Chronic neuropathic pain in spinal cord injury: The patient’s perspective

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BACKGROUND: Chronic neuropathic pain (CNP) in spinal cord injury (SCI) is recognized as severely compromising, in both 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 experience of CNP in SCI patients in relation with 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 living in the community. 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 audiorecordin and taped. A qualitative analysis of data involved a constant comparison approach, in 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 patients learn to live with CNP and coping strategies that facilitate adjustment to CNP in SCI patients.

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

The presence of chronic pain in SCI is viewed as seriously jeopardising the patient’s adjustment after injury and quality of life (11-15). Pain impedes the ability of SCI patients to participate in active rehabilitation programs (11,15), thus limiting their potential to regain an optimal level of function (16). Several studies report that chronic pain in SCI is associated with great emotional distress (17,18), over and above that of the injury itself (19). 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...
TABLE 1
Focus group questions

Q1. 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?  
Q2. What makes your pain worse and what makes it better?  
Q3. How has your pain affected your life?

SCI spinal cord injury

to trade pain relief for loss of bladder, bowel or sexual function. Stormer et al (20) 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 were also reported (19,21). In addition, chronic pain in SCI is a contributing factor in suicide (22,23).

The high prevalence, potentially early onset and severity of CNP in SCI patients (3,8), as well as the potential for improved life expectancy (6), 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 et al (24).

The present paper describes the findings of a study that explored the experiences of SCI patients living with CNP. A series of three focus groups explored the experience of CNP in SCI patients in relation to the 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 patients through the expression of the 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 patients because the dynamic of the group process provides a safe environment which encourages the spontaneous expression of varied viewpoints (25). 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 (26).

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 of the Ottawa Hospital, Rehabilitation Centre. Patient charts were consulted to confirm the diagnosis of CNP, level of SCI, Frankel classification (27), 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 declined due to scheduling or transportation difficulties. Written consent was obtained before the start of each focus group.

Procedure

Focus group questions were developed and piloted to determine their effectiveness in obtaining data that addressed the study objectives. The moderator posed three open-ended questions (Table 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 (28) 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.

RESULTS

Sample description

Seventeen men and seven women ranging in age from 34 to 60 years and 31 to 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 either cervical stenosis (an arteriovenous malformation related hemorrhage), 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. 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, there was a general consensus that coping with neuropathic pain was the most difficult. Their


Chronic neuropathic pain in SCI: The patient’s perspective

| Theme          | Definition                                                                 |
|----------------|---------------------------------------------------------------------------|
| Nature of pain | Chronic neuropathic pain (CNP) as characterised by spinal cord injury 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     | Medication failure described the overall 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.              |

“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.”

The use of metaphorical language was consistently evident in the participants’ efforts to explain the quality of their neuropathic pain. SCI individuals engage in daily “battles” with their pain. Forceful words which 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”, “vise”, 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 which seemed dependent on the influence of known or unknown factors. One participant stated:

“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 motorcycle 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 vise or something.”

The majority of participants reported the appearance of neuropathic pain within the first six months postinjury. 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 neurological 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 SCI and in this location allodynia was prominent.

Descriptors: The use of metaphorical language was consistently evident in the participants’ efforts to explain the quality of their neuropathic pain. SCI individuals engage in daily “battles” with their pain. Forceful words which 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”, “vise”, 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.”
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 laying 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 (Table 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 was used as a coping strategy. Relaxation and distraction provided brief periods of pain relief. Reported self-medicating practices included using 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 so 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 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 pop out of your head, like when I say nothing, I mean 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.”
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 nonopioid 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 opioids 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 where they grieve 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 regarding the inability of modern medicine to cure their pain. Participants reported visits to their family physician, rehabilitation physiatrist, and 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 demonstrated 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 (29), daily function, (4,5,30) inhibits work and social activity, and necessitates hospital admissions (11).
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 (31-33). 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 (19) reported that psychosocial factors were more closely associated with the experience of pain than physiological factors in SCI patients who have chronic pain. In addition, anger (19,34) and anxiety (35) 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 (19). Although acceptance of disability was reported to be negatively correlated with pain severity, that does not appear to be the case in this study. Participants commonly viewed their SCI 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. Transelectrical stimulation 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 (36). 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 take pain medications and had 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 (37) in his study where acceptance of pain predicts adjustment in chronic pain patients. The concept, acceptance of pain, was defined as the acknowledgment of pain as chronic and nondisabling, the relinquishing of attempts to control the pain, as well as the resolution to live a rewarding life despite the pain. These behaviors 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 (25). 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 (38) 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 (39) 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, resulted in the surfacing of strong emotions during the focus groups 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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