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Monika Löfgren & Cecilia Norrbrink

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RESEARCH PAPER

"But I know what works" – patients' experience of spinal cord injury neuropathic pain management

Monika Löfgren^{1,2} & Cecilia Norrbrink²

¹Department of Rehabilitation Medicine Stockholm, Danderyd Hospital, Stockholm, Sweden and ²Department of Clinical Sciences, Karolinska Institutet Danderyd Hospital, Stockholm, Sweden

Purpose: To explore and obtain increased knowledge about (i) strategies and treatments used by individuals with neuropathic pain following spinal cord injury (SCI) for handling long-term pain, and (ii) their experience, needs and expectations of SCI neuropathic pain management. **Methods:** Qualitative methods with an emergent research design were used. Eighteen informants who suffered from long-term SCI neuropathic pain participated. Data were collected with diaries and thematized research interviews. Content analysis and constant comparison according to grounded theory were used for the analyses. **Results:** A model with four categories emerged: "Pain is my main problem" explained the impact of pain in the informants' everyday life; "Drugs – the health care solution" described the informants' experience of pain management; "The gap in my meeting with health care" described the discrepancy between what the informants wanted and what health care could offer. "But...this works for me" described treatments and strategies, which the informants found helpful for pain control and pain relief. **Conclusion:** Neuropathic pain, one of the major problems following SCI, is difficult to treat successfully. To improve treatment outcome, health care needs to listen to, respond to and respect the patient's knowledge, experience and wishes. Future research needs to address treatments that patients find effective.

Keywords: Complementary treatment, non-pharmacological treatment, pain, patient expectation, spinal cord injury

Introduction

Medical care of individuals with spinal cord injury (SCI) has improved in recent decades. More people are surviving an SCI, and they are living longer. Quality of life (QoL) has therefore become a main focus in rehabilitation. Pain in

Implications for Rehabilitation

- Patients' experiences, knowledge and preferences need to be taken into account when designing pain management.
- Complementary treatments (non-pharmacological) ought to be an important part of successful neuropathic pain management.

individuals with an SCI is a common consequence, as many as 40–45% being diagnosed with neuropathic pain [1,2]. Many report more than one pain problem [1,3]. Pain is perceived as one of the most difficult consequences of SCI [4], influencing QoL and life satisfaction negatively [5,6] making neuropathic pain a challenge for everyone working with SCI and pain.

Current treatment recommendations on SCI neuropathic pain focus on pharmacological strategies [7] involving anti-convulsant and antidepressant drugs, followed by tramadol and opioid medication. However, these are unfortunately only partly successful in relieving pain. Unwanted side-effects and lack of effect limit compliance. Non-pharmacological options have not been well explored in SCI pain research, so these options are rarely included in treatment recommendations.

Yet studies show that non-pharmacological treatment strategies are commonly used in individuals with SCI [3,8] and that massage [3,8,9], physiotherapeutic interventions [9], and heat therapy [8] are widespread. A superior effect of non-pharmacological strategies than of pharmacological treatment was also reported by Heutink et al. [3] where treatment such as acupuncture/magnetizing, physiotherapy/exercise, massage/relaxation and psychological treatments were rated effective to a large extent by more than 55%. Opioids, followed by benzodiazepines were considered the

Correspondence: Monika Löfgren, Department of Rehabilitation Medicine Stockholm, Danderyd Hospital, Bldng 39, Floor 3, 182 88 Stockholm, Sweden. E-mail: monika.lofgren@ki.se

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most effective pharmacological drugs (rated as effective by 55 and 53% respectively). Patients often used more than one type of therapy [9]. This is in line with the biopsychosocial perspective [10], where pain is understood as a complex phenomenon where the psychological and social aspects are as important as the physiological, and different methods target different mechanisms.

However, neither of the surveys mentioned above differentiated between neuropathic and nociceptive pain. Even so, there may be a discrepancy between treatment recommendations and the actual use and subjective effectiveness amongst individuals with SCI and pain. Despite the wide use of different pain-relieving strategies among these people, many still report having high pain intensity levels [3].

One of the few qualitative studies in SCI pain research explored the patients' perspective on chronic neuropathic pain [11]. Medication failure was common and warm water, swimming, activity, and distraction could provide pain relief. Despite treatment algorithms we, as caregivers, obviously fail to give effective pain relief in individuals with SCI and neuropathic pain. Knowledge about these patients' preferences, wishes and how to increase their satisfaction with pain management has been little investigated. To improve the care and treatment of neuropathic pain following SCI we wanted to explore the sufferers' own strategies and treatment for handling long-term pain, and to survey their experience, needs and expectations of SCI neuropathic pain management.

