral origin (Ravenscroft, Ahmed, & Burnside, 2000; Siddall et al., 2000).

CNP typically presents within six months to one year post-injury (Cairns, Adkins, & Scott, 1996; Davidoff, Roth, Guarracini, Sliwa, & Yarkony, 1987; Kennedy, Frankel, Gardner, & Nuseibeh, 1997; Ravenscroft et al., 2000; Tasker, 2000), although later onset of CNP may occur which is often indicative of syringomyelia, a spinal cyst that develops secondary to the SCI (Tasker, 2000). Several authors have also reported that pain intensity associated with CNP gradually increases over time (Nepomuceno et al., 1979; New, Lim, Hill & Brown, 1997; Störmer et al., 1997).

Prevalence and Incidence of CNP

The prevalence of CNP as reported in the literature varies due to the lack of consensus regarding the definitions, terminology, and classification systems used to describe SCI related pain. In many studies, CNP tends to be distinguished from other types of pain based on the characteristics and qualities of the pain as described by the patient. A recent review of the literature indicates that the prevalence of CNP in SCI persons varies from 40 to 75% with 25 to 60% of individuals experiencing moderate to severe pain (AHRQ, 2001). Approximately 36,000 Canadians currently live with a SCI and each year an estimated 1,050 new injuries occur. Of these new injuries, 78% involve individuals between the ages of 15 and 34 years (The Canadian Paraplegic Association Ontario, 2000). Based on a prevalence of 75% (AHRQ, 2001), it is estimated that approximately 27,000 SCI persons are currently living with CNP in Canada.

Management of Neuropathic Pain

The management of CNP falls into two main categories, pharmacological including oral agents and infusion of drugs into the spinal canal and nonpharmacological interventions including stimulation techniques, surgical procedures, and psychological interventions.

Pharmacological Interventions. Chronic neuropathic pain is particularly difficult to treat (Eide, 1998) and no single treatment has been found to be effective over the long term (AHRQ, 2001). Medications alone or in combination include tricyclic antidepressants, anticonvulsants, sodium or potassium channel blockers, NMDA-receptor antagonists, GABA-receptor agonists, alpha-adrenergic agonists, antispasmotics and opiods (Attal, 2000; Finnerup, Yezierski, Sang, Burchiel, & Jensen, 2001). A recent review of the literature by the SCI Pain Task Force of the International Association for the Study of Pain (IASP) found that few randomized clinical trials (RCTs) have been conducted to evaluate the management of neuropathic pain in SCI and that the best available evidence is based on case reports or uncontrolled trials (Finnerup et al., 2001). To-date, there are no clear guidelines as to the optimal therapeutic strategy for CNP in SCI persons (Attal, 2000; Tasker, 2000) and variation in treatment practice among centers is apparent (Ravenscroft, Ahmed, & Burnside, 1999).

The long-term use of opiods in the management of CNP in SCI is problematic due to the risk of significant negative physiological outcomes (Radwanski, 1992). Potential side effects of these medications include bladder and bowel disruption, skin breakdown, decreased functional abilities and impaired cognition that can jeopardize SCI individuals' health and emotional well-being. In addition, pre-existing substance abuse problems can be further complicated with the use of opioid medications.

Nonpharmacological Interventions. One non-invasive pain management strategy, transcutaneous nerve stimulation (TENS), reportedly provides some limited pain relief in cases of neuropathic pain at the level of the injury. Results are less impressive, however, with respect to neuropathic pain that is situated below the level of the SCI (Siddall et al., 1995; Finnerup et al., 2001). A number of invasive surgical interventions have also been used in an effort to control pain in cases where CNP has been resistant to conventional noninvasive therapies. Spinal cord stimulation (SCS) and deep brain stimulation (DBS) are two strategies that involve the implantation of electrodes, either within the dorsal columns of the spinal cord or selected sites within the brain, respectively, with the intent of activating descending pain inhibitory pathways (AHRQ, 2001). SCS has been found to provide partial pain relief in cases of incomplete SCI or at-level pain but results are poor with regards to those individuals with complete SCI and in those who have intermittent and burning pain. There is no evidence that DBS provides any long-term benefit in terms of pain relief and initial efficacy is unpredictable (Finnerup et al., 2001). Other techniques such as cordotomy, cordectomy, and myelotomy involve neural transection in order to interrupt the pain pathways. There is no evidence that these strategies are effective in managing central neuropathic pain (Finnerup et al., 2001). Higher success rates in cases of diffuse and/or sacral pain are reported with dorsal root entry zone (DREZ), a surgical procedure that produces small, discrete lesions by means of a laser (Finnerup et al., 2001), however, the risk of adverse effects is unknown and more definitive studies are needed to determine it's safety (AHRQ, 2001). In general, surgical interventions that involve the destruction of healthy neurologic tissue as a means to interrupt pain pathways are viewed as unacceptable in cases of incomplete SCI's due to potential further losses in terms of sensation and bowel, bladder or sexual function (Tasker, 2000). The current emphasis on spinal regeneration has also made these strategies less attractive.

Although psychological interventions are recommended in the management of CNP in SCI (Umlauf, 1992), relatively few studies have evaluated their efficacy. One study reported that relaxation techniques were effective in reducing pain and improving mood in four patients (Grzesiak, 1977) and another indicated that laughter decreased pain in 11 patients (Henderson & Mowry, 1995).

Biopsychosocial Implications of CNP in SCI

CNP in SCI is associated with a number of physical, functional and psychosocial difficulties. Findings from several studies indicate that CNP is associated with a number of problems including sleep disturbance (Biering-Sorensen & Biering-Sorensen, 2001; Rintala, Loubser, Castro, Hart, & Fuhrer, 1998; Widerström-Noga, 2003), greater functional disability (Lundqvist, Siosteen, Blomstrand, Lind, & Sullivan, 1991; Widerström-Noga, 2003), interference with activities of daily living (Richards, Meredith, Nepomuceno, Fine, & Bennett, 1980; Turner & Cardenas, 1999), inhibited work capacity (Ravenscroft et al., 2000; Rose, Robinson, Ells, & Cole, 1988; Widerström-Noga, 2003) and reduced economic self-sufficiency (Putzke, Richards & Dowler, 2000), as well as restricted recreational and social activity (Murphy & Reid, 2001; Nepomuceno et al., 1979; Turner & Cardenas, 1999).

Psychosocial effects of CNP include anger (Conant, 1998; Summers, Rapoff, Varghese, Porter, & Palmer, 1991), anxiety (Richards et al., 1980, depression (Cairns, Adkins, & Scott, 1996; Kennedy et al., 1997; Ravenscroft et al., 2000; Störmer et al., 1997), social isolation (Putzke et al., 2000), and family problems (Haythornthwaite & Benrud-Larson, 2000; Britell, Umlauf, Loehr, & DeLisa, 1986; Mariano, 1992; Richards et al., 1980). The early onset, the tendency for CNP to increase in severity over time (Beric, 1997; Nepomuceno et al., 1979; New et al., 1997; Störmer et al., 1997), and the relative lack of effective treatment options (Beric, 1997; Eide, 1998; Westgren & Levi, 1998) contribute to further disability that negatively impact the rehabilitative process, adaptation to the SCI, and quality of life (Levi, Hulting, Nash, & Seiger, 1995; Lundqvist et al., 1991; Putzke et al., 2000; Stensman, 1994; Westgren & Levi, 1998). SCI persons with CNP are the most active health care consumers, as compared to those that are pain free. They require frequent clinic visits and often have the most extensive list of medical problems (Britell & Mariano, 1991; Mariano, 1992). Given that SCI often occurs at an early age and the life expectancy of SCI persons approximates that of the general population (Devivo, Rutt, Black, Go, & Stover, 1992; Tunks, 1986; Whiteneck et al., 1992), SCI persons may expect to live with CNP for a very long time.

At present little is known about the experience of living with CNP from the SCI persons' perspective. There are few studies that have examined the effects of CNP in SCI and to-date there are no studies that have examined the problem from the SCI persons perspective.

Purpose and Objectives

The purpose of this thesis was to explore the perception of living with CNP from the SCI persons' perspective. The research objectives were as follows: 1) examine the impact of CNP in SCI persons in relation to physical, emotional, psychosocial, environmental, informational, practical, and spiritual domains, 2) identify both effective and ineffective strategies used by SCI persons in the management of CNP, and 3) describe the process of acceptance of pain.

The research conducted to accomplish these objectives is described in the following papers. Chapter 2, "Chronic Neuropathic Pain in Spinal Cord Injured Persons: The Patient's Perspective" addresses objectives one and two and describes the findings of an exploratory study that determined the effects of CNP in SCI persons. The impact of CNP as reported by SCI persons who participated in one of three focus groups is recounted. The finding that some SCI persons appeared to have accepted their CNP led to the development of the second study. Chapter 3, "Exploring Acceptance of Chronic Neuropathic Pain in Spinal Cord Injured Persons" deals with the third objective and represents an initial effort to understand the process of 'acceptance of pain' as it relates to adjustment to CNP in SCI individuals. Chapter 4 provides a general discussion and conclusion that integrates the findings from the two studies with implications for theory development, clinical practice and research. Chapters 2 and 3 are presented as manuscripts intended for publication and as such are able to stand on their own. Chapter

2 was published in volume 9 of the journal 'Pain Research & Management' (Henwood & Ellis, 2004). (see Appendix A for Authorship Credit).

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Chapter Two

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Chronic Neuropathic Pain in Spinal Cord Injury: The Patient's Perspective

By

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Abstract

Background. Chronic neuropathic pain (CNP) in spinal cord injury (SCI) is recognized as severely compromising adjustment after injury and quality of life. Studies indicate that chronic pain in SCI is associated with great emotional distress over and above that of the injury itself. Currently, little is known about the SCI patient's perception of the impact of living with chronic neuropathic pain.

Objectives. The purpose of this study was to explore the effects of CNP in SCI persons in relation to physical, emotional, psychosocial, environmental, informational, practical, and spiritual domains and to identify effective and ineffective pain coping strategies.

Methods. Three focus groups were conducted that included 24 SCI individuals. Participants were selected to maximize variation in terms of type of SCI, Frankel classification, years since onset of SCI, age, and sex. The sessions were audiotaped and tapes were transcribed. A qualitative analysis of data involved a constant comparison approach by which categories and themes were identified.

Results. Many complex themes emerged including nature of pain, coping as process and product, medication failure, and the impact of CNP on physical, cognitive, emotional, interpersonal, social, and life activities.

Conclusions. Medication failure was identified as a common outcome, while strategies including use of warm water, swimming, increased activity and distraction provided temporary pain relief. Learning to live with the pain appeared to be related to acceptance of pain, which in turn seemed to facilitate adjustment. Further research is warranted to determine the process by which SCI persons learn to live with CNP and those coping strategies that facilitate adjustment to CNP in SCI.

Keywords: Chronic neuropathic pain; Qualitative methods; Quality of life; Spinal cord injury

Chronic Neuropathic Pain in Spinal Cord Injured Persons: The Patient's Perspective

Introduction

Chronic neuropathic pain (CNP) in spinal cord injury (SCI) is a significant post-injury sequella with an overall prevalence of on average 65%, of which one-third of patients experience severe pain (Siddall, Yezierski, & Loeser, 2000). Neuropathic pain is defined as pain that is initiated or caused by a primary lesion or dysfunction in the nervous system (Mersky & Bogduk, 1994), and is considered to be the most disabling of all sensory disruptions associated with SCI (Beric, Dimitrijevic, & Lindblom, 1988; Davidoff, Roth, Guarracini, Sliwa, & Yarkony, 1987; Nepomuceno et al., 1979; Tunks, 1986). Typically, CNP presents within the first year post-injury (Davidoff et al., 1987; Tasker, 2000), and fails to respond to conventional physical, pharmacologic, psychological or surgical treatments (Beric, 1997; Eide, 1998; Murphy & Reid, 2001).

The presence of chronic pain in SCI is viewed as seriously jeopardising adjustment after injury and quality of life (Cairns, Adkins, & Scott, 1996; Lundqvist, Siosteen, Blomstrand, Lind, & Sullivan, 1991; Stensman, 1994; Westgren & Levi, 1998; Yezierski, 1996). Pain impedes the ability of SCI patients to participate in active rehabilitation programs (Cairns et al., 1996; Yezierski, 1996), thus limiting their potential to regain an optimal level of function (Siddall, Taylor, & Cousins, 1997). Several studies report that chronic pain in SCI is associated with great emotional distress (Anke, Stenehjem, & Stranghelle, 1995; Widerström-Noga, Felipe-Cuervo, Broton, Duncan, & Yezierski, 1999), over and above that of the SCI itself (Summers, Rapoff, Varghese, Porter, & Palmer, 1991). Results of one study showed that 37% of SCI patients with cervical and high thoracic lesions and 23% of those with low thoracic or lumbosacral lesions were willing to trade pain relief for loss of bladder, bowel, or sexual function (Nepomuceno et al., 1979). Stormer et al. (1997) noted a correlation between CNP in SCI and depressed mood, psychosomatic disturbances of well-being and coping with paralysis. Greater perceived stress, lower acceptance of injury and poorer self-assessed health in relation to chronic pain are also reported (Summers et al., 1991; Rintala, Loubser, Castro, Hart, & Fuhrer, 1998). In addition, chronic pain in SCI is a contributing factor in suicide (Kewman & Tate, 1998; Segatore, 1994).

The high prevalence, potential early onset and severity of CNP in SCI persons (Nepomuceno et al., 1979; Beric, 1997), as well as improved life expectancy (Tunks, 1986), provide the impetus to develop an understanding of SCI patients' experience of living with CNP. Because pain is a subjective experience, it would be beneficial to explore SCI patients' pain as reflected through their experience. Qualitative methods have not as yet been used to examine this problem, a need that was emphasized by Siddall, Taylor, and Cousins (1995).

The present paper describes the findings of a study that explored the effects of CNP in the lives of SCI patients. A series of three focus groups explored the experience of CNP in SCI persons in relation to physical, emotional, psychosocial, environmental, informational, practical, and spiritual domains, and identified effective and ineffective pain coping strategies.

Methods

Design

Focus groups were conducted to explore the experience of CNP in SCI persons through the expression of participants' perceptions, attitudes, beliefs, opinions and behaviours. A focus group approach is particularly well suited to capture the complexity of the chronic pain experience in SCI persons as the dynamic of the group process provides a safe environment which encourages the spontaneous expression of varied viewpoints (Sim, 1998). In addition, when exploring a new research area, such as CNP in SCI individuals, a qualitative design provides the means to describe a phenomena of interest through the meanings, variations and perceptual experiences of respondents (Crabtree & Miller, 1992).

Participants

Before recruiting participants, the research protocol was approved by the Research Ethics Committee. SCI outpatients, diagnosed with CNP that lasted longer than six months, were eligible to participate in the study. Purposeful sampling of 54 prospective participants known to have moderate to severe CNP was conducted by the investigator from a list of outpatients of the Neurospinal Service at The Ottawa Hospital, Rehabilitation Centre. Patient charts were consulted to confirm the diagnosis of CNP, level of SCI, Frankel classification (American Spinal Injury Association/International Medical Society of Paraplegia, 2000), time since onset of SCI and CNP, and to maximize participant variability. All participants were known to have moderate to severe CNP. The research assistant contacted 30 potential participants, and 24 people agreed to participate in the focus groups. Two people declined due to complaints of severe pain that restricted their participation, and one other who had health problems. One person declined due to a lack of interest in participation and two who had either scheduling or transportation difficulties. Written consent was obtained prior to the start of each focus group (see Appendix A and B for Information Sheet/Statement of Informed Consent).