Methods

Theoretical perspective

To analyse individuals' experience, needs and expectations of long-term pain management, we chose a qualitative approach. Qualitative methods are suitable for exploring the meanings of social phenomena as experienced by individuals [12]. Grounded theory was chosen as the main research method, since it is suitable where knowledge is still scarce, and for generating new models. We used an emergent design and purposive sampling technique, for a focused research process [13]. For data collection, diaries and thematized individual research interviews were used, followed by content analyses and constant comparison [14,15].

Informants

To include people with a wide range of experience of long-term pain management, informants were recruited in two ways: by advertising at the website of two patient organizations and in collaboration with five national rehabilitation units (two university hospitals and three regional ones) (Figure 1). Inclusion criteria were SCI for over 2 years, neuropathic pain for more than 6 months, and aged 25–65 years. Exclusion criteria were diagnosed brain injury, and difficulties to understand and speak Swedish. In total, 18 participants volunteered to participate in the study and were thus included.

The volunteers were informed about the study and their right to withdraw at any time. Information about the study, instructions on keeping a diary, and a consent-to-participate form, were posted to those who accepted to participate. All 18



Figure 1. The informants lived in large cities, small towns and rural areas in the south of Sweden. The circles represent the cities and the striped areas show where the informants lived.

volunteers gave their informed consent: 11 men and 7 women with a median age of 46 years, range 28–66, and a median time since injury of 14 years. Fifteen had had a traumatic injury. All suffered from long-lasting pain (median 9.5 years, range 3–31 years). Pain intensity was rated as a median of 6.5 on a 0–10 numerical rating scale (NRS) during the previous week. All had pain daily and most ($n = 13$) had experienced continuous pain during the previous week. Thirteen used analgesic drugs, and opioid medication was the most common ($n = 10$). For patient and pain characteristics see Table I.

Data collection and analysis

The informants were first instructed to write a diary for at least five days a week for two weeks. The diaries were either written on a computer and e-mailed to one of the authors (ML) or written in a booklet posted to the informants.

The informants were instructed to write about what they did to handle their pain and how successful they were, e.g. their strategies, whether they used any treatment, what they thought and how they felt about their pain. Four informants chose not to write diaries because of lack of time.

Fourteen diaries were written and analysed according to content analysis [15]. First, the two authors read the diaries independently, identified the most important parts and summarized these into themes. This was followed by comparison and discussion that ended up in an outcome negotiated between the authors. Central themes about strategies the informants employed to handle their pain were described in the material. To deepen the knowledge, all 18 informants were interviewed individually, with the diary themes as the basis for the interview guide. These themes concerned the use of different strategies to control pain, circumstances affecting pain, the effects of complementary treatment and of pain-relieving drugs, the role of family and friends, and experience from pain management. As one of the aims of the study was to explore ideas and thoughts on how to improve current pain care, questions about this were added.

Table I. Patient and pain characteristics.

	n	%	md (range)
Patient characteristics			
Male/female	11/7	61/39	
Age (years)			46.5 (28–66)
Cause of injury (trauma/non-trauma)	15/3	83/17	
Time since injury			14.2 (3–31)
Level of injury			
Cervical	4	22	
Thoracic	11	61	
Lumbar	3	17	
ASIA impairment grade (AIS)			
AIS A	11	61	
AIS B	0	0	
AIS C	2	11	
AIS D	5	28	
Occupational situation			
Working 75%	3	17	
Working 50%	7	39	
Working 25%	2	11	
Sick leave	5	28	
Retired	1	5	
Educational level			
9-year compulsory school	2	11	
Trade school	1	6	
Upper-secondary school	5	28	
University	10	56	
Marital status			
Married/cohabiting	9	50	
Single	9	50	
Children living at home	8	44	
Pain characteristics			
Years with pain			9.5 (3–31)
Ratings of pain intensity last week on an NRS			6.5 (3–9)
Number of days with pain last week			7.0 (7–7)
Duration of pain			
One minute or less	0	0	
More than one minute but less than one hour	0	0	
At least one h but less than 24 h	3	17	
At least 24 h but not continuous	2	11	
Constant/continuous	13	72	
Analgesic drugs			
Anticonvulsant drugs	8	44	
Tricyclic antidepressant drugs	2	11	
Serotonin and norepinephrine reuptake inhibitors	1	6	
Opioids	10	56	
NSAID, ASA and/or paracetamol	4	22	
Sleeping pills	2	11	

ASA, acetylsalicylic acid; NRS, numerical rating scale; NSAID, non-steroidal anti-inflammatory drugs.