Procedure

Focus group questions were developed and piloted to determine their effectiveness in obtaining data that addressed the study objectives. The moderator posed 3 open-ended questions (see Table 2.1) and respondents were encouraged to share their thoughts and feelings with their fellow participants. Additional probing questions and/or cues were introduced to generate an expansion of ideas. Focus group sessions were audiotaped, field notes were taken and debriefing sessions were subsequently conducted with the research assistant to compare observations and capture initial thoughts on the main ideas that were discussed.

Data Analysis

Audiotapes of each focus group were transcribed and reviewed by the primary investigator (Penelope Henwood) to ensure accuracy. Potentially important comments, quotations, and observations from the field notes were highlighted on the transcripts. The unit of data analysis in coding included any statement of thought, feeling, or action related to the SCI participant's experience of CNP. The two investigators jointly coded the data and consensus was negotiated when there were disagreements. A constant comparative method of analysis (Patton, 1990) was used, and codes were grouped and compared across and between the focus groups. This process aided in the recognition of commonalities across focus groups, the analysis of different perspectives on key issues and the identification of emerging themes.

Findings

Sample Description

Seventeen men and seven women ranging in age from 34-60 years, and 31-69 years, respectively, attended one of three focus groups. The number of years since the onset of the SCI ranged from one to 30 years. The majority of participants had a traumatic SCI. The remaining four participants' SCI resulted from cervical stenosis, an arteriovenous malformation related haemorrhage, or a spinal tumour. There was widespread representation of neurological level and extent of spinal cord involvement with 13 quadriplegics and 11 paraplegics, four of whom were ambulatory.

Themes

The impact of CNP as perceived by the 24 SCI individuals was reflected in four themes, which are defined in Table 2.2. These interrelated themes provide a snapshot into the lives of SCI patients who cope daily with CNP.

The Nature of Pain

Type. Participants described having one or more types of pain including: neuropathic pain, muscle and joint pain, headaches, and spasticity. However, a general consensus existed that coping with neuropathic pain was the most difficult. Their dialogue provides a mental image of enmeshed layers of pain, with neuropathic pain providing the background upon which other pains are superimposed. Despite this enmeshment, the experience of neuropathic pain as described by these participants was distinctive. In some cases, muscle pain and spasticity seemed to be related to altered body postures assumed in an effort to find a comfortable position during heightened intervals of neuropathic pain. A cyclical pattern was identified with respect to spasticity and CNP.

Increased CNP contributed to the exacerbation of spasticity that further amplified the severity of CNP. For certain individuals, teeth grinding in response to severe CNP precipitated headaches.

Pain Onset. Participants were capable of recalling the onset of neuropathic pain following their spinal cord injury. Neuropathic pain emerged either as a gradual process or as an abrupt occurrence. The onset of CNP varied from immediately post-injury, to weeks, several months, or in a few isolated cases, several years post-injury. The following two quotes illustrate the clarity with which these participants recalled the onset of their CNP:

> I had a construction accident, as a matter of fact, to the date, two years ago and this pain [CNP] that I'm having now started about three months after the accident and it's just been coming on and still keeps coming. And;
>
> I had a motor cycle accident in June '89, a T10 and pretty much from my injury level down it [CNP] started almost immediately. It's just a burning sensation constantly in my legs and my feet. It just feels like you're on fire or in a vice or something.

The majority of participants reported the appearance of neuropathic pain within the first six months post-injury. In a few cases, pain was associated with the first recognition of sensation following the SCI. One individual perceived the presence of pain as a positive indicator of improvement in his neurologic status. Another remarked that he was told that the pain was temporary and would go away, but "it never did".

Distribution. Pain distribution was variable, involving the trunk, viscera, buttocks, and/or lower extremities. A few participants reported the involvement of an isolated area such as a segment of an arm. A band of pain was commonly found adjacent to the level of the spinal cord injury and in this location allodynia was prominent.

Descriptors. The use of metaphorical language was consistently evident in participants' efforts to explain the quality of their neuropathic pain. SCI individuals engage in daily "battles" with their pain. Forceful words that are typically used in other contexts to describe violence and destruction revealed the magnitude of suffering. A sample of the pain descriptors include "a sharp hot dagger", "sharp needle", "stabbing", "hacksaw", "burning", "searing", "frozen", "pressure", "vice", and "hit by a hammer". Examples of metaphor include these statements, "it's like you cut a piece of plywood and formed it around my waist and you're driving into it"; or, "it seems as if I'm standing over a flame and the skin at all points is burned."

Despite the mental images that these words construct, participants commonly expressed frustration in their efforts to describe their pain, and generally believe that others including health practitioners are incapable of appreciating the true sense of their pain. This belief is exemplified in the following statement:

> It's hard enough to understand yourself when you're going through it. Part of the problem is that there's no language to describe it. So when you're trying to describe it to somebody, you're thinking, like in pre-accident description terms. You're trying to describe a certain pain and it just doesn't work.

Severity. Although the descriptors do convey a sense of the severity of pain, participants further described CNP in terms of being, "very, very, very bad", "excruciating", or "terrible." Rarely did participants describe their pain in terms of a numerical rating scale.

Pattern. Many participants said that their neuropathic pain had increased in severity over the years since the onset of their SCI. The majority described a constant baseline of severe pain, while some reported intermittent episodes of pain. Variation was also noted in terms of pain, either being relatively stable or having cyclical patterns. The majority, however, described daily, weekly or monthly cycles of pain. Daily patterns were noted with increased pain, either in the morning or at night. Waking with pain was often a predictor of an expected "bad day." Pain for some people was described as progressively building throughout the day or over the week. One individual suggested a relationship between increased pain and the moon's phases. Regardless of the pattern, participants actively sought to understand the nature of their pain and commonly expressed frustration at the inherent unpredictability of their pain that seems dependent upon the influence of known or unknown factors. One participant stated:

> Yea, you can have a really, you know, busy day the day before and wake up and feel great. And it's, ok, well, maybe if I'm active all the time I'll feel better. And then you wake up feeling really sore and, you know, everything that comes with being sore. And then, ok, well maybe I have to do nothing. And then you think maybe I'm doing too little . . . you know, I've gotten it down to what I eat, the sun, the moon, the tides. I keep turning over rocks to justify it.

Augmenters. Pain was intensified by physical and environmental factors including urinary tract infections, constipation, prolonged sitting or lying positions, cold or hot temperatures, humidity and weather changes. Emotional factors that contributed to increased pain included stress, anxiety, depression, frustration and anger. When spasticity, (a common problem in SCI) involved areas of the body below the level of the injury, it seemed to interact with fatigue and heighten the pain. The following quotes demonstrate a few pain augmenters, “the spasm tends to gear where the pain is and it will make the pain worse”; and “they (spasms and pain) fall hand in hand and when you’re lying on your side, if your spasms are kicking up like that, they surely wake you up.” One participant further offered:

> The being awake and not being able to get properly rested, the exhaustion gets settled in and I do sleep sometimes for quite a bit. Like that’s when I’m totally finished and then I get to the point where the pain won’t let me sleep anymore ... because the pain gets too unbearable because I’ve been staying in one position too long. So, it’s a constant fight to see who’s going to win what today. And the exhaustion is gonna win once you hit a certain spot. Then, the point, the pain will come back saying oh you’re rested up, now it’s my turn to play. So, it’s always a constant battle to see which one’s gonna get you first.

Coping

Coping was viewed as both a ‘process’ and a ‘product’ of living with CNP. Coping as a process involved coping strategies which were viewed as positive or negative in terms of pain relief. Coping as a product was viewed in terms of global adjustment. Participants invested considerable physical and emotional energy while employing multiple strategies in their daily efforts to seek pain relief (see Table 2.3). Coping strategies such as swimming in warm water, using a hot tub or taking hot showers, heat, massage, stretching and increased physical activity, provided temporary pain relief. Variable effects were reported with complementary therapies such as acupuncture, massage, or hypnosis. In a few cases, seeking information and seeking support via the internet were used as a coping strategy. Relaxation and distraction provided brief periods of pain relief. Reported self-medicating practices included use of over-the-counter, prescription, and illicit drugs, or alcohol. One participant stated:

> I've taken Aspirin because the pain [CNP] that I have gives me headaches, gives me a stiff neck, gives me a stiff shoulder, so at least the Aspirin will take a headache away for an hour or so and then, like I'm talking handfuls of Aspirin.

Marijuana, tried by a few participants, provided partial and temporary relief but had no lasting effect on CNP. One participant shared:

> I smoke pot a lot, ... when I smoke a joint the pain [CNP] is not there ... but when I finish smoking the joint, 10 or 15 minutes after that the pain comes back but I'm stoned; it gives me help to deal with it.

Cognitive coping mechanisms were evident in terms of positive self-statements, humour, rational thinking and behaviours that promote a sense of self-efficacy. As one participant noted:

> You have to push yourself to the limit. I know it's hard for people to live with the pain but if you keep thinking about the pain, the more you think about the pain, the worse it is.... I have pain and some days it's really, really, really bad. But I still go to work, smile in front of the people. The people don't know I'm suffering inside.

Negative cognitions that described feelings of helplessness were associated with increased pain severity, heightened emotional distress, and the expectancy that others are responsible for managing their pain. This example portrays a few elements of negative cognitions:

> Well what happens when there is no good time? When it's just a bad time? My problem is, nothing can touch me in that broken area. Like when I say nothing, I mean a t-shirt or a drop of water that's gonna drop down on top of you, or your blanket when you sleep at night. You cannot touch that area. Now I have my clothes touching that area now, but right now I could scream every time I breathe.... I've had a year and a half to practice on this and I can't build up no tolerance.... your voice goes up in such a high pitch, you feel like your eyeballs want to fall out, if I were to lie in bed and think about that, I'd just be so depressed I'd want to jump off a roof.

Conversely, "learning to live with the pain" was a common statement among those who seemed to have accepted and possibly adjusted to their pain.

One participant said:

> After eight or nine years of going through that [CNP], you get to a point where you know you're at a certain level, where that's the lowest the pain will go. It will never go away. So at that point when you're feeling at that lowest point of pain, you're feeling actually good because to you it doesn't hurt and after that there's varying degrees of it, but I don't know, there's just the question of living with it every day.

Medication Failure

Participants reported numerous attempts to find pain relief through the use of prescription medications including antidepressants, anticonvulsants, antispasmodics, anti-inflammatories, and opioid or non-opioid analgesics. Six participants reported that amitriptyline, carbamazepine or neurontin were partially effective; however, in most cases, participants indicated that medications were ineffective in relieving pain and problematic in terms of side effects. One participant shared, " it's [medication] like throwing a cup of water on a house fire. It just doesn't do it." Diminished cognitive ability and constipation were the most prevalent side effects of medications. Another participant shared, "I don't like to be on drugs because I'm not myself." Typically, medication trials involved a cyclical pattern in which a drug was prescribed, the dosage elevated, followed by discontinuation and initiation of an alternate medication. Tolerance to opiods such as morphine or methadone was reported in several cases resulting in discontinuation of the medication. The following statements describe two participant's experience with medications:

> My doctor went down, he had a list of the drugs, and he went down, "you didn't get that one, you did get this one, you didn't get that one, did you get that one?" And I think I must have tried every drug in the book and it's not working.... I look at it this way, you take the drugs and you hurt, you don't take the drugs, you hurt. So you might as well hurt without the drugs. And;
>
> I took Morphine for like almost a year. It didn't help. I just felt like I was in and out of consciousness. I was kind of like hazy. I had to get off the drugs because, I mean, I didn't realize what was reality and what wasn't.

Pain Impact

Pain impact refers to the physical and psychosocial consequences of living with CNP. The daily work of living with CNP resulted in fatigue that was compounded by significant sleep disturbance in terms of insomnia, and frequent awakening. CNP also contributed to the occurrence of headaches, muscle tension, and painful jaws from teeth grinding. As one individual stated:

> It's not the outside world that lets you down, it's your own body telling you, no, not today, we're not getting in our chair, we're bedridden today. And that's what I have found has been very annoying is not knowing how to plan your life around chronic pain all the time.

Pain, fatigue and the effects of sedating medications, resulted in impaired cognition and reduced capacity to engage in school, work, leisure or social activities. This often led to varied degrees of social isolation. Trade offs were a common element of living with CNP, and the costs of participating in daily activities may be perceived as too great. Despite the pain, several individuals reported that maintaining their functional independence was important regardless of the consequence of increased pain.

Participants reported negative emotions such as frustration, irritability, impatience, anxiety and anger, and described how these impacted their relationships with partners, family, friends and personal care attendants. Several individuals were aware that depression increased their pain and monitored themselves for indicators as a means of prevention. Several individuals expressed concern over the impact of their pain on their partner and children. Two participants shared:

> You know yourself, like when you see your child fall down and scrape an arm, you can feel that scrape yourself. So your better half is going to see you in pain and start living that pain also and feeling helpless because she can't help you cause there isn't nothing to help you with. And;

> What limits me with friends, I don't want to talk to them so much. I don't have that much energy so they come around, I should say, less and less. I'm going to a church, so I was very active there before and I find that it's difficult to get out to my church. And the same with my family in the area, I have four brothers and, ... basically I see them less and less.

In addition to enduring severe pain, participants described a process of grieving the losses related to their SCI. Several, however, indicated that coping with the pain is far more disabling than the SCI itself. Others perceived themselves as "old before my time" and feared further potential losses in functional independence as they age with SCI and pain. Seeking an understanding of the underlying physical cause of their pain was noted in several cases, as well as a lack of comprehension as to the inability of modern medicine to cure their pain. Participants reported visits to their family physician, rehabilitation physiatrist, emergency room visits and hospital admissions in their efforts to seek pain relief. Psychological support was less often accessed or noted as beneficial. Several expressed frustration in communicating with family physicians as pain was not perceived as an issue due to lack of sensation associated with paralysis. Participants also expressed frustration given the irony that insurance companies often accept the cost of medications which are ineffective, while refusing coverage for complementary therapies which provide some degree of pain relief.

Discussion

The four themes that emerged from the data were the nature of pain, coping, medication failure and pain impact. These interrelated themes demonstrate the multidimensional impact of CNP in SCI. It was apparent that all of these participants experienced significant physical pain that impacted their ability to live fully functioning and rewarding lives. These findings are consistent with the literature which reports that CNP interferes with activities of daily living (Turner & Cardenas, 1999), daily function (Davidoff et al., 1987; Nepomuceno et al., 1979; Mariano, 1992), inhibits work and social activity, and necessitates hospital admissions (Cairns et al., 1996). Several physical factors contributed to increased pain; most prominently, fatigue and spasticity. Fatigue was a significant problem in the majority of SCI participants. The physical, emotional and cognitive energies required on a daily basis to cope with the pain coupled with severe sleep disturbance resulted in greater difficulties in coping. Several studies have reported that CNP in spinal cord injury is a significant factor contributing to sleep interference (Biering-Sorensen & Biering-Sorensen, 2001; Haythornthwaite & Benrud-Larson, 2000; Widerström-Noga, 2003). Spasticity was also distinguished as problematic, in that spasms interact with pain resulting in sleep disturbance, which increases fatigue and pain intensity.

CNP was also found to impact these participants' psychological well-being. Participants experienced a wide range of negative emotions that contributed to increased pain. Summers et al. (1991) reported that psychosocial factors were more closely associated with the experience of pain than physiological factors in SCI persons who have chronic pain. In addition, anger (Summers et al., 1991; Conant, 1998) and anxiety (Richards, Meredith, Nepomuceno, Fine & Bennett, 1980) are associated with greater pain severity. Negative cognitions and helplessness beliefs also seemed to be associated with pain severity, interference with life activities, and greater disability. Negative appraisals, also evident, have been significantly correlated with pain severity (Summers et al., 1991). Although, acceptance of disability was reported to be negatively correlated with pain severity, it does not appear to be the case in this study. Participants commonly viewed their spinal cord injury as a minor issue in relation to the difficulty in coping with the severity of CNP.