One researcher (ML) conducted the interviews, at a place convenient for the informant, such as a nearby hospital or the informant's workplace or home. The interviews lasted for a mean of 62 min (range 21–94 min), and were all recorded and transcribed verbatim.

The interviews were analysed in accordance with grounded theory [14] using the method of constant comparison. The data were analysed concurrently with data collection in order to develop a focused research process. After the first three interviews, the open coding started, using the Open Code computer program [16]. First, both authors listened to the interviews for gist, and then they separately coded sentences or phrases. The coding was descriptive and aimed at capturing the content of the data. The emerging codes were thereafter discussed until agreement.

The interviews and the analysis continued in parallel, and after five interviews the next step, selective coding, started [17]. The codes were labeled together in categories. At this point thirteen categories emerged from the data; physical activity, attitude to the circumstances, complementary medicine, knowledge, drugs and the patient, drugs and health care, relations and social life, significance of pain, sleep, health care, warmth, conflict, wishes. The categories described the informants' relations to their caregivers, their treatment and strategies used for pain alleviation and their relations with significant others. The researchers decided which codes were important for the research aim and changed the interview guide according to the emerging results. Thus "described strategies" and "pain management" were explored in more detail while "relations with family and friends" turned out to be less important than expected in relation to pain-coping strategies. The relationships within and between categories were explored; the authors discussed the categories' dimensions and the emerging connections between them. The thirteen categories were later merged to ten and finally to four (Figure 2).

A model, termed "But I know what works" emerged and was refined during the research process (Figure 3). The last four interviews confirmed the categories and the model. Saturation was reached in the main parts of all categories.

Trustworthiness [12] was accomplished in several ways throughout the study. For transferability [12], the informants were chosen to represent a wide variety of experience of pain management, they lived in large cities, small towns and rural areas; they represented a wide spread of age, education, occupation and time since injury. Triangulation [12] was used to ensure credibility. Thus the data collection involved diaries and individual interviews, the analyses involved content analysis and grounded theory and the two researchers had different professional backgrounds. Both were physical therapists. One (ML) had experience of qualitative research and musculoskeletal pain rehabilitation but no earlier experience of SCI neuropathic pain rehabilitation. The other researcher (CN) lacked experience of qualitative research but had long experience of SCI neuropathic pain rehabilitation. Both perspectives contributed to the results. More than five years earlier, CN had been involved in rehabilitation of some of the informants' rehabilitation. ML conducted