The impact of pain on family stress and interpersonal relationships was noted in several cases. A number of participants expressed concerns of burdening their partner and made efforts to balance their dependency needs with the needs of their partner. In addition, the inability to cope with the pain led to decreased social interaction.

Participants employed a wide range of coping strategies to manage their pain. Swimming in warm water was found to be equally beneficial for both paraplegics and quadriplegics. Massage, physical activity, and position change were the next most effective strategies. Trans-electrical stimulation (TENS) and acupuncture were infrequently used. While physician prescribed medications were largely ineffective over the long term, SCI individuals self-medicated with over-the-counter medications, as well as alcohol and marijuana. The cyclical pattern of trying medications typically prescribed for the management of CNP resulted in feelings of frustration and mounting levels of anxiety in relation to the inability to manage CNP. Unexpectedly, there were no participants that achieved acceptable pain relief as a result of taking prescribed medications. As such, health professionals' continued efforts to control chronic pain could be seen as contributing to increased pain and disability (Jacobson & Mariano, 2001). When efforts to control the pain are fruitless, SCI patients are often told that they will need to learn to live with the pain. Learning to live with the pain appeared to be related to acceptance of pain, which facilitated adjustment. These participants were less likely to be taking pain medications and have active lives, despite the pain. As well, adjustment did not seem to be related to the level of injury, the duration of the SCI or the severity of pain. These observations share several features noted by McCracken (1998) in his study where acceptance of pain predicted adjustment in chronic pain patients. The concept, acceptance of pain, was defined as the acknowledgement of pain as chronic and non-disabling, the relinquishing of attempts to control the pain, as well as the resolution to live a rewarding life despite the pain. These behaviours were evident among those SCI individuals who expressed an ability to learn to live with the pain.

Limitations

This study constitutes an initial step in gathering qualitative data regarding the impact of CNP in SCI. Although conducting three focus groups increases the reliability of the data, it cannot be assumed that a saturation of themes was achieved. Retrospective self-report can be subject to inaccuracy and the potential for attitudinal consensus within focus group participants is also possible (Sim, 1998). Despite these limitations, commonalities and differences of experience were evident in the emergent themes. Theoretical generalizations are suggested given the rigour of data collection and analysis; however, the availability of empirical data will further strengthen the validity of knowledge attained.

Recommendations

Based on the findings of this study, several recommendations are warranted. A plethora of pain management programs are in place for individuals with chronic musculoskeletal pain; however, little is available for SCI individuals with CNP. Innovative strategies are needed to assist SCI persons to manage CNP when medications are ineffective and side effects are problematic. Mariano (2000) suggests that the goal of chronic pain treatment is to form a cooperative partnership in rehabilitation in which treatment efforts are directed towards reducing suffering and disability; where pain relief is secondary. When medications are ineffective and side effects are unacceptable the focus should be directed toward managing the pain, rather than pain relief. Umlauf (1992) outlines a potentially promising self-management approach for SCI patients with CNP, offering a range of psychological and socially based coping strategies. However, further research is needed to determine which coping strategies are most effective. Research is also warranted to examine concepts such as acceptance of pain in SCI, as well as the relationships between acceptance and adjustment, fatigue and coping, and spasticity and coping with CNP.

In conclusion, this topic was sensitive in nature and on occasion discussion resulted in the surfacing of strong emotions during the focus group discussions. However, these SCI participants generally felt supported and empowered by the group members. Participants expressed appreciation for the opportunity to share their experience and felt that the group approach was beneficial to them individually.

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Table 2.1

Focus Group Questions

Question Number	Question
1	Since your SCI, think back to when you first experienced your pain. Briefly describe what your pain was like then and what it is like now?
2	What makes your pain worse and what makes it better?
3	How has your pain affected your life?

Table 2.2

Definitions of Themes

Theme	*Definition*
Nature of Pain	CNP as characterised by SCI individuals included the following components: type, pain onset, distribution, descriptors, severity, patterns, and augmenters.
Coping	Coping consisted of both the process that involves the use of coping strategies to manage CNP, and the product, which resulted in some level of adjustment.
Medication Failure	Medication failure described the over-all inadequacy in terms of pain relief, and the problematic side effects of analgesia and adjuvant medications.
Pain Impact	The physical and psychosocial consequences of living with CNP.

Table 2.3

Positive and Negative Coping Strategies

Positive Coping Strategies	*Negative Coping Strategies*
Swimming in warm water	Medication (general lack of efficacy, and unacceptable side effects)
Application of heat	Inappropriate self-medication
Massage	Use of alcohol, illicit drugs
Stretching, shifting position	Emergency room visits and hospital admissions
Acupuncture	Focus on pain
Physical activity	Negative self-statements and pain
Leisure activity	Over generalization about pain impact
Retaining family roles	Negative emotions
Engaging in work or school activities	View self as different from others in pain
Information seeking	View others as responsible for pain relief
Rest and relaxation	Social Isolation
Distraction	
Positive self-statements	
Humour	
Resisting negative emotions	
Reliance on spiritual faith	

Chapter 3

Exploring Acceptance of Chronic Neuropathic Pain in Spinal Cord Injured Persons

This chapter is based on the following unpublished manuscript

By

Henwood, P., Ellis, J., Logan, J., Dubouloz, C.J. & D'Eon, J.

Abstract

Background: Chronic neuropathic pain (CNP) in spinal cord injury (SCI) is a significant problem that has physical, functional and psychosocial repercussions beyond the consequences of SCI. Studies indicate that acceptance of pain is associated with lower pain intensity, less pain-related anxiety and avoidance, less depression, less physical and psychosocial disability, more daily uptime and improved work status in patients who have other types of chronic benign pain. Currently, little is known about acceptance of pain in relation to adjustment to CNP in SCI persons.

Purpose: The purpose of this study was to explore the process of acceptance of pain in SCI persons who have CNP.

Method: Grounded theory was used to describe the process of acceptance of pain in SCI persons with CNP. Data was obtained from in-depth interviews with seven SCI individuals.

Results: Six phases were identified in the process of acceptance of pain including 'defining pain', 'seeking pain resolution', 'acknowledging pain permanence', 'redefining core values', 'learning to live with the pain', and 'integrating pain'. Two driving forces, 'increasing independence' and 'evolving pain view', were noted to move the process of acceptance forward.

Conclusions: The findings in this study reveal that acceptance of pain was beneficial in terms of reducing suffering and facilitating a more satisfying and fulfilling life in these SCI persons. Movement away from beliefs in a medical cure for CNP and toward a self-management approach led to increased coping with pain. Further research is needed to examine the process of 'acceptance of pain' and it's relation to adjustment to CNP in a larger sample of SCI persons.

Keywords: Acceptance of Pain; Chronic neuropathic pain; Qualitative methods; Spinal cord injury

Exploring Acceptance of Chronic Neuropathic Pain in Spinal Cord Injured Persons

Introduction

Acceptance of pain is a relatively new construct, however, there are an increasing number of studies that discuss acceptance and it's relation to adjustment in chronic pain patients (Crombez, Morley, McCracken, Sensky, & Pincus, 2003; Geiser, 1992; McCracken, 1998, 1999; McCracken, Spertus, Janeck, Sinclair, & Wetzel, 1999; McCracken & Eccleston, 2003; McCracken, Ecclston, & Bell, n.d.; McCracken, Vowles, & Eccleston, 2004; Ridson, Eccleston, Crombez, & McCracken, 2003; Rankin, H. & Holttum, 2003; Viane et al., 2003). These studies have focused primarily on chronic pain patients who suffer from back pain. Acceptance of pain has been described as a cognitive, emotional, and behavioral response to chronic pain by individuals who recognize the futility of their continued struggle to alleviate their pain (Geiser, 1992; McCracken, 1998). This construct is based on the premise that continued efforts to eradicate chronic pain result in increased disability (Geiser, 1992; McCracken, 1998). Acceptance of pain in these patients is associated with lower pain intensity, less pain-related anxiety and avoidance, less depression, less physical and psychosocial disability, more daily uptime and improved work status (Geiser, 1992; McCracken, 1998; McCracken & Eccleston, 2003). Hence, acceptance of pain is viewed as a favorable alternative to the deconditioning and increased disability that result from efforts to avoid painful activities.

Acceptance of chronic neuropathic pain (CNP) in spinal cord injury (SCI) may be a realistic alternative to prolonged suffering and increased disability when pain eradication is unattainable. Although the few studies of 'acceptance of pain' in persons with chronic benign pain have yielded important findings, this evidence may not generalize to SCI persons who have CNP. The absence of studies and a conceptual framework that describes the process of acceptance as it relates to CNP in SCI suggests a need to explore acceptance of pain in this population.

Purpose

The purpose of this study was to explore the process of acceptance of pain as it relates to adjustment to CNP in SCI persons. In-depth interviews were conducted with seven SCI persons who have CNP. A grounded theory approach was used to analyze the data and construct a conceptual model.

The Problem of CNP in SCI

CNP in SCI is a significant problem that has physical, functional and psychosocial repercussions beyond the consequences of the SCI itself. Neuropathic pain, defined as "pain initiated or caused by a primary lesion or dysfunction in the nervous system" (Mersky & Bogduk, 1994, p.212), is considered to be one of the most disabling sensory disturbances associated with SCI (Nepomuceno et al., 1979; Tasker, 2000; Tunks, 1986). Trauma to the nerve roots or spinal cord as well as changes to the central nervous system that take place over time (Siddall, Taylor, & Cousins, 1995) purportedly result in a cascade of neurochemical, anatomical and physiological changes within the spinal cord and possibly supraspinal structures in the brain that are responsible for the development of clinical symptoms (Agency for Healthcare Research & Quality [AHRQ], 2001; Yezierski, 1996). Clinically, neuropathic pain is identified by anatomical site or the quality of the pain. "At level" pain that presents in a segmental pattern at the level of the SCI, has been described as "burning", "tingling", "sharp", "aching", and "shooting" (Mersky & Bogduk, 1994; Siddall, Taylor, & Cousins, 1997; Siddall, Yezierski, Loeser, 2000), or as an area of severe hypersensitivity that is evoked by non-painful stimuli (Tasker, 2000). “Below level” pain, also known as “deafferentation pain” refers to diffuse pain found in all parts of the body below the level of injury. “Below level” pain, typically described as “burning” “tingling”, “aching” “shooting”, or “stabbing”, is considered to be the most common and difficult to treat (Ravenscroft, Ahmed, & Burnside, 2000; Tasker, 2000). SCI patients may experience more than one type of neuropathic pain, in addition to nociceptive pain types of a musculoskeletal or visceral origin (Ravenscroft et al., 2000; Siddall et al., 2000). In addition, the intensity of CNP is reported to gradually increase over time (Nepomuceno et al., 1979; New, Lim, Hill & Brown, 1997; Störmer et al., 1997).

Typically, CNP presents within six months to one year post-injury (Cairns, Adkins, & Scott, 1996; Davidoff, Roth, Guarracini, Sliwa, & Yarkony, 1987; Siddall et al., 2000; Tasker, 2000), however, later onset of CNP may also occur, often indicative of syringomyelia, a spinal cyst which develops secondary to the SCI (Tasker, 2000).

The prevalence of CNP as reported in the literature varies due to the lack of consensus regarding the definitions, terminology, and classification systems used to describe SCI related pain and the lack of a valid instrument to assess CNP in SCI persons (AHRQ, 2001). In many studies, CNP tends to be distinguished from other types of pain based on the characteristics and qualities of the pain as described by the patient. A review of the literature indicates that the prevalence of CNP in SCI persons varies from 40 to 75% with 25 to 60% of individuals experiencing moderate to severe pain (AHRQ, 2001). Approximately 36,000 Canadians currently live with a SCI and each year an estimated 1,050 new injuries occur. Of these new injuries, 78% involve individuals between the ages of 15 and 34 years (The Canadian Paraplegic Association Ontario, 2000). Based on a prevalence of 75% (AHRQ, 2001), it is estimated that up to 27,000 SCI persons are currently living with CNP in Canada.

A number of studies indicate that CNP negatively impacts SCI individuals in a number of ways. SCI persons with CNP are reported to have greater functional disability (Davidoff et al., 1987; Lundqvist, Siosteen, Blomstrand, Lind, & Sullivan, 1991; Mariano, 1992; Widerström-Noga, 2003) and interference with activities of daily living (Richards, Meredith, Nepomuceno, Fine, & Bennett, 1980; Turner & Cardenas, 1999), decreased mobility, sleep disturbance (Biering-Sorensen & Biering-Sorensen, 2001; Rintala, Loubser, Castro, Hart, & Fuhrer,1998), and overall poorer self-rated physical and mental health (Putzke, Richards, & Dowler, 2000). SCI persons with CNP often have more medical problems that require frequent clinic visits (Britell & Mariano, 1991; Mariano, 1992) and a greater number of re-hospitalizations than those who do not have pain (Nepomuceno et al., 1979; Rintala et al., 1998; Turner & Cardenas, 1999; Westgren & Levi, 1998).

Several studies indicate that CNP in SCI is also associated with significant psychological distress (Anke, Stenehjem, & Stanghelle, 1995; Rintala et al., 1998) over and above that of the SCI itself (Summers, Rapoff, Varghese, Porter, & Palmer, 1991). Psychological factors such as anger (Conant, 1998; Summers et al., 1991), anxiety (Richards et al, 1980), loneliness, and depression (Cairns et al, 1996; Kennedy, Frankel, Gardner, & Nuseibeh, 1997; Störmer et al., 1997) have been shown to correlate significantly with CNP in SCI. Summers et al. (1991) reported that greater pain severity was associated with more anger, the perception of a punishing response from significant others, and less acceptance of disability. Pain severity was correlated with psychological factors rather than physiological factors. Cairns et al. (1996) reported that SCI persons are more likely to become depressed if their pain increases in severity over time rather than the converse.

SCI persons with CNP are also noted to experience social and family problems (Britell, Umlauf, Loehr, & DeLisa, 1986; Haythornthwaite & Benrud-Larson, 2000; Mariano, 1992; Putzke et al., 2000; Richards et al., 1980), less social and recreational activity (Murphy & Reid, 2001; Nepomuceno et al., 1979; Ravenscroft et al., 2000; Turner & Cardenas, 1999), interference with work (Rose, Robinson, Ells, & Cole, 1988; Widerström-Noga, 2003) and decreased economic self- sufficiency (Putzke et al., 2000; Ravenscroft et al., 2000; Westgren & Levi, 1998).

Unrelieved pain can lead to maladaptive behaviours that interfere with SCI persons' ability to pursue life goals and activities. The early onset and the tendency for CNP to increase in severity over time (Beric, 1997; Nepomuceno et al., 1979; New et al., 1997; Störmer et al., 1997), as well as the relative lack of effective treatment options (Beric, 1997; Eide, 1998) contribute to further disability that negatively impact the rehabilitative process, adaptation to the SCI, and quality of life (Levi, Hulting, Nash, & Seiger, 1995; Lundqvist et al., 1991; Putzke et al., 2000; Stensman, 1994; Westgren & Levi, 1998). Since SCI often occurs at an early age and the life expectancy of SCI persons approximates that of the general population (Devivo, Rutt, Black, Go, & Stover, 1992; Tunks, 1986; Whiteneck et al., 1992), SCI persons may expect to live with CNP for a very long time.

When efforts to alleviate pain have not been successful, SCI patients are often told that they will need to "learn to live" with the pain. This statement is reflected in studies that explored the concept of 'acceptance of pain' in chronic pain patients who suffer primarily from musculoskeletal pain. Acceptance of pain as defined by McCracken (1998) entails "giving up the struggle with unyielding pain and learning to live a better life" despite having chronic pain (p.22). The notion of 'acceptance' as it relates to coping with CNP in SCI emerged from an exploratory study that investigated the effects of CNP in SCI individuals (Henwood & Ellis, 2004). During the focus groups, several SCI participants spoke of 'learning to live with the pain'. Given McCracken's definition, acceptance of pain seems to be reflected in the following statement, "As time went on and a year went on, I started getting adjusted to it and learned to live with it and life went on since then." Other SCI participants who were struggling with their pain asked, "How do those persons learn to live with their pain?"

Methods

A grounded theory approach was used to understand the construct and the process of acceptance of pain in SCI persons with CNP. This approach is useful when trying to understand complex social and psychological processes that people use to help them deal with difficult problems (Strauss & Corbin, 1998, Streubert & Carpenter, 1995; Norwood, 2000). In addition, grounded theory provides researchers the means to investigate important health related phenomena that can lead to the development of clinically relevant interventions.

Sample Selection

The sample for this study was comprised of community-living SCI persons with CNP, who were currently receiving, or had previously received, treatment at a rehabilitation center in Ontario. The spinal cord outpatient clinics currently provide services to approximately 350 community-living SCI individuals. Participants were selected based on the following criteria: a) the presence of a spinal cord injury; b) a medical diagnosis of neuropathic pain lasting more than one year; c) individuals over the age of 18 years; and d) a proficiency in the English language. Participants were excluded if they had: a) an acute medical problem that restricted the ability to participate; b) a cognitive impairment that limited the ability to communicate effectively; c) a co-existing psychiatric condition; and d) an active substance abuse problem. The study protocol was approved by the Research Ethics Board of The Ottawa Hospital, Rehabilitation Centre. A nurse practitioner identified potential participants from a list of SCI outpatients, according to the inclusion criteria. Her clinical involvement with these patients provided her with the knowledge of those individuals who were no longer solely invested in seeking a cure for their CNP. With their permission, the investigator invited nine SCI persons to participate in the study. Seven persons agreed to participate while two declined due to a lack of available time. An information sheet outlining the purpose, procedure, risks, benefits and participant rights was provided (Appendix D). Written consent was obtained at the time of the interview (Appendix E).

Data Collection and Analysis

Data sources included participant interviews, field notes and demographic and clinical information obtained from each participant's hospital chart (Appendix F and G) .

Audiotaped interviews, 60-90 minutes in length, were conducted in the participants' home or at the rehabilitation facility. A semi-structured interview guide was used to facilitate discussion and data collection (see Table 3.1). Probing questions were introduced to explore in greater detail each participant's thoughts that were reflective of the process of acceptance of pain. The interview guide was piloted with one SCI person who had CNP in order to determine the clarity and effectiveness of the questions.

The audiotapes from each interview were transcribed verbatim. Following data screening and editing, a constant comparative analysis of all the transcripts was performed. ATLAS.ti, a computer software package designed for qualitative research, was used to facilitate data management. The analytical techniques and procedures for developing the substantive theory were adopted from Corbin and Strauss (1998). Three levels of coding (open, axial and selective) were used to analyze the data obtained during in-depth interviews with the seven SCI participants. 'Open' and 'axial' coding aided in the identification of concepts reflective of acceptance of pain, their respective characteristics (properties) and range of variation (dimensions). As the concepts were grouped and collapsed into categories and sub-categories, an analytic tool referred to as a 'paradigm' was used to integrate 'structure' and 'process' which facilitated tracking the interrelationships between each of the developing key categories. Each category was analyzed for 'structure' and 'process' by examining the range of 'conditions' of events that were representative of acceptance of pain and intervening 'contingencies' with the strategic or routine 'actions/interactions' taken in response to each condition and the subsequent 'consequences' of these actions. The constant comparative analysis of data, writing of progressively more complex theoretical memos, and construction of increasingly integrative diagrams led to the emergence of provisional hypotheses that explained the interrelationships between the categories. These hypotheses were confirmed during subsequent interviews and the categories were saturated with ‘theoretical sampling’ of data through the posing of relevant questions. Identification of the core category and integration of the key categories occurred during the process of ‘selective’ coding. A descriptive account of the process of acceptance of pain was written that incorporated all of the key categories. The conceptual framework was further refined as the theoretical memos and diagrams were systematically reviewed, ensuring that there was no evidence of gaps or departures in logic.

Several strategies were used to ensure the trustworthiness of the data analysis. A comprehensive audit trail derived from a series of memos was maintained to facilitate understanding of the decision-making process around codes and categories. The second author (JE) participated in the development of the codes to avoid the risk of bias. Periodic debriefing was conducted with the co-authors (JE, JL, CJD, JD) to validate the developing conceptual framework. A summary of the research findings including an illustration of the conceptual framework was given to five of the six participants who consented to verify the accuracy and comprehensiveness of the researcher’s interpretation of the data (Appendix H). One SCI person who had given consent could not be located and one other person had declined the offer to participate.

Findings

Sample Description

Five men and two women ranging in age from 30-60 years, and 30-67 years, respectively, participated in this study. Years since the onset of the SCI ranged from two to 36 years. Four participants had a traumatic SCI and the remaining three resulted from cord compression due to cervical stenosis, lumbar disc protrusion or the progressive effects of Arnold Chirari Malformation. There was widespread representation of neurologic level and extent of spinal cord involvement with four persons having quadriplegia and three having paraplegia. Three of the participants were ambulatory to varying degrees. The onset of neuropathic pain occurred immediately post-injury in four cases, during the first six months to one year in two cases, and twenty-one years post-injury in one case. The duration of living with CNP ranged from two to thirty-six years.

Conceptual Framework Development

The conceptual framework to describe the process of acceptance of CNP in SCI persons was developed around the core category, ‘moving forward with pain’, also referred to as the basic social process (BSP). The BSP is defined as a core category that integrates all of the major categories, accounts for variation in behavior and demonstrates process and change (Glaser, 1978). In this study, ‘moving forward with pain’ emerged as the BSP as it was evident in each of the six major categories that include ‘defining pain’, ‘seeking pain resolution’, ‘acknowledging pain permanence’, ‘re-defining core values’, ‘learning to live with the pain’, and ‘integrating pain’. These categories, as presented in Table 3.4, constitute the phases that describe the conceptual framework, ‘acceptance of CNP’.

The conceptual framework to describe the process of ‘acceptance of CNP’ in SCI persons is best described in terms of a wheel (see Figure 3.1). The six segments within this wheel represent each of the six phases. These SCI persons typically advanced through the six phases in a sequential fashion. They moved forward gradually through each phase as they gained experience in living with CNP. Overlap between the respective phases occurred as the cognitive, emotional, and behavioural adjustments that were characteristic of each phase were adopted. The spokes of the wheel that separate each phase illustrate the periodic setbacks to a prior phase that can occur in response to an increase in pain severity. As the necessary adjustments were made overtime, these SCI participants continued to move forward toward acceptance of CNP. Variation was noted in the time span required to pass through each phase and not all individuals had achieved the final phase of acceptance at the time of the interviews. In these individuals it seemed that the rate of passage through each of the six phases was not linked with the extent or chronicity of the SCI, the chronicity of CNP, or the age of the SCI person.

Two processes, ‘increasing independence’ and ‘evolving pain view’, that were integral to ‘moving forward’ through each phase, are represented by the area between the two outer concentric circles. Acceptance of pain is illustrated as the inner circle. The following findings describe each phase and the associated adjustments undertaken during the process of ‘acceptance of CNP’ as based on information obtained from the participants.

Defining Pain

CNP was described as being “an intense cold sensation”, “burning”, “throbbing”, “aching”, “shooting”, “electric shocks”, “stabbing”, “sharp”, and “like a constrictive belt”. The quality of pain was also expressed by means of metaphor such as “like you go skating in the winter and your skates are too tight”, “like someone putting a cigarette out on your bones”, or “it feels like somebody’s pulling my toenails off”. Although pain intensity scales were not the primary means used to describe CNP, two persons described their average pain severity as being seven and eight on a ten point numerical rating scale. Four persons indicated that their CNP had worsened over time. In one case, the pain severity had decreased somewhat but was still considered to be severe. In most cases, these participants also lived with other pain types including back pain, upper extremity pain, hip pain, bladder pain, or painful spasms in the lower extremities. One individual stated, "Paraplegics, get more aches and pains, as you go along, it's just unbelievable." Numerous factors were reported to exacerbate CNP including bladder infections, constipation, activity and/or inactivity, prolonged sitting, spasticity, exposure to heat or cold, fatigue and anxiety.

The Enigma of CNP. Initially these SCI persons did not associate CNP with their SCI and often appeared to question on an existential level the 'why' of overwhelming pain when they were already burdened with functional limitations related to their SCI. A lack of understanding regarding the nature of CNP appeared to be associated with fear of the "unknown" that influenced the ability to accept the pain. The following quote illustrates the initial challenge that these participants faced in making sense of CNP:

> When I had my injury at the beginning in 1981 when I was thinking of this pain, of the burning sensation, I would often go and cry in the corner because I couldn't deal with the pain. I found it too hard to take and I was wondering why I was having these pains since I had my injury.... I was disabled plus I had to suffer throughout this pain, take this pain with me and I couldn't deal with this. It was way too much, having the disability plus the pain, the burning pain and burning sensation. It was too much at the beginning.

The unpredictability of CNP in terms of pain severity and the tendency for CNP to increase in severity over time was one of the most confounding and disruptive features impacting the physical and psychosocial well-being of these SCI persons. Although there appeared to be a somewhat predictable pattern of pain, in terms of pain increasing throughout the day and following activity, within that pattern, unpredictable spikes in pain intensity could also occur. The source or triggers of increased pain were often inexplicable. It seems that these illusive factors represented an enigma that contributed to some form of inner conflict. As one participant stated:

> Me, day to day it's pretty much the same, but within that sameness there's ... like some days I wake up like this and I have no idea why my feet hurt so much. You know, I'm starting to chalk it up to the moon, is it the tides and I don't know, maybe I'm starting to think, man what did I eat? … And I have no idea why. That erraticness [sic] plays on your peace of mind.

Pain Impact. There was a general consensus that CNP represents a significant problem that is equal to or greater than the disability resulting from the SCI. CNP was initially perceived as impeding the ability to live "a basically normal life". The physical repercussions of CNP including energy depletion, fatigue, and activity intolerance affected these participants ability to cope with their pain. A synergistic balance between energy and CNP was notable in its relationship to coping with pain. Energy is consumed in daily activities and in coping with CNP; however, when pain levels are increased, more energy is re-directed toward coping with pain. Energy depletion resulted in physical and emotional exhaustion, activity intolerance, and exacerbation of pain severity that decreased coping ability. The relationship between energy consumption and coping with CNP as described by these two participants is significant:

> My most precious commodity is energy. I'm energy deficient and because energy and chronic pain are so closely linked, right? The days where you're having those 7 out of 10's from the minute you get out of bed, well you've got less gas to go that day, because most of it's getting consumed by just coping with the disabling pain. When the pain is a little lower, you seem to be able to do a little more. And; Physically it drains and mentally ... it just sucks the energy out of you, fighting the pain, just going through your daily routine, it takes more effort. And you tire yourself out.

CNP also resulted in a number of functional limitations including decreased self-care, impaired mobility, prolonged bedrest that resulted in deconditioning and decreased seating tolerance, as well as decreased capacity for instrumental activities. A synergistic interaction between CNP and spasticity further contributed to greater functional limitations as evident in the following quote, “When the pain is bad the spasms are worse”.... “and just everything gets harder. And it takes more effort and it takes more time.”

The presence of CNP in SCI was also perceived to limit functional capacity and level of independence as reflected in the following quote:

> You see yourself moving backward a little bit, and it's not a very nice feeling, you know, when you've made progress and now you're slowly inching backwards again. It's like, gone.

SCI persons also reported that CNP contributed to impaired thinking, significant emotional distress, and social isolation. Cognitive difficulties in terms of concentration, clarity of thought, diminished short-term memory and creativity resulted in decreased work productivity, especially with increased pain severity. Negative emotions and cognitions associated with CNP such as anger, frustration and bitterness were found to increase the severity of pain, create greater emotional distress, and a lowered sense of self-efficacy and self-esteem that seriously limited the ability to cope with pain. One participant stated that "having CNP affects, the way you see it [pain], the way you think and the way you see yourself with pain … pain actually gets you mentally where you are the weakest … I think pain in my life amplified everything."

CNP contributed to a decreased sense of control over life that prevented them from actualizing their dreams, regardless of the disability. These SCI persons may have perceived themselves as incapable of managing the responsibilities of having a spouse, family, work or school, thereby limiting the pursuit of meaningful relationships and/or potentially rewarding activities. The stress of living with CNP reportedly reduced tolerance for frustration contributing to negative interactions with others. The fear of being ostracized should they focus on their pain could also cause them to suffer in silence, ultimately leading to self-imposed social isolation. The frequent loss of social and recreational opportunities, one of the most frustrating effects associated with the unpredictability of CNP, may result in the sense that life is passing them by. The impact of CNP in terms of physical suffering and its psychosocial ramifications led these SCI persons to the second phase in the process of 'acceptance of pain' that being 'seeking pain resolution'.

Seeking Pain Resolution

Pain Focus. Seeking pain resolution was a prolonged phase that was related to the nature of CNP and its impact on life. Throughout this phase, SCI persons' attention, time and energy were expended in actively pursuing a means to alleviate their suffering while struggling to cope. The driving force behind seeking pain resolution was the commonly held belief that a cure for chronic pain is achievable. The belief that CNP was resolvable generated self-expectations or expectations from family, friends and even health care providers to continue the pursuit of pain relief despite evidence to the contrary, thus reinforcing a continued pain focus. However, each successive effort to find the 'magic bullet' to control CNP resulted in mounting frustration. Each person eventually reached his or her own individual limit as to how far and how long they would continue their search. During this often-lengthy phase, SCI persons perceived their pain as being a "disabling factor" that intruded on their daily life, a factor over which they had no control.

Cyclical Process. As these SCI persons strived to find resolution of their pain, they typically became engaged in a cyclical process of trying medications commonly prescribed for neuropathic pain. Each medication was tried for a period of weeks to months and the dosage was adjusted to achieve the maximum effect. Despite the dosage increase, pain relief was inadequate and the presence of unacceptable side effects often led to the decision to discontinue the medication and proceed to the next available option. This participant describes his experience with medications:

> Yea, well we explored the pharmacological ends. I tried this one, that one. It didn't work, it didn't work, it didn't work.... I tried going off one of them.

> Carbamazepine, my legs felt like they weighed 1000 lbs each. And that humming was to the power of 10 or worse. So I couldn't go off of that.... So, and then I just thought, well no problem there doctor. Just reach to the right or to the left on the medical shelf and grab me the next drug.... And that's when I found out that there aren't as many pills out there as we would like to believe.

When the hope of pain relief through medications was exhausted, several of these SCI persons turned to alternative treatments in an effort to seek pain relief. While these treatments may have provided partial and temporary pain relief, the costs in terms of time, energy, money, and the potential for treatment-induced pain were often judged as unacceptable. As such, these strategies were frequently abandoned. Efforts to alleviate CNP through alternative therapies are noted in this quote:

> I went to see a psychologist to do that hypnosis at the ____, and I think I followed this doctor for a period of a month and a half at least, to try some hypnosis, and that didn't do anything. So I stopped that. Maybe I stopped too fast, but after a while if it didn't work for a period of a month or two I would stop the treatment.... And then I decided to go for meditation. I tried that for a period of 3 months. I went to a course, a four hour course of meditation and then that didn't work either.