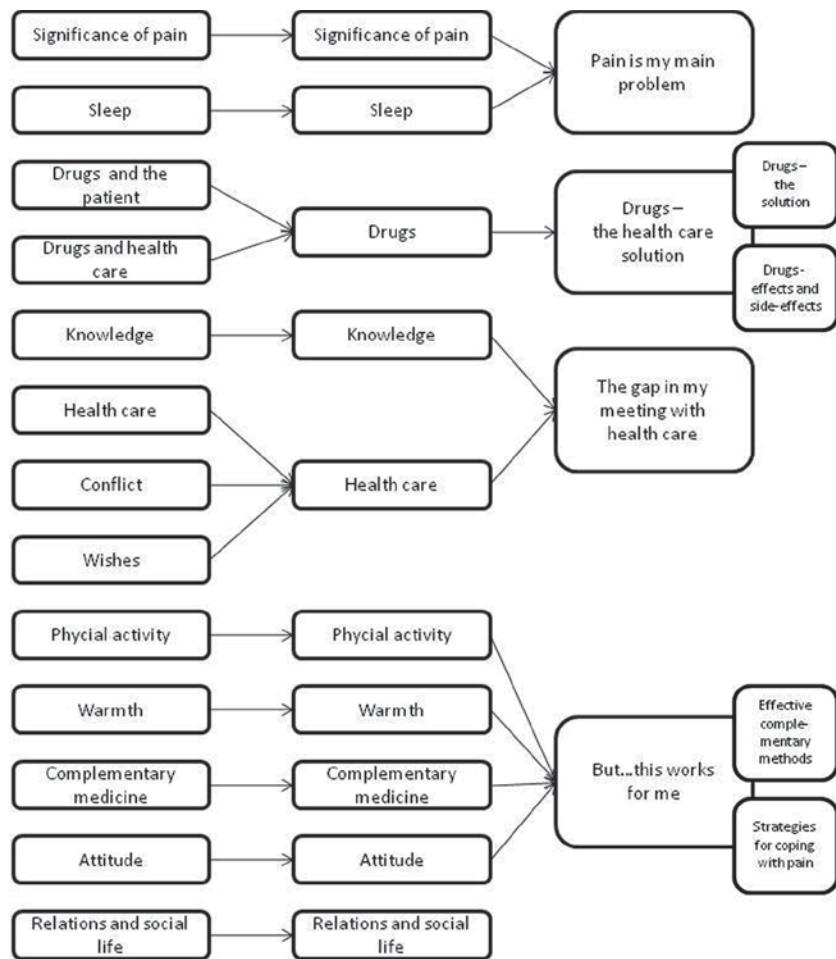


Figure 2. How the themes were developed from thirteen to four.

all the interviews, since it was supposed that she would be the most naïve interviewer with no prior connection with the informants. For confirmability [12] the authors' pre-understanding was highlighted and discussed throughout the analysis to keep the result as neutral as possible.

The study was approved by Ethics Committee 2 in Stockholm, Case no. 2008/2:1.

Results

The themes that emerged from the content analyses of the diaries were; strategies to control pain, circumstances affecting pain, use of complementary treatments and pain-relieving drugs, the role of family and friends and experience of pain management.

In relation to the themes, the informants described a wide range of strategies that they used to control or decrease the pain. The emerging themes were used as a basis for continued data collection with interviews. In the continued analysis of the interviews thirteen categories emerged. They were finally merged to four; "Pain is my main problem", "Drugs – the health care solution", "The gap in my meeting with health care" and "But....this works for me" (Figure 2).

The model "But I know what works" was constructed to illustrate the factors affecting the situation described by

informants (Figure 3). The categories with subcategories are described more thoroughly below, together with quotations from the interviews.

"Pain is my main problem"

Pain was considered to be the informants' main problem following SCI, being the largest, but still invisible hindrance in their daily life. The informants had to relate to the pain in every activity as well as during rest and sleep. They constantly had to use their energy and knowledge with all means to keep pain at a tolerable level. Experiencing a day, or even minutes, without pain was rare and when it occurred it was described as "heaven". The informant's number is presented after each quotation in brackets.

"No, if I'd only had to use a wheelchair, that would have been no trouble. But life becomes hell some days when the pain's at its most awful." [15]

Sleep quality influenced pain and vice versa. Good sleep enabled the informants to escape the pain: the opposite resulted in decreased ability to cope.

The informants described tiredness, exhaustion and fatigue due to their pain. It limited, and sometimes even controlled them, in their physical and mental performance at work and

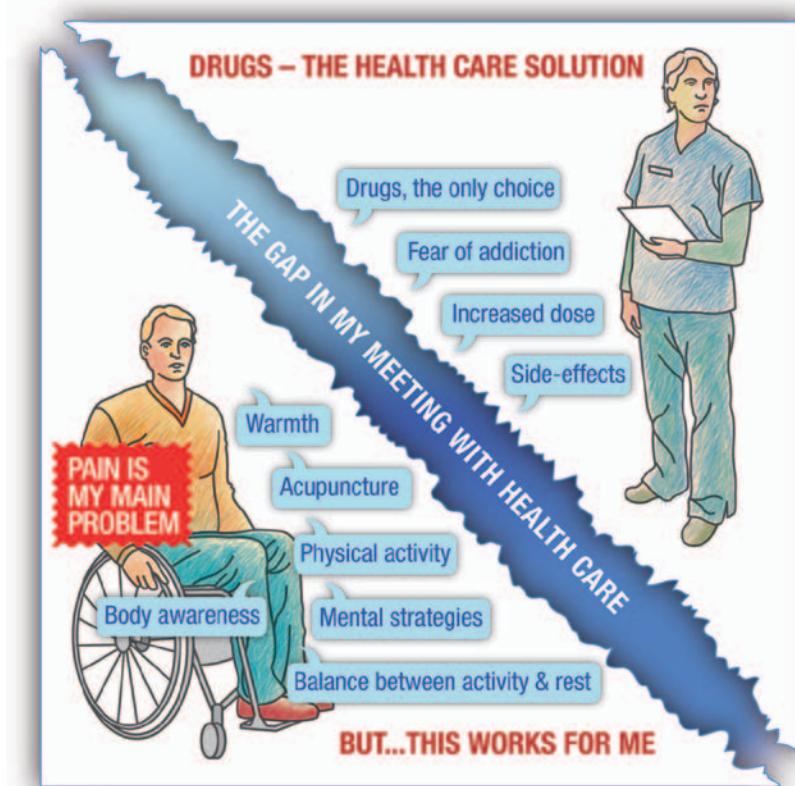


Figure 3. The model "But I know what works" consists of four categories. Pain was described as the informants' main problem. When seeking health care, they found that drugs were the only treatment offered. They described positive effects of non-pharmacological treatments, but these were rarely offered. Thus a gap was identified in the informants' meeting with health care.