Acknowledging Pain Permanence

Futility in seeking pain resolution. During a prolonged phase of 'seeking pain resolution', these SCI persons gradually came to recognize the permanence of CNP, the futility in the continued pursuit for a pain cure and the need to "learn to deal with it". Awareness of this fact signified a pivotal turning point in the process of acceptance because it reflects the initiation of behavioral change. Since the resolution of pain was no longer an expectation, the intensity of behaviors aimed at seeking pain resolution decreased. Acknowledging pain permanence is reflected in the following quote:

> And then I finally said to myself, nothing's going to work. I might as well try to live with it, and learn to live with it, and that's when I made the decision and since then I haven't tried pursuing any type of pain relief.

As these SCI persons acknowledged the permanence of CNP, they proceeded to the fourth phase of acceptance of CNP, ‘re-defining core values’.

Redefining Core Values

Redefining core values involved a cognitive process of introspection and self-talk whereby the relative importance that pain played in their lives and future life aspirations was considered. The determination of core values in life coupled with the acknowledgement that they had no control over their pain led to an attitudinal shift to ‘move forward’ in life despite having CNP. Reflection of core values is noted in the following quote:

> When I was doing my studying and I had these burning sensations I was saying to myself, geez, is it worth it for me to go to school and try to learn all this stuff while I'm having burning sensations. Am I going to have this for the rest of my life? And I kept saying this on and on for a long period of time. Then I said to myself, well I may be stuck with this for the rest of my life and then I'll have to make a decision. Am I going to live with it or am I going to dwell on it, and … just dwell on the pain and the pain and the pain, the constant pain. Then I decided

> for myself, no, I'm going to change my attitude and then go on, do my studying, do my learning, and then forget about the pain.

Pain and Uncertainty. As each SCI person evaluated their way of living with CNP while contemplating future wishes, this led them to decide to get on with life and no longer invest time and energy in an unattainable goal, alleviation of pain. However, the decision to redirect attention away from seeking pain resolution was a difficult endeavor for these SCI persons as they recognized that they alone must learn to live with the pain. Uncertainty remained as to how they would learn to cope with CNP and their potential to actualize life goals. Despite this uncertainty, the perception of CNP began to shift from a "disabling" to a "limiting" factor. The following quote reflects the difficulty of facing a life with CNP without the means to cope:

> So all I knew back then was the pain and the frustration of not being able to deal with the pain, and how limiting it all was on top of the impairment itself.... At first it's ... I'm not going to be able to do anything.... at first it would hit me and then I wouldn't know what to do. I would be just totally disabled by it.

The uncertainty of how they could come to live with CNP signaled the commencement of the fifth phase, 'learning to live with the pain'.

Learning to live with the pain

Learning to live with CNP was a critical phase in the process of accepting CNP. Indeed, a symbiotic relationship was found to exist between learning to live with the pain and acceptance of pain with the interaction between each component contributing to greater coping with CNP. One participant referred to acceptance as, "It's like a coin with two sides. One depends on the other [acceptance and learning]." Another participant shared their belief that learning to live with CNP involves a gradual process that unfolds with experience as “you take it [learning] step by step and accept it [pain] step by step”.

Overall, learning to live with CNP was a prolonged phase that was perceived to be a challenging undertaking requiring a firmness of resolve that transcends the negative impact of pain. Just as the SCI person struggles to overcome the limitations of the disability associated with their spinal injury, they applied considerable effort and willpower in learning to live with CNP. Learning to live with CNP involved a process whereby their cognitive, emotional and behavioral approach to coping with pain was modified. Learning to live with the pain and acceptance of pain were realized by these participants as they ‘moved forward’ through a series of adjustments as described in the following sub-processes: ‘de-valuing pain’, ‘learning one’s functional limitations’, ‘setting and achieving goals’, ‘maximizing function’, ‘mind-body connection’, and ‘adopting pain management strategies’.

De-valuing Pain. An attitudinal shift was noted as these SCI persons underwent a process of devaluing the importance that CNP played in their lives. Although they may not have a choice as to whether they have pain, these participants recognized that they have a choice as to how they will live their life in spite of pain. During this phase, a gradual evolution in pain view occurred whereby CNP was no longer considered to be a “disabling” factor, dictating what they could or could not do in terms of activity, but rather as a “limiting” factor. The following two quotes reflect the notion of de-valuing pain:

> You kind of have the choice of letting the pain take over or like I said, being not as important. So I've put it on the backburner as much as I could. And;

> I've accepted that that's [CNP] the way it is. I haven't accepted that it's going to totally limit my life. You know, I've accepted that it does impose limitations. But I mean what doesn't in life? Right?

Learning one's functional limitations. Through a process of trial and error while analyzing the body's response to activity, SCI persons gradually learned their functional limitations related to CNP. The ability to accurately interpret pain rather than catastrophizing the presence of CNP, developed as they became aware of "body cues", thereby enabling them to make choices regarding participation in activity. An understanding of their functional limitations related to CNP, fostered these SCI persons learning to perform cost-benefit analyses considering positive and negative influencing factors, as well as potential consequences of their involvement in a particular activity. The ability to assess and choose activities based on energy expenditure and the associated recuperative period and restorative activities needed was an important skill to be learned.

Grieving the losses associated with the limitations imposed by pain and disability occurred as they accepted that life would not be as they ever imagined it would be. Gradually these limitations were accepted as they adjusted their expectations in terms of the capacity for activity. Gaining an understanding of one's functional limitations associated with CNP is demonstrated in the following quotes:

> And your body gives you choices. You just have to listen to the choices it gives you. That's the first thing you have to do is learn how to listen to your body, which a lot of people can never master. And;
>
> And then certainly you learn that you can do things. You just can't do everything. You just can't do them all the time. And you just can't do them as much. And;

> It's through little steps that I'll relearn ... what I can and can't do, or... it's more ... how much of it I can do, and not being, I can't do it at all. So, I guess it's being realistic in how much the pain is there without exaggerating it, and also like I was saying, it's building my life differently to be able to accept all that.

Setting and achieving goals. Similar to learning their functional limitations associated with CNP, these participants to learned about their functional capacity in relation to CNP by setting small achievable goals in valued activities, providing them with a sense of satisfaction and accomplishment. Achievements were noted to support continued participation in activity, a view of pain as a "limiting factor" and a lessened impact of CNP in life that fostered optimism regarding the potential to actualize greater life goals. This participant spoke of setting realistic goals in terms of enhancing her level of fitness and emotional well-being:

> So it's getting everything fit again to minimize the pain, but again through little steps. Setting little goals instead of huge goals that was my problem, I would set goals that were way too high for the amount of fitness that I had.

Maximizing function. The process of 'learning to live with CNP' was likened to that of learning to live with the disability attributed to the SCI. As a SCI person becomes familiar with the body's functional limitations, they learn and incorporate various strategies that facilitate independent functioning within the restrictions of the neurological impairment. In the context of CNP, maximizing one's functional capacity translated into a greater level of independence. The ability to "do for oneself" was noted to decrease the impact of the pain and create a perception of greater control over CNP because it facilitated the ability to lead a more active life. Similarly, the ability to be independently mobile through the use of mobility aids such as a power wheelchair or adapted vehicle for transportation enabled those SCI persons with severe physical impairment to exert some degree of control over their pain. One person with quadriplegia who had experienced a prolonged period of bedrest due to CNP reported rediscovering the joy of independence when he resumed sitting in his wheelchair, thereby enabling him to live a more fulfilling life.

Mind-Body Connection. During the 'learning' phase, participants also spoke of developing an awareness of the impact of negative and positive thoughts and emotions on the quality of their pain and their ability to cope. Changing a "train of thought" from negative to positive thoughts facilitated the development of greater patience, a positive attitude, and optimism with respect to the ability to manage their pain and attainment of future goals. Awareness of the effect of positive and negative cognitions is demonstrated in the following quote:

> Knowing the effect that pain has, you're able to control it. If you don't know it, you can't do anything about it.... it's being able to put everything in perspective again, the perspective I lost through letting pain take over.... knowing that pain is aggravating if you let it be aggravating, and drain your energy, and drain everything, then all you're left with is negative emotions.... They're always on the surface. Also being angry at the situation, angry because you have pain. It gets those emotions too. So again it's being trained to ... changing the train of thought. Before with pain I can't do anything, always being negative about everything.... well, now I see it differently.... I have pain, but I can get the good emotions out now, where before ... I let the good emotions take the backburner to the pain.

Adopting Pain Management Strategies. Pain management strategies were learned through discovery, experimentation and problem-solving. With experience gained over time and much practice, SCI persons learned what type and combination of strategies enhance their ability to function and cope with CNP. Although there were common strategies used by these SCI persons, each person's "tool bag" may vary dependent upon their experience in learning to live with the pain. Their "toolbag" may include pain management strategies such as redirecting attention, keeping busy, pacing, exercise, rest, humor and prayer. Other activities or modalities reported to provide temporary and partial pain relief that facilitated coping with CNP included the use of hot water/hot tub, massage, and acupuncture. The following two quotes illustrate the adoption of pain management strategies through discovery, experimentation and problem solving:

> Back then, … my tool bag was empty.... as time goes by, you live and hopefully learn a little bit and then you figure out that you get a little relief from stretching, and from exercising. Because if you don't exercise any, you hurt more, which is even ... you know, that's what makes it so mind boggling. If I do nothing I hurt, if I do lots I hurt, if I do a little bit, so it's you got to find the happy medium. So yea, you find out that stretching works. Probably after you found out that resting works better than anything else. Then you discover ... not everything works for everybody. Then you discover, like I discovered that I benefit from massage therapy. And;
>
> I think it's the sum of the total of everything that I'm doing that benefits me. Because I've tweaked with it in different combinations, and whenever I take one of these things out of the order, I'm that much less better off. So, you know, I

> don't think any one of them per se by itself is any miracle, you know, cure. But sum of the total is my bag of tricks for managing, you know, my pain. That's the way I look at it.

Integrating Pain

Incorporating Pain Management Strategies. As each SCI person's "tool bag" of pain management strategies was integrated into daily life, such that they became familiar behaviors, they were better able to tolerate CNP. Established routines that provided daily structure in living with pain also engendered a greater sense of control over life and optimism regarding their ability to fulfill future goals. Experience in 'living' with CNP acted as an educator, guiding these SCI persons to draw upon the most appropriate pain management strategies given a set of conditions. The notion of drawing upon experience in coping with CNP is illustrated in the following quote:

> After a while you get accustomed to that procedure of doing battle. You become kind of like an old soldier.... The new soldier will want to find out and get specific directions at all times. An old soldier will go out and he can cope without having to be directed at all times.... After a while you get to that point where your mind works in a way where it serves you well.

Normalizing Pain. Just as these SCI persons' approach to managing CNP evolved over time, so too did their view of the pain. During this final phase, CNP was considered to be a "known" factor that can be managed. Living with constant pain was normalized in the sense that they expected and adapted to its continued presence. They became accustomed to a constant baseline level of pain severity, did not anticipate increased pain, or catastrophize the presence of unpredictable pain spikes that are part of the enigmatic nature of CNP. CNP was accepted as being a part of everyday life, recognizing that the pain can vary from day to day. These participants appreciated the need to apply their "tool bag" of pain management strategies in order to maintain their pain at a "liveable level". The normality of CNP is reflected in the following quote:

> Well, I refer to pain as just being part of my reality, part of my world. You know, I'm still looking for ways. I'll never stop turning over rocks, but, I'm not going to dedicate my life to it. So I accept it as being part ... you know, of my day-to-day life, and having to deal with it as part of my day to day life. And that varies from day to day, yes, but nevertheless on any given day I have to do certain things for the sole purpose of maintaining my chronic pain to a liveable level. That's just the way it is. And if you can't realize that, well then that'll be your downfall because only by realizing that and operating the best you can within the limits set out, and the tools that you've chosen, can you truly maximize or hope to maximize yourself as a person.

One SCI person said that "although you learn to live with the pain and accept the pain, you never, ever would be able to turn a blind eye to it". It can still be a struggle to cope and when pain levels are increased "you must then go deep down inside" to draw upon personal resources and experience in finding creative ways to cope with the pain. Although each SCI person remained open to the possibility of trying new pain management strategies, life was not dedicated to the pursuit of pain resolution. Adjusting to increased pain severity in relation to acceptance is reflected in the following quote:

> Yes, I learned to live with it but still I know the pain is there and when the pain is really, really high it's hard some days to go on but it doesn't affect me.... It doesn't change my acceptance of the pain.... It's just an adjustment during the daytime.

Rebuilding an active lifestyle. Re-building an active lifestyle based on ability and not disability was considered to be a key factor in enabling these SCI persons to accept CNP. “Being in pain or living with pain” are viewed as being “two different lifestyles”. “It's what you make of your lifestyle that can help you to go through it [CNP].” Pain was integrated into daily life while rebuilding an active life centered on valued activities. The presence of pain no longer superseded the decision to participate in valued activities nor prohibited the pursuit of life aspirations. Maintaining an active lifestyle was associated with redirecting attention away from the pain that further supported efforts to actualize goals and fostered greater coping and acceptance of CNP. The notion that CNP is no longer a priority in life is demonstrated in this quote:

> When I get up in the morning I know I have some pain and I know the pain is probably going to increase during the daytime ... but it's something that I've learned to live with and I keep myself busy enough that I accept the pain being there with me all the time. And not to stop me from doing what I love doing, going to work and taking care of the family, and that's how I learn to accept the pain.

Unifying pain with ones' identity. As these SCI persons rebuilt an active lifestyle while integrating CNP into their daily lives, a transformation occurred whereby pain was merged with their self-identity. Initially, CNP was distinguished as a separate entity from the disability associated with the SCI, a force over which they had no control. With acceptance, CNP became “part of what you are”. The following quote illustrates a more complete self that includes disability, CNP, and a fuller life:

> So there's other aspects involved in my life, not just me, spinal cord injury, and chronic pain. Now there's me, spinal cord injury, chronic pain, I go to physio 3 times a week, I go out, I have friends, I go for coffee, I go to movies.... I mean it still infiltrates every aspect of your life, but it's ... you know, once you start to know more things, well it just becomes part of a mix.

Discussion

A grounded theory approach (Strauss & Corbin, 1998) was used to develop a conceptual framework that describes the process of acceptance of CNP in SCI persons. The rich data obtained from these SCI participants portrays ‘acceptance of CNP’ as a complex phenomenon involving a series of cognitive, emotional and behavioural adaptations that unfold within six phases. These phases include: ‘defining pain’, ‘seeking pain resolution’, ‘acknowledging pain permanence’, ‘redefining core values’, ‘learning to live with the pain’, and ‘integrating pain’. During these phases, SCI persons were continuously pushing forward in their efforts to cope with their pain while striving to regain an active life. Two driving forces, ‘increasing independence’ and ‘evolving pain view’ were noted to move the process of acceptance forward.

Support for the concepts in the proposed framework can be found in the literature related to chronic pain and adaptation to disability. The components of the framework that describe the process of acceptance of CNP in SCI persons are similar in a number of ways to concepts that describe ‘acceptance of pain’ in chronic pain patients; however, differences are also apparent. These concepts are discussed in relation to the six phases in the process of acceptance of CNP.

While the concept, 'defining pain', is not generally considered to be a component of 'acceptance of pain' in chronic pain of other types, the unique nature of CNP in SCI persons supports its inclusion in this framework. The use of metaphor including words of a violent nature was common because descriptors typically used for other types of chronic pain were viewed as inadequate to convey the magnitude of suffering. The peculiar features of CNP in terms of its quality, unpredictable pattern and tortuous intensity represented an enigma that was difficult for these SCI persons to interpret and easily describe. Initially these SCI persons were trying to understand why they had pain in addition to the disability caused by the SCI. The absence of an apparent source of CNP coupled with its unpredictable nature was perplexing and resulted in cognitive and emotional turmoil.