in leisure. They had to take into account the consequences of their pain when planning activities; they paid the price or refrained from the activity.

"If I had 100% energy to use one day, that everyone has, I know that my pain grabs some percent. Then I only have the rest to play with." [15]

"Drugs – the health care solution"

The drugs category consists of two subcategories; "drugs – the solution" and "drugs – effects and side-effects". The category explains the informants' experience of pharmacological treatment as the solution health care offers, and the effects they experience from the drugs.

In "drugs – the solution" pharmacological treatment for pain was described as the only choice offered by the informants' physicians. Drugs were liberally prescribed without questioning their sometimes extensive use and without discussion regarding use and misuse. Pain-relieving drugs were the only treatment option available for the informants, even when they considered e.g. acupuncture or massage to be effective. When medication failed and they asked for alternatives, increased doses or other drugs were offered.

"Contacts with my doctors usually consist of their foisting medicines onto me and I say thank you very much – but no thanks – and sometimes I say yes, write me a prescription then so I can stop nagging and then I don't go and get them." [6]

"You go in... hi, we've got these medicines..., yes, but I don't want medicine I want a different kind of help. But then you get stuck, because there isn't anything else." [7]

In "drugs – effects and side-effects", when the informants had tried many different pharmacological options, they reported that the effects on pain varied from none or limited to moderate. They had experienced extensive unwanted side-effects from their medication, both physical and mental. The latter was the most bothersome: e.g. hallucinations, feelings of being drugged or high, unfocused and personality changes.

"When 3–4 months had gone, then it wasn't only the aches that sailed out the window, reality went with them." [12]

"I was totally nuts." [14]

Former addiction to opioids was described. The consequences for social life, economy, work and family life had been vast; detoxification had then been initiated by the informants themselves. Resistance to or fear of using pain-relieving drugs was described as a consequence.

"Well, I'd been taking morphine and got addicted. So right, I started the morning with two morphine tablets and then went on like this and perhaps wasn't the world's most social person. Most of the time went to taking morphine and hanging about doing nothing and I don't think it ought to be like that." [5]

"The gap in my meeting with health care"

The "gap" category represents the informants' experience when encountering health care staff to discuss their pain management, with both positive and negative experience.

Good relations and dialogue with health care people was described as being respected and understood, believed in and not questioned. Those caregivers were described as experts often, but not always, with a specialization in pain relief. They were of different professions and they often had a years-long relation with the informants.

"She doesn't ignore the fact that I say I'm in pain. And she also says, 'if you say you're in pain then you're in pain'... And just that comment makes me feel she's taking me seriously." [3]

On the other hand, the informants described lack of support for and interest in anything beyond medication. They never got suggestions for non-pharmacological treatment; nor did they experience any interest when they themselves suggested this.

"I kind of think if it wasn't so taboo to talk about alternative medicine, because there's so much prestige in medical science. But I think self-confidence and reliance and your own strength, that comes into it too." [3]

The informants felt that the caregivers lacked interest in their own [the informants'] experience and knowledge of their pain and how to treat it. Situations were described when they felt their pain experience was being called into question.

"The first time the bone pin in my leg broke..... I said.... It's a different kind of pain and an ache which isn't.... like before.. and it feels wrong. It turned out when I got an X-ray after three or four visits perhaps, that I'd been going around with a bone pin that had broken off and a bone fracture that hadn't healed." [3]

The informants described how, when questioning the prescription of drugs, they felt that they were being difficult. They struggled for treatment alternatives but were rarely successful. This made them lose confidence, give up on health care, become bitter, and seek other alternatives.

"If you're a patient who makes demands, and asks questions about things, expects things, they just shut the door. You have to be a good patient who does what they tell you." [8]

The informants wished to have a dialogue with health care where they were listened to, confirmed and could discuss possible strategies and complementary treatment. They wanted to be met as people with individual needs, to be met with respect, and as knowledgeable and experienced equals in their pain management.

"Then if it's physical therapy or massage or ... if it's TENS or if its acupuncture that helps, you have to find, something that works for the individual, and do that on a regular basis." [7]

"But...this works for me"

The category "But...this works for me" has two subcategories; "Effective complementary methods" and "Strategies for coping

with pain". It describes complementary methods and strategies the informants used to keep pain under control. Medication could also be of help, as described under "Drugs – the health care solution."

"*Effective complementary methods*" were massage, acupuncture, exercise, yoga, meditation, relaxation, and cognitive and behavioral treatment. The informants had mostly initiated these themselves and found by trial and error what was most helpful. Most of these treatments/methods were paid for by the informants, which restricted use.

Massage and acupuncture had given pain relief and relaxation.

"TENS is good, acupuncture is good, massage is incredibly good..." [8]

Warmth was a common means of pain relief, increased wellbeing and relaxation. Warmth was used in many ways: hot showers/baths, saunas, hydrotherapy, hot packs, warm clothes and heaters. Hot and/or stable weather could decrease pain while cold and windy weather resulted in the opposite. However, excessively hot weather could also increase pain.

"...and there I find [steam sauna], there are seconds when I'm sitting in there... Then, then, no pain! I enjoy these seconds so much, for they aren't many, but they're so clear, so even if it's only three seconds, its like heaven. Now no pain at all!" [3]

"okay, summertime, when I have almost no pain if it's not raining cats and dogs, because then it kind of creeps in and it hurts all over. But it's summer outdoors and about the same temperature indoors and outdoors, that's when it works...." [5]

Physical activity [18], e.g. being constantly on the move, walking, wheeling and gardening, gave reduced pain during the activity and a sense of bodily and psychological wellbeing. At best, a way to start the day could be a slow pace with gentle movements and stretching, preferably still in the warmth under the bedclothes. Then being constantly on the move was the optimal strategy to control pain. Being unable to move, e.g. in a sedentary occupation, was "devastating".

"It's a job where you move about all the time, don't sit still, because sitting still in front of a computer, that just doesn't work, you have to keep moving." [16]

Those informants who exercised several times weekly, at high intensity for one hour or more at a time, obtained pain relief that could last for hours, and was occasionally also complete. If the exercise was done in the evening the effect could last until the next day. Different types of exercise were used, e.g. wheeling, swimming, strengthening exercises and biking. Exercise helped most of the time, but not always. Muscular soreness after exercise could replace the neuropathic pain and was experienced as positive and pleasant.

"It's like a flat fizzy drink compared with one that's full of bubbles. Just little bubbles now and then." [17]

"I mean you train hard, you get rid of the pain." [5]

Physical exercise [18] gave relaxation and pain relief which could last for hours. It could also help against spasticity, which in turn worsened the neuropathic pain.

"But then again I can blunt it ... so I don't have this, sharp, this really awful [pain], I just file it down" [12]

Not all the informants were able to perform exercises at the high intensity required for pain relief; instead exercise made their pain increase.

"training... is actually extremely hard for me, cause I get a real pain hangover, it's hard to judge how much... I should exert myself" [2]

Others could exert themselves to a certain level beyond which pain worsened. All kinds of physical activity and exercise were individually "designed", everyone had to find their own balance between strain and rest.

Physical activity and exercise in natural surroundings gave pain relief and increased the informants' physical and mental wellbeing, e.g. kayaking, walking, wheeling and biking. Swimming and/or exercising in a warm water pool was described as an efficient way of decreasing pain, where the combination of training and warmth was highlighted.

"Ever since I came home ... went to a rehab bath, one morning a week. ... if I didn't have that Tuesday, my whole week collapsed." [3]

Strategies for coping with pain: Over time the informants described that they developed good body awareness. Knowing their own body's limitations, and respecting them was a way to control the pain.

"This is why I've kind of had to learn a balance to, really learn to listen when my body teaches me that 'now it's enough', then it IS enough." [12]

They further reported that they had learnt how to distinguish noxious pain from their general neuropathic pain.

"In the beginning training hurt terribly, and it hurt terribly after training. And then it's a pretty long journey to kind of learn what's soreness after training and what's pain-pain." [6]

To control pain it was important to find a balance between rest and activity. This balance was individual and could differ for the same person in different situations. To find it, listening to one's body was the most important tool. Avoiding stress as much as possible, e.g. by waking up early or planning the day to get enough time, were other useful tools.