In general, living with chronic pain contributes to a gruelling lifestyle and the perception that one's body is under attack. Pain is perceived as an indicator of physical dysfunction and as such requires intervention (Aldrich & Eccleston, 2000). Initially these SCI persons viewed CNP as an inordinate obstacle that they were powerless to overcome. The debilitating physical, emotional and cognitive effects of CNP were believed to be as great as, or greater than those attributed to their SCI.

Although 'seeking pain resolution' is a common characteristic of the chronic pain experience (Aronoff & McAlary, 1992), total and permanent pain relief is rarely attained (Turk, 1990). Persistence in changing an inherently resistant condition such as chronic pain (Aldrich, & Eccleston, 2000) can result in greater physical impairment and emotional suffering that reinforces a focus on pain, impeding adjustment and the pursuit of alternative positive life experiences and goals (McCracken, 1998; McCracken et al., 1999). Bland and Henning (2000) suggest that psychological discord often occurs because of a lack of congruence between what is and what should be; that is the expectation that chronic pain is fixable and one can return to his or her 'normal' way of functioning.

The physical and emotional suffering attributed to CNP set in motion vigorous efforts to eradicate the pain based on the commonly held belief that chronic pain is resolvable. Amongst these SCI participants, seeking a cure for CNP was not only viewed as feasible, but also, in some cases was considered to be a responsibility in terms of 'fixing' oneself. While behavior involved in 'seeking pain resolution' is viewed as contrary to the notion of acceptance, the findings in this study suggest that this phase is a necessary component in the process of acceptance of CNP. Through a process of trial and error, these SCI persons' eventually came to recognize that their efforts to entirely resolve their pain were ineffectual.

Acknowledgement of the futility in the continued search for a cure for persistent pain is considered to be an important component of 'acceptance of pain' in chronic pain patients. Recognition that pain is intractable and that the struggle to achieve pain resolution is unproductive is key to relinquishing the relentless goal of pain control (Geiser, 1992; McCracken, 1998; McCracken et al., 1999; Risdon et al., 2003). Geiser (1992) proposed that the process of acceptance involves several stages prior to abandoning the struggle to control chronic pain. These stages are reported to include: a) an understanding that one has 'chronic' pain, that is, pain that is unlikely to change; b) an awareness of one's struggles to fight chronic pain; c) recognition of the costs involved in the continued pursuit of pain control; d) relinquishing the fight to control pain, and; e) identifying "other realistic activity interests and goals" (p.14).

'Acknowledging pain permanence' emerged as a key phase in the process of acceptance of CNP in these SCI persons. Repeated unsuccessful attempts to eradicate CNP through the use of medications and alternative therapies eventually led these SCI persons to acknowledge the permanence of CNP and the futility of their continued search for pain control. A considerable amount of time and physical and emotional energy were invested prior to realising that the struggle to eradicate pain was ineffectual. The initial realisation that the ongoing pursuit of pain resolution may not be "worth it" set the stage for giving up the struggle and accepting the eventuality of living with CNP. The decision to cease the pursuit of pain eradication was a gradual process that was based on the consequences of prior efforts to resolve the pain, a seeming lack of further available options, and a willingness, albeit tentative, to learn to live with the pain.

Although the process of 'acceptance of pain' in chronic pain patients is reported to involve the determination of realistic activities and personally relevant goals (Geiser, 1992), there is no indication in the pain literature of how this is done. However, the notion of 'redefining core values' as described in phase four appears to be similar to a cognitive process that facilitates adaptation to chronic illness and disability (Antonak & Livneh, 1991; Livneh, 1980, 1986a, 1986b; Livneh & Antonak, 1990, 1997; Livneh & Evans, 1984). A re-evaluation of life values and priorities and a search for new meaning and goals were reported to be elements of cognitive acceptance that preceded emotional acceptance and final adjustment to disability. In these SCI persons, 'redefining core values' was instrumental to moving forward with pain, apart from the disability related to the SCI. As efforts to disengage from the pursuit of pain control took place, these SCI persons turned their attention to the importance that pain plays in their lives while identifying their personal goals and future potentialities given the inevitability of CNP. Values such as attaining an education, rewarding employment, acquiring and maintaining meaningful interpersonal relationships, as well as previously cherished activities were reflected upon while considering what would be realistic in the face of CNP. The extent to which their current or prior experience with values clarification in relation to their disability aided these SCI persons in this phase of acceptance of pain is unknown. What is notable is that 'acceptance of disability' has been associated with adjustment to SCI and decreased pain severity in SCI individuals who have CNP (Hanson, Buckelew, Hewett, & O'Neal, 1993; Summers et al., 1991). The relationship between values clarification and acceptance of pain in chronic pain patients as well as SCI persons who have CNP requires further investigation.

In these SCI persons 're-defining core values' was associated with an attitudinal shift whereby the view of CNP gradually began to evolve from a "disabling" factor to a "limiting" factor. Furthermore, these SCI persons held the conviction that pain would not "totally limit" their way of living; however, uncertainty remained in terms of how they would actuate this goal.

'Learning to live with the pain' emerged as the most critical and perhaps difficult phase in the process of acceptance of CNP. To a large degree, these SCI persons affirmed that 'learning' and 'acceptance' were interdependent functions. A series of activities described as "reprogramming" occurred during this phase that not only enabled these SCI persons to better manage their CNP, but also enhanced their coping and acceptance of the pain. These SCI persons were able to put pain in "perspective", thereby enabling them to cope better with the frustrations centered on the limitations associated with pain. Focusing on ability rather than disability related to pain also helped to foster a greater sense of control over the pain and life. Through a process of trial and error, functional limitations were learned in relation to CNP. Overtime, the ability to perform cost-benefit analyses developed with consideration given to the positive and negative effects of participation in activities on pain and fatigue. The approach to activity was also adapted in order to limit fatigue and the exacerbation of pain. While 'learning to live with the pain' is not specifically defined in the pain literature, several components of this phase are evident. Accepting the limitations imposed by chronic pain (Risdon et al., 2003) is reported to provide a greater degree of control over life (Jacob, Kerns, Rosenberg, & Haythronthwaite, 1993). Although these limitations may require finding new ways of living this does not imply acceptance of the disability attributed to chronic pain (Risdon et al., 2003).

'Taking control' is also considered to be a feature of acceptance of pain (Risdon et al., 2003) that entails controlling for the negative effects of chronic pain, rather than controlling the pain itself. 'Taking control' of pain may also be construed as taking responsibility in caring for oneself thereby relinquishing reliance on others for one's well-being. Consistent with this view is the adoption of a self-management approach to pain management, often espoused in chronic pain treatment programs (Jensen, Nielson, Turner, Romano, & Hill, 2003). In this study, these SCI persons independently incorporated their own self-management approach to learning to live with CNP as a means to regain control over their lives. The discovery, experimentation, application and eventual integration of several pain management strategies contributed to enhanced coping and acceptance of pain. Re-directing attention to non-painful aspects of their life, exercise/stretching, pacing, relaxation and rest, in addition to the use of physical modalities such as massage, acupuncture, and hot water were found to provide partial and temporary pain relief that generated an overall greater sense of control. Other adaptive coping strategies that supported their acceptance of the pain included controlling for negative thoughts and emotions, a strategy reported to be strongly associated with decreased pain as well as acceptance of pain in chronic pain of other types (Viane et al., 2003). In these SCI persons, a growing awareness of the 'mind and body connection' on their experience of CNP led to efforts to decrease negative and catastrophizing thoughts. While many of these aforementioned strategies have been found effective in managing chronic pain in general, they have not as yet been tested for reducing pain and pain-related disability in SCI persons (Ehde et al., 2003; Umlauf, 1992).

The most definitive indicator of acceptance of chronic pain is reported to be the extent to which individuals assume an active and fulfilling life regardless of the pain (McCracken, 1999; McCracken et al., 1999; McCracken et al., 2004). This was also an important component noted in the final phase, 'integrating pain'. In these SCI persons, rebuilding an active and satisfying lifestyle was viewed as essential to acceptance of CNP. The integration of pain management strategies into their daily life enhanced their ability to engage in life more fully, freeing them to pursue enjoyable interests and actualize their goals.

While CNP was originally perceived as a threat that impeded these SCI persons' way of living, during the final phase, pain was now perceived to be a "normal" part of life. As this attitude towards pain evolved with acceptance so did these participants self-perception as being capable individuals who are able to deal with the pain. Acceptance acts to reshape the self-identity from negative to more positive as pain is redefined as an aspect of self (Bland & Henning, 2000). Several factors appear to have contributed to a recreation of 'self' in these SCI persons' including efforts to redefine their core values, setting and achieving goals, rebuilding an active lifestyle and reframing the meaning of their pain. In phase one and two, the 'self' was portrayed as powerless to function due to the disabling effects of CNP and the inability to eradicate the pain, respectively. However, in phase six, these SCI persons viewed themselves as capable of managing their pain. The adaptations that occurred throughout the six phases served to improve their self-confidence and self-esteem. While initially CNP was viewed as a distinct phenomenon separate from their disability, the 'self' was now transformed to include pain as a component of their disability.

Integral Processes to Acceptance of CNP

Enhancing independence is a fundamental component of the rehabilitative process. As an active member of the interdisciplinary team, SCI persons participate in goal setting and implementing strategies to enable them to live as independently as possible. Similarly, increasing independence appears to have been an important process that facilitated acceptance of CNP in these SCI persons, regardless of the degree of impairment. The desire to function as independently as possible within the context of restrictions imposed by the SCI and CNP, acted as a motivator to learn pain management strategies that enabled them to attain some degree of pain relief. ‘Self-management’ skills learned in adapting to their disability were adopted in their approach to learning to live with CNP, exemplified by “finding ways” through discovery, experimentation, and problem-solving. These ‘learned’ strategies more importantly facilitated the perception of greater control over their life, which further enhanced independence in terms of living a fulfilling life. The desire to function independently in spite of pain also led to efforts to maximize functional capacity that had the additional benefit of increasing physical strength.

‘Evolving pain view’ is a dynamic process that is similar to the notion of ‘‘reframing’ the meaning of pain (Hanson, 2003). ‘Reframing’ is a cognitive process whereby a negative perception of a situation is reinterpreted in a more positive light. Transforming the meaning of chronic pain through the use of cognitive techniques such as reframing can make the pain more bearable (Thompson, 1981) and strengthen acceptance (Geiser, 1992). As these SCI persons ‘moved forward’ through each phase of acceptance, a gradual shift in thinking occurred whereby CNP was interpreted differently. The view that pain is a ‘limiting’ factor was associated with an active style of pain coping. Instead of passively complaining, SCI persons approached their pain "head on openly". The adaptations associated with each successive phase served to reinforce a sense of greater control over life and acceptance of CNP irrespective of whether the pain remained essentially the same or increased in severity over time. This unfolding pain view had additional benefits in terms of the development of greater patience, perceived satisfaction in small achievements, and enhanced self-esteem.

Implications

This research provides an initial understanding of the process of acceptance of CNP in SCI persons. The findings reveal that 'acceptance of pain' is an important process that improves our understanding of the physical and emotional torment and impaired function of SCI persons with CNP and the means by which they come to terms with their pain. Movement away from a belief in a medical cure for CNP and toward a self-management approach led to increased coping with pain in these SCI persons. 'Acceptance of pain' was likened to that of 'acceptance of disability' in terms of finding new ways of living and being. Acceptance of disability in SCI has been associated with cognitive restructuring (Hanson et al., 1993), positive problem orientation and rational thinking, skills which are thought to contribute to adjustment to chronic pain in SCI (Cundiff, Blair, & Puckett, 1995; Mourer, 1994; Radwinski, 1992). It is unclear, however, to what extent acceptance of the disability played a part in acceptance of pain and further research is needed to examine this complex interrelationship.

Most importantly, the process of 'acceptance of pain' is potentially useful for guiding behavioural change in SCI persons who have CNP. Umlauf (1992) provides an outline of an adapted self-management pain program based on a biopsychosocial model to meet the needs of community-living SCI persons. While the suggested interventions incorporate many of the pain management strategies used by these SCI persons, further research is needed to determine if these benefits would be equally effective in other SCI persons who have CNP. As yet the ideal time to initiate psychological intervention in the treatment of chronic pain in SCI is not empirically defined (Umlauf, 1992). Although the initial onset of neuropathic pain is not predictive of the pain becoming chronic in nature, clinical experience indicates that this is often the case. Although efforts should be made to maintain hope that CNP will be resolved, a balance between seeking pain resolution through medical interventions and the need to disengage from treatment measures is suggested. Early steps toward acceptance of CNP may include the following interventions: 1) education regarding the unpredictable and resistant nature of CNP to medical management; 2) introduction to the notion of reducing suffering rather than an expectation of a pain cure; 3) a review of the range of medical options with a focus on individual experience when evaluating results; 4) a review of potential pain management strategies that other SCI persons have found beneficial, and; 5) a group treatment approach that incorporates peer support from other SCI persons who have accepted their pain and successfully adjusted to it.

The findings in this study revealed that acceptance of pain was beneficial in terms of reducing suffering and facilitating a more satisfying and fulfilling life in these SCI persons. Many of the components of acceptance of pain as described by these SCI persons with CNP were found to be similar to those experienced by persons with chronic benign pain (Geiser, 1992; McCracken, 1998, 1999; McCracken et al., 1999; McCracken et al., 2004; Risdon et al., 2003). This finding is significant for two reasons. Clinically, SCI persons are viewed as being very different from their counterparts who have chronic benign pain due to the superimposed physical impairment. CNP is also inherently different from chronic pain of other types. Despite these differences, it seems that these two groups of patients who have different types of pain do have similar experiences in accepting and adapting to their pain. Furthermore, a number of pain management strategies used by these SCI persons are in common with those implemented in standard chronic pain programs. This finding provides further support for the development of self-management interventions in the care of SCI who have CNP.

The credibility of this study's findings is supported by the feedback obtained from five of the SCI participants. Their overall impression of the conceptual framework was that it provided an accurate representation of their experience in coming to accept their pain. Several participants indicated that realizing that their experience was common to that of other SCI persons was both reassuring and comforting in terms of knowing that they are not alone in their struggle to adapt to CNP. The participants confirmed that the process, 'increasing independence' was a particularly important factor that moved them forward in the process of acceptance.

A limitation in this research that may impact on the transferability of findings, relates to data saturation. Saturation of the main categories occurred relatively quickly which may be related to the homogeneity of the sample. While the process of accepting CNP involved a pattern of progressive cognitive, emotional and behavioural change during the six phases, it cannot be assumed that this pattern would be identical for all SCI persons who live with CNP. Additional research is needed to examine the process of 'acceptance of pain' and it's relation to adjustment to CNP in a larger sample of SCI persons. This may result in the identification of other psychosocial and environmental contextual factors that could facilitate and/or inhibit SCI persons' progression in the process of acceptance of pain, leading to the development of a more comprehensive conceptual framework.