"I mustn't feel stressed and it [the day] must have quite a good balance between sitting still and moving about, so I can change my positions about quite a lot." [15]

When the pain was too intense, the usual strategies did not work. Instead, the informants bit the bullet, went to bed and tried to rest or sleep until the worst had passed. Then less demanding activities like watching TV, surfing on the internet or listening to the radio could help distract pain.

"You can think it away to a certain extent, you can, but then you feel it too much and this doesn't work any more ... so that when it's somewhere between 8 and 10, when it's as severe as that I can't think it away." [5]

"Once it's got that far there's nothing that works, you just have to hope next day when you wake up it isn't so awful" [9]

The informants described how they frequently used conscious mental strategies to distract pain. These were mainly self-taught by trial and error and could consist either of focusing on something else than pain, doing an activity or relaxation/meditation/yoga. Distracting activities could be work, movies, theater, listening to music, working, having sex, being physically active or meeting friends. The more important, interesting, fun and positively demanding the task or activity was, the more effective the distraction of pain.

"Things I think are fun to do, they relieve the pain a bit, or relieve it, you're distracted." [7]

"After a fairly simple yoga exercise or a say fifteen-twenty minutes meditation the pain is halved." [12]

The mental strategies resulted in less perceived pain or a change of focus away from pain. The ability to change focus was difficult and could take several years to learn. It was important to be in good shape and not too tired to be able to use the acquired mental strategies fully.

"The trick is to block the pain away from your brain, and this is incredibly difficult, but it's something you try and work on yourself. I try to not to feel that it's there, actually, but it's incredibly difficult... It's different, it ebbs out it, perhaps, I don't know, it can be that things get a little easier." [8]

Learning to live with and accept pain took several years. You were told by health care that you had to learn to live with pain, but not how this should be accomplished.

"So this expression 'you have to learn to live with it' is hateful. And you quickly learn to translate it to 'they don't believe me' and 'they don't understand what I'm telling them'. While we who are living with pain, have long been doing it, we know it's true... You can say it differently, then ... 'there's so much you can do yourself'." [15]

"I've not met a pain expert who has helped me to handle pain, but what I've been prescribed is pills." [8]

Discussion

The key finding in this study is the informants' experience of a discrepancy between what they want from health care and what health care offers for pain management. The informants report requesting complementary treatment and knowledge of how to live with their pain, while health care offered drugs. The informants described a situation where few listened to their knowledge and experience of living with pain and their wishes regarding pain management. They felt disrespected and this led to resignation.

Initially, the biopsychosocial perspective [10] was the theoretical framework for this study, addressing pain as a complex phenomenon affected by many aspects, different for each individual. Here, pain has to be managed individually, with the sufferer's preferences taken into account. During the analysis, theory on patient satisfaction [19] also proved important for perspectives on the relation between informants and caregivers.

Our informants with neuropathic pain after SCI described, as did those in the qualitative study by Henwood and Ellis [11], how they had tried many drugs for pain relief, mostly with more side-effects than were worth the limited pain-relieving effects. Over the years the informants in both studies had tried different non-pharmacological treatments and learned a variety of strategies for pain control and pain relief. Their meetings with health care were described as frustrating, hopeless, and as a struggle where they experienced lack of interest or knowledge from health care regarding their choice of pain relief. Drugs, more or new, were the only option health care would offer.

Former studies, both qualitative [11] and quantitative [3,8,9], have pointed out that medication has but limited effects on SCI neuropathic pain. Complementary treatment, e.g. acupuncture, exercise and physical therapy, are rated by the patients as effective for pain relief more often than drugs (opioids) [3,9]. Still, complementary treatments were reportedly not recommended by health care professionals in our study; rather, the informants had struggled to get them. There is limited evidence from intervention studies for the efficacy of many complementary treatments in this patient group, but surveys and qualitative studies alike support the use of complementary strategies for pain relief [3,8,9,20,21]. A limitation in several of these studies was that not all their participants had neuropathic pain. However, our study, where all had neuropathic pain, confirms these findings.

In their 2009 review Cardenas and Felix [22] discuss possible gains from complementary treatment, despite lack of evidence from treatment studies. They give examples of exercise following a well-established theoretical model for treatment efficacy, but no scientific evidence from treatment studies of neuropathic pain. The present informants gained pain relief for hours after exercising, provided they tolerated the exercise. Strenuous exercise was well tolerated by, and effective for pain relief in some informants; while for others it worsened the pain. These results stress the importance of individual programs to reach a successful result. They also highlight the difficulties in designing an intervention study as well as generalizing its results.