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Table 3.1

Semi-Structured Interview Guide

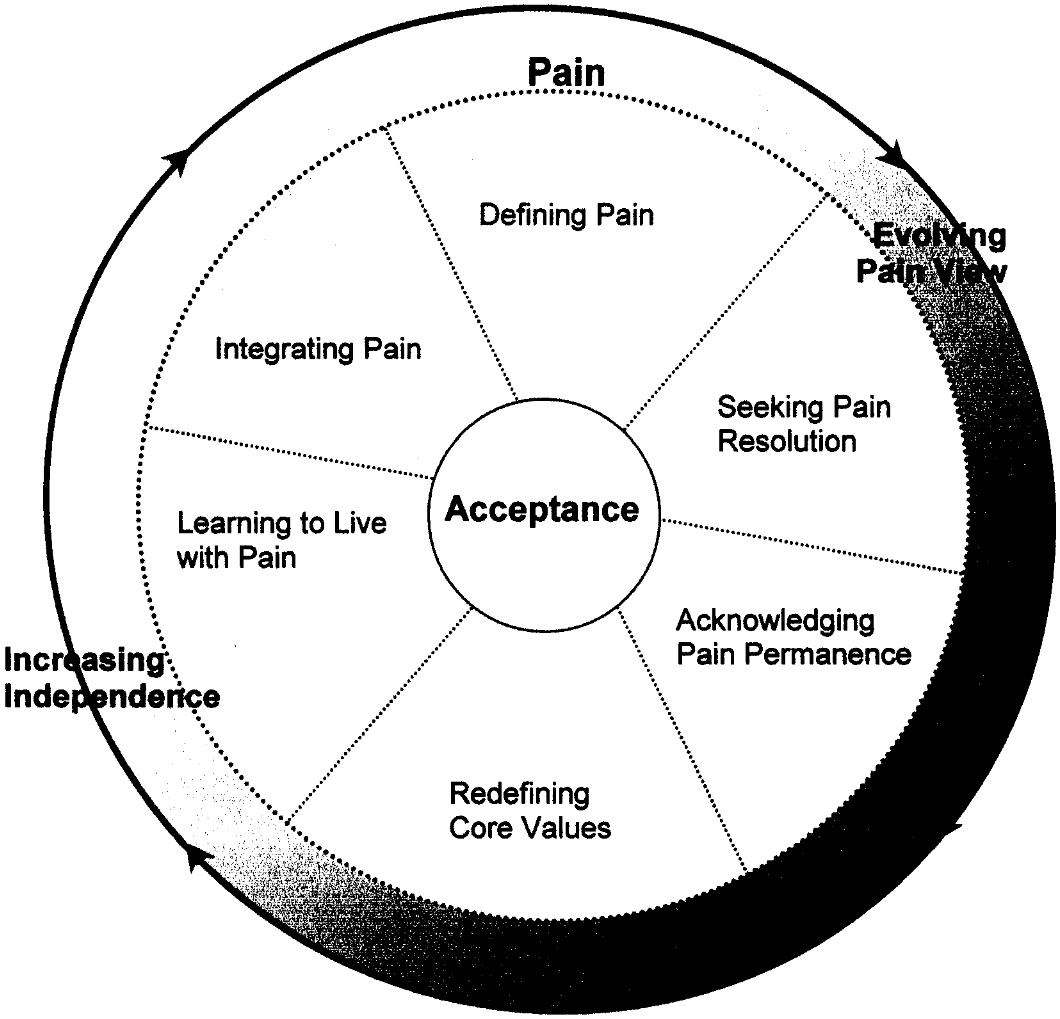
Question Number	Question
1	How would you describe your pain?
2	Describe your experience of CNP?
3	Is the way you feel about your pain different now than it was when it started?
4	Is the way you live your life with chronic neuropathic pain different now than when it started?
5	What does acceptance of pain mean to you?
6	Is learning to live with the pain similar or different than acceptance of pain?
7	Do you think that you accept your pain?

Table 3.2

Definitions of Phases in the Process of Acceptance of CNP in SCI Persons

Phases	*Definition*
Defining Pain	The unpredictable nature of CNP and the ways in which pain impact one's well being.
Seeking Pain Resolution	Focus of attention directed at a means to eradicate pain.
Acknowledging Pain Permanence	Recognition that CNP is resistant to medical management and the futility in the continued search for pain resolution.
Re-defining Core Values	Process of clarifying one's personal beliefs as to what is important in life when faced with CNP.
Learning to live with the pain	Cognitive, emotional and behavioral activities involved in adaptation to CNP.
Integrating Pain	Action and outcome of unifying pain with aspects of one's being and approach to life.

Figure 3.1 The Process of Moving Forward with Chronic Neuropathic Pain in Spinal Cord Injured Persons



Chapter 4

General Discussion and Conclusion

This chapter discusses the findings of the two studies that comprise this thesis and their relationship to theory development, implications for clinical practice, and the need for further research

Chapter 4 - General Discussion and Conclusion

Introduction

The intent of this thesis was to increase health professionals understanding of the effects of CNP in the lives of community-living SCI persons and the ways in which they adapt to their pain. It was anticipated that the knowledge gained from this research would provide some direction to nurses and team members of other disciplines that provide care to SCI patients. Two qualitative studies were conducted to better understand how SCI patients live with CNP. The first study involved three focus groups with 24 SCI participants and the second, in-depth interviews with seven SCI participants. The findings of each study are discussed in relation to new knowledge acquired, theory development, and the implications for further research and clinical practice.

Study 1. The findings of this exploratory study, 'Chronic Neuropathic Pain in Spinal Cord Injured Persons: The Patient's Perspective' (Chapter2) indicate that the effects of CNP were more detrimental than the effects of the SCI with respect to attaining a reasonable quality of life (Henwood & Ellis, 2004). While this study found that many of the physical, cognitive and emotional effects of CNP were consistent with findings reported in the SCI literature, new information was discovered that contributes to our understanding of the experience of CNP in SCI persons. The prominent use of metaphor, the view that common pain descriptors are inadequate to describe CNP, and the infrequent use of numerical rating scales suggest that pain assessment scales typically used by health professionals may be lacking in terms of providing a clear picture of the SCI persons' experience of pain. When describing their pain, SCI persons reported experiencing variable patterns of CNP including daily, weekly or monthly cycles. Within these cycles of pain, a variety of physical, emotional and environmental factors were noted to influence pain severity; however, the interplay between fatigue and spasticity was noted to be the most significant ‘pain augmenter’ that negatively affected coping ability. It was also evident that prescribed medication was inadequate in terms of providing pain control. A range of other pain management strategies were employed, several being effective in terms of enhancing coping ability, while others appeared to contribute to increased physical and emotional disability. Several maladaptive coping strategies included catastrophizing thoughts, inappropriate self-medication with over-the-counter drugs, use of alcohol and illicit drugs, and frequent emergency room visits. Use of adaptive coping strategies such as the use of distraction, resisting negative thoughts and emotions, exercise, swimming in warm water, engagement in work, school, and leisure pursuits appeared to be associated with adjustment to the pain.

The realization that some SCI persons had “learned to live with the pain” led to the research objective for the second study. A review of the chronic pain literature revealed that ‘acceptance of pain’ includes the notion of relinquishing the pursuit of a pain cure based on the recognition that this goal is unlikely to be achieved (Geiser, 1992; McCracken, 1998; 1999). ‘Acceptance of pain’ is reported to be associated with decreased severity of pain, less physical and emotional disability, less avoidance of pain, increased daily up-time and enhanced capacity for work in chronic pain patients who suffer primarily from back pain (Geiser, 1992; McCracken, 1998; McCracken, & Eccleston, 2003). The notion that ‘acceptance of pain’ may be an adaptive option for SCI persons who have CNP that is unresponsive to medical management, led to the development of study two, 'Exploring Acceptance of Chronic Neuropathic Pain in Spinal Cord Injured Persons' (Chapter 3).

Study 2. A qualitative approach provided a broader perspective of the construct, acceptance of pain, than is currently understood. Grounded theory was used to explore the construct 'acceptance of pain', as it relates to adjustment to CNP in SCI persons (Strauss & Corbin, 1998). The constant comparative analysis of data, inductive and deductive reasoning and structured analytical procedures resulted in findings that support the current conceptualization of 'acceptance' as described in the chronic pain literature. Several key concepts identified by Geiser (1992) and McCracken (1998, 1999) and colleagues (2004) were confirmed by the SCI participants including 'recognition that a cure for pain is unlikely', 'decreased efforts to find a pain cure' and 'increased efforts to reclaim an active life'. However, other findings contribute to the further development and refinement of the construct, adding to the existing body of knowledge.

As the key concepts, characteristics, and conceptual interrelationships emerged during analysis, the structural foundation and integral processes of a conceptual framework were developed to describe the process of acceptance of pain. This conceptual framework, as illustrated in a schematic representation, demonstrates the relationship between all the components involved in the process of 'acceptance of pain' (see Figure 3.1). In these SCI persons, 'acceptance of pain' was noted to be a dynamic process involving six phases, corresponding cognitive, emotional, and behavioral adaptations, and two integral processes that drive the process forward. The inclusion of phase 4 and 5, 'redefining core values' and 'learning to live with the pain', respectively add further dimensions to 'acceptance' that have not as yet been addressed in the 'acceptance of pain' literature. Conceptual models that describe adaptation to chronic illness and disability place considerable emphasis on value appraisal and value adjustment (Antonak & Livneh, 1991; Livneh, 1980; 1986a; 1986b; Livneh & Antonak, 1990; Livneh & Evans, 1984), concepts that may contribute to an overall greater understanding of 'acceptance of pain'. The notion that 'learning to live with pain' was similar to that of learning to live with a SCI-related disability is of significance. The self-management approach adopted in 'learning to live with pain' appears to be comparable with the 'self-care' philosophy that is integral to the rehabilitative process (Umlauf, 1992). The individual is responsible to him or herself in setting and collaboratively working toward achieving personally relevant goals.

The two processes, 'evolving pain view' and 'increasing independence', were also central to 'moving forward' in life with CNP, the latter process seeming to be of particular importance. Umlauf (1992) suggested that the ability to cope with pain may vary dependent upon the extent of the SCI and associated expectations to perform daily activities; however, this study's findings do not support this view. Although quadriplegia may result in physical dependence for personal care, SCI persons with severe physical impairment remain capable of exerting independence in their daily lives in other ways. Directing others in their self-care and the use of adaptive and technical aids enabled them to exert their independence in the pursuit of personally relevant interests and goals. It would seem that in cases of severe impairment, it is the perception of independence that is of greater importance than the actual physical independence in terms of enhancing 'acceptance of pain'.

Although the use of coping strategies is not considered to be a part of acceptance of pain, acceptance does not require that one abandon the use of strategies that are effective in terms of providing some pain relief (McCracken, 1998; McCracken & Eccleston, 2003). Integration of a variety of pain management strategies resulted in a 'reframing' of the meaning of CNP as being "normal" which reinforced the perception of greater control over life and facilitated engagement in an active lifestyle. Ultimately, the combined effects of the adaptations that occurred through each phase contributed to a change in self-identity, that being a person having both a SCI and CNP who is living their life to the fullest.

Implications for Clinical Practice

The results of study two (Chapter 3) suggest that a self-management approach to pain management would be beneficial in assisting SCI persons to better cope with CNP. Chronic pain is best treated through a multidisciplinary approach where practical, feasible, and measurable goals are clearly delineated. The advanced practice nurse (APN), who has clinical expertise in the rehabilitative care of SCI persons', is ideally suited to contribute to strategic planning in the development, implementation, and evaluation of a pain program for SCI persons. This involves assuming all of the five major advanced practice nursing (APN) role components including clinical practice, consultation, education, research and leadership (DeGrasse & Nicklin, 2001). For example, a local pain program is being revised to include special programs for SCI persons with CNP. The results of these two studies may be useful when planning this program. The APN can provide leadership through participation on program planning committees, offer consultation services to colleagues, education to patients and their family members, and contribute to the development of outcome evaluation research.

Several findings from this research are potentially useful in the development of a pain program to meet the needs of SCI persons with CNP. From a clinical perspective, one of the possible benefits of the conceptual framework is that it can help nurses and members of other disciplines to better understand and more accurately assess the experience of CNP in SCI persons in relation to the six phases of 'acceptance of pain'. In terms of therapy, group pain management is one avenue to facilitate education regarding the biopsychosocial components of CNP in SCI and the acquisition of new pain management skills. This approach may be advantageous given the feedback provided by the focus group participants in Study 1 (Chapter 2). These SCI persons considered the opportunity to express their thoughts and feelings about their pain and learn possible coping strategies from their peers to be more supportive and credible than talking with a health professional. Role modeling of effective coping strategies could be introduced from SCI persons who have accepted and adjusted to their pain. Cognitive-behavioral therapy could target the necessary adaptations in each phase to facilitate forward movement through the process of acceptance. A number of strategies adopted by the SCI persons in this research have been suggested in the treatment of chronic pain in SCI persons. Goal-setting, self-monitoring, rational thinking and problem-solving skills could be introduced in the context of CNP. Strategies such as adapted relaxation techniques, self-hypnosis, imagery-based strategies, or biofeedback have been suggested in the treatment of chronic pain in SCI (Cundiff, Blair, & Puckett, 1995; Haythornthwaite & Benrud-Larson, 2000; Mourer, 1994; Radwinski, 1992; Umlauf, 1992). Maximizing physical conditioning and functional independence through exercise such as wheelchair aerobics, recreational activities (Balazy, 1992; Britell & Mariano, 1991) and pool therapy could also contribute to enhanced physical and psychological well-being and greater coping with CNP. Educational topics targeting health promotion and prevention of potential SCI related health problems including prevention of skin breakdown, bladder and bowel distension, urinary tract infections, and the management of spasticity (Balazy, 1992; Britell & Mariano, 1991) may also help to reduce the risk of exacerbating CNP.

Implications for Further Research

The proposed conceptual framework elaborates on the current conceptualization of 'acceptance of pain' and as such enables us to generate hypotheses and potential research questions that could ultimately improve clinical practice. Several topics for future research arose from these two studies. A complex cyclical relationship was noted between pain severity, energy depletion, fatigue, and coping with CNP that seemed to be important. Because unpredictable spikes in CNP can occur, it would be beneficial to better understand how SCI persons learn to manage this vicious cycle. Further research is warranted to gain a more comprehensive understanding of acceptance of pain in SCI persons with CNP and build upon the proposed conceptual framework. Other potential areas to explore include the relationships between acceptance of pain and spasticity, sleep disturbance and fatigue associated with CNP.

It seemed that the process of acceptance was hampered when an additional type of pain was present along with CNP. One SCI participant reported experiencing CNP along with pain of an unknown origin that was not only resistant to treatment but also caused additional functional impairment. The lack of diagnosis of this second pain may have negatively influenced moving forward with pain. Since SCI persons often experience multiple types of pain, the relationship between acceptance and the co-occurrence of CNP with other types of pain requires further investigation. An understanding of the relationship between acceptance and co-morbidities, cognitive and emotional developmental level, and social factors would also be beneficial in the expansion of the conceptual framework. Outcome evaluation research will also be needed to ascertain the effectiveness of a self-management pain program designed to treat chronic pain in SCI persons.

Limitations

For the most part, these SCI participants appeared to have attained a level of maturity and had a degree of cognitive insight that enabled them to reflect upon their response to pain, which seemed to facilitate their progression through the phases. While these characteristics may have been advantageous, it is unknown whether they constitute an "elite bias" (Appleton, 1995; Sandelowski, 1986) that could potentially threaten the transferability of the findings. While the proposed conceptual framework may not be generalized to all SCI persons who have CNP, the empirical grounding of the conceptualisations support the value and applicability for clinicians and researchers given a similar context and set of conditions. Further research with a larger and less homogeneous sample may reveal differences in the process of acceptance of pain should individuals with less insight be included.

Despite this possible limitation, the findings do appear to be credible. A general consensus existed among these SCI participants that the conceptual framework accurately reflected their experience in the process of accepting their nerve pain. The number and order of the six phases and the notion of back stepping to a prior phase in response to an increase in pain were perceived to be correct. While the two processes were viewed as facilitating movement toward greater acceptance of pain, 'increasing independence' was considered to be particularly important by SCI persons with both paraplegia and quadriplegia.

Conclusion

This thesis represents an initial effort to explore the effects of CNP in the lives of SCI persons from their own perspective, and the ways they learn to adapt to their pain through acceptance. The two studies revealed the interactive effects of many of the biopsychosocial components of chronic pain that impacted the well-being of the SCI participants. The independent and interactive effects of spasticity, fatigue and pain severity on coping with pain were significant and point to the need for further research. While medications were, for the most part, ineffective in providing adequate pain control, a variety of pain management strategies were found to be effective in providing some degree of pain relief. CNP resulted in functional limitations beyond those related to the SCI; however, the drive to maintain independence in daily living was an important factor that supported adaptation to the pain.