Warmth for pain relief is common, alone or in combination with exercise [warm-water training]. The physiological explanation of warmth to relieve neuropathic pain is unclear and no studies exist for this patient group. But also, warmth/heat, is frequently used and reported effective in several studies [3,8,9,21]. It could constitute part of self-care strategies offered by health care.

Finally, treatment with massage was reportedly effective for relieving pain, and this is supported by other surveys and studies [3,8,11]. Massage was not given within health care but was initiated and paid for by the informants themselves, limiting the use of this strategy.

The biopsychosocial perspective on pain has provided a framework [22] where pain can be understood as a complex phenomenon, with the psychological and social parts as important as the physiological. Our informants who used psychological strategies like mental distraction, focusing on interesting and demanding tasks or doing meditation described these as effective. They wanted to learn more

about such strategies and to try e.g. cognitive behavioral therapy or hypnosis; but, again, these were not offered by health care.

Patient satisfaction is recognized as an important part of health care [19]. Patients who are dissatisfied with their care are less likely to comply with advice and recommendations. Although successful communication is one of the most important parts to reach patient satisfaction, communication failure is a common problem within health care [19]. Patients in all kinds of health care express dissatisfaction with health care personnel e.g. they fail to let patients report their concerns fully in their own way. Further, they do not convey reassurance and do not encourage patients to share decisions [19]. The informants had all found their own individual mix of different strategies as had Henwood's and Ellis's [23] informants. To support the individual to continue developing effective strategies, we as health care professionals need to recognize the unique knowledge of every patient who visits us [24]. Studies have revealed that people with SCI do have a high level of knowledge about "their" research [25]. Their earlier experience of treatment, body awareness and pain-coping strategies learned by trial and error over many years needs to be met seriously. We as health care professionals have much to learn from our patients. This is in line with the concept of patient empowerment, which includes patients' right to support in their own choices regarding treatment and care [26].

Our informants wanted to be viewed as equal partners in discussions of pain relief and pain control, but had seldom experienced support or interest in what they had to offer or interest in other options than drugs. They felt they were being 'difficult' if they questioned drug treatment: it was easier to find their own ways outside the health care system or alone. The disinterest led to feelings of disappointment, frustration and resignation. Health care personnel were often not viewed as open-minded and knowledgeable in questions about pain coping or treatment except with drugs.

Pain acceptance is an important part of learning to live and cope with long-term pain [23,27]. Our informants described how it had taken them several years to learn, if they succeeded, to live with their pain. When they were told "you have to live with pain", it was a terrible thing to hear, and was not followed by any help regarding how to do so. Instead they sought encouragement about different things they as patients could do themselves to improve their situation. We have not yet found in the literature any self-help information for sufferers from SCI neuropathic pain.

One of the most important strategies described was to find the balance between activity and rest, and this had often taken years. Doing too much or too little could both aggravate pain. Sometimes total rest was warranted, especially when pain intensity rose. Resting in order to manage pain has also been described in patients with neuropathic pain of other origin [28]. This and other strategies could be accomplished faster if health care staff actively acknowledged and promoted them.

Qualitative research methods are used to explore structures, processes and phenomena which affect humans in society. The knowledge obtained from this study might

be generalized to other similar situations [12]. To ensure the best possible transferability, our informants represented a wide variation in background and pain management. They came from different parts of Sweden and underwent pain management at five different SCI rehabilitation hospitals. There were no differences between their experience relating to locality or hospital. However, note that the transferability of the knowledge from this study is not statistical but theoretical, drawn from the concrete level of the data [interviews] to the abstract, theoretical level. This implies that the reader has to decide the accuracy of the results for every situation.

A possible methodological weakness could be that one of the authors [CN] had taken part in the prior rehabilitation of some informants and also had great knowledge that might have affected the analysis [12]. Neutrality [12] was maintained in that ML performed all the interviews and both authors were fully aware of these issues during analysis and their continued discussions. CNs' earlier knowledge was of great value to the research process.

The present results indicate the complexity of aspects needing to be observed when managing neuropathic pain following SCI. In the clinic each patient's experience, knowledge and preferences need to be discussed to find the best mix of methods for pain management.

Complementary treatments, including mental and behavioral strategies, are safe and helpful for pain management, and our patients expressed a desire to use them. For this reason, we recommend that such treatment be included in pain management of SCI neuropathic pain.

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