The proposed conceptual framework provides a broad understanding of the construct, 'acceptance of pain'. The six phases, related adaptations, and integral processes that describe the 'process' of acceptance of pain add several new dimensions to the construct that have not been previously described in quantitative research findings. Additional research is needed to identify the range of possible contextual factors that shape acceptance of pain in SCI.

The findings of this research support the view that a self-management approach to pain management can assist SCI persons to adapt to living with CNP. While a number of authors have recommended that energies be directed toward the development and evaluation of multidisciplinary and self-management approaches in the treatment of chronic pain in SCI, (Agency for Healthcare Research and Quality, 2001; Cundiff et al., 1995; Haythornthwaite & Benrud-Larson, 2000; Mourer, 1994; Radwinski, 1992; Umlauf, 1992), to-date there is little research that confirms the effectiveness of this approach. The need for theory to support clinical practice is equally important. The findings of this research suggest that 'acceptance of pain' may provide the theoretical underpinnings to guide the development and implementation of pain programs for SCI persons. While the proposed conceptual framework is in its infancy, it provides a possible foundation for the further development of a substantive theory to explain acceptance of CNP in SCI that can ultimately guide clinical practice.

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Appendices

Appendix A

Authorship Credit

This thesis was manuscript-based and as such is comprised of chapters that were intended for publication in a peer-review journal. Chapter 2 was submitted to 'Pain Research & Management' and was published in volume 9, 2004. Chapter 3 will be further revised and subsequently submitted for publication in a journal that has yet to be chosen.

Contribution of Collaborators:

In the first study, there were two contributing authors, Penelope Henwood (PH) and Jacqueline Ellis (JE). The principal author (PH) was responsible for the design of the study, data collection, analysis and writing of the manuscript. JE also participated in formation of the design, joint coding of the data, provided feedback throughout the analytical process, reviewed the drafts and edited the final manuscript.

There were four authors who participated in the development of the second study and subsequent manuscript, Penelope Henwood (PH), Jacqueline Ellis (JE), Jo Logan (JL), Claire Jeanne Dubouloz (CJD) and Joyce D'Eon (JD). PH was responsible for the conception of the design, data collection and analysis, drafting, revising and completion of the final manuscript. JE contributed to the formation of the design, confirmed the coding of the transcripts, provided critical feedback during the analytical process and development of the conceptual framework and edited the drafts of the manuscript. JL and CJD also contributed to the formation of the study's design and emerging conceptual framework throughout the analytical process by providing critical input and guidance in terms of implementing grounded theory methodology. They also provided feedback in revision of the manuscript. JD provided important intellectual content in regards to chronic pain and SCI and provided feedback in revision of the manuscript. The order of authorship was determined by consensus of the thesis committee members and graduate student.

Appendix B

CHRONIC NEUROPATHIC PAIN IN SPINAL CORD INJURY: THE PATIENT'S PERSPECTIVE

INFORMATION SHEET

As part of my academic studies at the University of Ottawa Master of Science in Nursing Program, and my role as nurse clinician of the Neurospinal Service at The Rehabilitation Centre, I am interested in learning from spinal cord injured persons about their thoughts, feelings, beliefs, opinions, and actions in relation to living with chronic neuropathic pain in order that we can better meet your needs.

This project involves your participating in a small group session that will last up to 2 hours. **The focus group will take place on November , 2000 at 1:30 p.m. in Conference Room _ at The Rehabilitation Centre.** The session will be audio-taped to allow for a detailed study of the groups comments as a whole. The audiotape will be destroyed following the review of the transcription. All personal information will be kept confidential.

We recognize that life is often difficult with chronic pain and that it may be upsetting for you to talk about it. If you feel that you need to leave the session at any time, you are free to do so and support will be made available to you from myself and/or our psychologist, Dr. Karen Cohen. As well, your comments or feedback concerning the Neurospinal Service will in no way affect your present and/or future treatment at The Rehabilitation Centre.

You will be reimbursed for any transportation or parking costs associated with the small group session. Refreshments will also be served during the session. I would like to thank you for your support in permitting me to gain a better understanding of the impact of chronic neuropathic pain in your life. The overall findings of this project will be shared with the Neurospinal team members, nursing staff, and the Institute of Rehabilitation Research and Development at The Rehabilitation Centre. You will not be personally identified in any reports or presentations.

This project has been approved by the Research Ethics Committee of The Rehabilitation Centre.

If you have any questions or concerns regarding your participation in this project, you may contact:

Penny Henwood RN, BScN, CRRN
The Rehabilitation Centre
Phone: (613) 737-7350 ext.5521

Dr. Dan DeForge, Chair, Research Ethics Board
The Rehabilitation Centre
Phone: (613) 737-7350 ext.5598

Appendix C

CHRONIC NEUROPATHIC PAIN IN SPINAL CORD INJURY:

THE PATIENT'S PERSPECTIVE

STATEMENT OF INFORMED CONSENT

I have read the information sheet and I have been told about the purpose of this project. I understand that I will be taking part in a focus group at The Rehabilitation Centre that will last up to 2 hours.

I agree to participate in this study with the understanding that information will be collected and used for research purposes only and will be treated as confidential. I have been informed about the purpose of the study and realize that I am under no obligation to participate and may withdraw at any time. Refusal to participate or withdrawing from the study will in no way affect my present and/or future treatment at The Rehabilitation Centre.

I agree to permit the researcher, Penny Henwood, to consult my medical chart for diagnostic and demographic information. I also agree that Penny Henwood and The Rehabilitation Centre may produce an audio-tape of the focus group and know that the tape will be destroyed following review of the transcription.

Signed: ___________________________ Date: __________

Witness: __________________________ Date: __________

Penny Henwood RN BScN CRRN

The Rehabilitation Centre

(613) 737-7350 ext.5521

Appendix D

INFORMATION SHEET FOR RESEARCH PARTICIPANTS

Study: Exploring 'Acceptance of Chronic Neuropathic Pain' in Spinal Cord Injured Persons

Purpose:
The purpose of this study is to learn more about how spinal cord injured (SCI) persons learn to live with chronic neuropathic pain. The knowledge gained from this study will assist nurses and other health professionals to assist SCI persons to learn to cope with their pain.

Procedure:
I wish to interview you about how you learned to live with chronic neuropathic pain. You will be asked to describe your experience of chronic neuropathic pain, and asked questions such as the ways in which you learned to live with your pain, and how you feel about your pain now as compared to during the first year when it occurred. The interview will take place in a location of your preference and will last for approximately 1 to 1 1/2 hours depending on how you feel and how much you want to talk. The interview will be tape-recorded in order to help me to interpret the information accurately. Demographic data will be obtained from you and/or your hospital chart. Only the researcher will see this information and it will be kept in a locked filing cabinet. This information will be used to describe the general characteristics of the group as a whole.
If you wish, you may continue to participate after the interview by reading the research results and giving your comments in writing or over the telephone to the investigator. You will be reimbursed for any traveling and parking costs incurred as a participant in the study.

Risks and Benefits:
Some people may find it helpful to talk about how they learned to live with their pain, while others may find it emotionally difficult. If you find it troubling to talk about your experience, you will be asked if you wish to be referred to a nurse and/or psychologist. I will respect your wish to stop the interview at any time.

Rights of Participants:
You are under no obligation to participate in this study and you may withdraw from the study at any time without any change in your present and/or future care at The Rehabilitation Centre. The information collected during this study will be kept confidential. A code number will be used to identify the information so your name will not appear on any documents. The tape recording will be destroyed at the end of the study.

Publication of Study Findings:

The findings of this study will be submitted for publication to a professional journal and newsletters of the Canadian Paraplegic Association and the Independent Living Centre. Submissions will also be made for presentations at several professional nursing and rehabilitation conferences. No personal identifying information will be used in any published work or presentations.

Appendix E

STATEMENT OF INFORMED CONSENT

Study: Exploring 'Acceptance of Chronic Neuropathic Pain' in Spinal Cord Injured Persons

CONSENT

I agree to participate in this study with the understanding that information will be collected and used for research purposes only and will be treated as confidential. I have been informed about the purpose of this study and realize that I am under no obligation to participate and may withdraw at any time. Refusal to participate or withdrawing from the study will in no way affect my present and/or future treatment at The Rehabilitation Centre.

I am also interested in reading and commenting on the results. (Yes ___; No ___)

Phone contact ____

Email ____ (email address: ____________)

Mail: ____ (address: ___________________________)

Name: ________________________ **Date:** ____________

Witness: ________________________

You will receive a copy of this consent. If you have any additional questions about this study, you can telephone the investigator or the chairperson of the Research Ethics Board at The Rehabilitation Centre.

Penny Henwood RN BScN CRRN, MScN (Candidate). The Rehabilitation Centre.
Telephone: (613) 737-7350 Ext.5521.

Dr. Shawn Marshall, Chairperson, Research Ethics Board, The Rehabilitation Centre
Telephone: (613) 737-7350 Ext.5595.

Appendix F

Participant Demographic Data Sheet

Name

Address

Phone Number

Age

Gender
  Male
  Female

Marital Status
  Single
  Married/Common-law/Partner
  Separated
  Divorced
  Widowed

Educational Level
  Grade School
  Grade School/Some High School
  High School
  High School/Some College
  College
  College/Some University
  University
    Undergraduate
    Graduate Studies

Occupational Status
  Employed
  Unemployed
  Student

Appendix G

Participant Clinical Data Sheet

Name

Level of Injury
- Cervical
- Thoracic
- Lumbar-sacral

Extent of Injury
- Incomplete
- Complete

Age at Onset of SCI

Onset of CNP

Pain Duration
- Less than 5 yrs
- 5-10 yrs
- > 10 yrs

Co-morbidities

Pain Management Strategies

Appendix H

Exploring Acceptance of Chronic Neuropathic Pain in Spinal Cord Injured Persons

Summary of Research Findings

This study was developed to help nurses and other health professionals understand how persons with a spinal cord injury learn to live with and accept persistent nerve pain. As you know, you took part in this study and were interviewed about your nerve pain and how you live with it. There were many similarities in the answers given by the seven participants. I have included for your review a diagram and a summary of the findings that captures all viewpoints. I am very interested in getting your opinion about whether I understood the meaning of what was said and does it accurately reflect your experience of living with persistent nerve pain.

Explanation of Diagram

The attached diagram shows the steps that are involved in the 'Process of Moving Forward with Chronic Neuropathic Pain in Spinal Cord Injured Persons'. The process is like a 'wheel' and starts at the first step, 'Defining Pain' and finishes with the sixth step, 'Integrating Pain.' The six segments within the wheel represent each of the six steps. Participants in this study moved forward through the six steps as they gained experience in living with their nerve pain. The spokes of the wheel that separate each step show the periodic setbacks to a prior step that can happen when the pain increases in severity. Overlap between the steps can happen while adjusting to a new situation. In spite of setbacks, the participants continued moving forward toward greater acceptance of their pain. Each person went through the six steps at their own pace. There were two driving forces that moved people towards accepting their nerve pain. One of them is 'increasing independence' or the desire to function as independently as possible within the limits of the pain and the SCI. The other driving force is 'evolving pain view' or the gradual change from a negative attitude towards living with the nerve pain to a more positive attitude. This change in attitude helped the participants to live better lives despite the pain.

Summary of Findings

Participants described six steps that they go through in accepting the nerve pain. With movement through each step, changes in thinking, feeling and action occurred. The first step starts with 'defining pain' or 'what kind of pain is this', 'why do I have it', and 'why is it happening to me'? Nerve pain was described as being "an intense cold sensation", "burning", "throbbing", "aching", "shooting", "electric shocks", "stabbing", "sharp", and "like a constrictive belt". Nerve pain was commonly described as being severe. Four persons indicated that their nerve pain had worsened over time. In most cases, the participants also lived with other types of pain including upper arm, hip or back pain, bladder pain, or painful spasms in the legs.

Although a number of things worsened the nerve pain such as bladder infections, constipation, activity and/or inactivity, prolonged sitting, spasms, exposure to heat or cold, fatigue and anxiety, it was not always clear what made the pain worse. It was difficult to predict when the pain would worsen and understand why it was so changeable. This was very difficult to deal with emotionally and physically.

Overall, the nerve pain was considered to be as much or more of a problem than the disability related to the SCI. Physically, emotionally and mentally, the nerve pain caused a number of problems. The pain made it more difficult to do things, care for oneself and move about. Participants said that the pain caused them to have more spasms and they were often tired. Emotionally, the pain caused participants' to be angry, frustrated, irritable and depressed at times. All of these problems prevented participants from socializing with friends and family as often as they would like. Mentally the pain made it more difficult to concentrate, think clearly, remember as well and be creative. The frustration caused by the pain made participants feel less good about themselves and feel that they had less control over their lives. In order to deal with the pain, participants turned to their physician for help.

The second step is 'seeking pain resolution' or 'trying to stop the pain'. This step took a lot of time and energy as attempts were made to try to stop the pain. Many medications were tried to stop the pain, however, there was little pain relief and the side effects of the medications were sometimes difficult to live with. After many months of trying different medications, some other ways to stop the pain such as massage, acupuncture and hypnosis were tried. For the most part these methods gave little relief and often they too were stopped. This led to the third step.

In the third step, 'acknowledging pain permanence', participants came to realize that whatever they were doing was not relieving the pain and that they would most likely have to live with it for the rest of their lives. It gradually dawned on them that continuing to fight the pain was useless. Instead they needed to find a way to live with the pain. This realization did not happen all at once. When it happened, this led to the fourth step.

In the fourth step, 'redefining core values', participants questioned their life and thought about what goals, plans and dreams were most important to them. As they stopped looking for a cure for the pain, participants' started thinking about their personal goals and was it possible to reach them given that they would have to live with the pain. It was not easy to stop looking for a cure for the pain because they didn't know how they would go about learning to live with the pain. This led them to the fifth step.

The fifth step, 'learning to live with the pain' involves the ways in which participants came to live with their pain. This was one of the most difficult steps. Gradually, participants discovered through trial and error what helped them to manage their pain and what did not. Several things were found to help; however, not all of them were used by each participant or found to be equally effective. These strategies included exercise, stretching, pacing activity, relaxation and rest, keeping busy, getting involved in activities that take the mind off of the pain, humor and prayer. Participants would also try to stay away from negative thoughts and stress because they realized that it would increase the pain. All of these things made it easier to cope with the pain.

Participants changed their attitude about the pain and saw it as being a limiting factor in their lives. Pain was placed on the 'backburner' that made it easier to cope with the frustration and limitations imposed by the pain. As the participants adopted a more positive attitude, they put more emphasis on what they can do, rather than what they cannot do. As the participants learned to live with the pain, they were better able to accept it. They said that learning to live with the pain was similar to learning to live with the spinal cord injury in terms of thinking about, and finding new ways of doing things. As they learned what they could or could not do, they started to challenge themselves to do the things that they valued. These accomplishments made them feel in greater control of their lives, and more optimistic for the future. This led them to the final step.

The sixth step, 'integrating pain' is living a full and enjoyable life despite having nerve pain. It was by going through these steps that the participants were able to get back to living their life in the best way that they could. Though the level of the pain can vary from day to day, they see the nerve pain as being a normal part of their lives, it's not a big deal and it doesn't take over their lives anymore. They realize that they need to use their strategies to manage the pain on a daily basis, however, some days it is more difficult than others. Using what they learned helped them live their lives better, to do what they like or want to do the most. Re-building an active lifestyle based on ability and not disability was considered to be a key factor in enabling people to accept nerve pain.