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Managing the symptoms of neuropathic pain: an exploration of patients' experiences

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Abstract

The debilitating effects of chronic neuropathic pain on everyday life are considerable but little is known about how individual sufferers manage these effects. Virtually nothing is known about what patients prefer, what measures they take themselves, when, or in what combinations. The aim of this study was to explore patients' reports of how they managed their neuropathic pain symptoms. Three focus groups including 10 participants were used to generate qualitative data on both individual and shared experiences of managing their symptoms of neuropathic pain. Discussions were recorded and transcribed verbatim. Data were analysed using thematic analysis, identifying categories and broader themes of importance to patients. The most common management strategy was the use of conventional medications, often associated with poor effectiveness and unpleasant side-effects. Complementary and alternative medicine was ineffective but many found resting or retreating helpful. They exhibited a repeated cycle of seeking help to manage the pain, with each unsuccessful attempt followed by new attempts. Some had tried to accept their pain, but there was insufficient psychological, social, emotional and practical support to allow them to do this successfully. This exploratory study provides a basis from which to develop a larger study to validate and extend the findings. Other issues meriting research are the effectiveness of cognitive behavioural therapies for those with neuropathic pain; and an exploration and subsequent evaluation of different types of social, practical and emotional support needed to help live with neuropathic pain.

Introduction

The debilitating effects of chronic neuropathic pain on everyday life are considerable¹⁻² but little is known about how individual sufferers manage these effects. There is modest evidence to inform how symptoms can successfully be treated³⁻⁶; and very little about what patients prefer, what measures they take themselves, when, or in what combinations.

While the management of chronic pain has received considerable attention in the research literature, far less has been given to the subset of people with chronic neuropathic pain. A search of the Cochrane Library revealed only four systematic reviews of interventions for neuropathic pain. These suggested some effectiveness from anti-depressants, local anaesthetics and tramadol³⁻⁵ while the evidence for sympathectomy was poor.⁶ The Cochrane Central register held 77 relevant trials, of which 70 were concerned with pharmacological interventions, three the effect of radiotherapy, three electrical stimulation and the remaining one with behavioural interventions. Subsequent structured searches of Medline, Embase, PsychInfo and AMED (1996-2006) produced a similar picture. Studies of pharmacological and surgical interventions were relatively common (n=136), while very few papers considered the effectiveness of complementary and alternative medicine (CAM) (n=2) or cognitive/behavioural therapies (n=2) on neuropathic pain.

Overall, this literature indicates that conventional analgesics have had highly variable success for a range of different types of neuropathic pain. Adjuvant analgesics, such as tricyclic anti-depressants (eg amitriptyline, desipramine) and anti-epileptics (eg phenytoin, gabapentin) have had some success in the treatment of neuropathic symptoms.

Unfortunately, the side-effects of anti-epileptics are common, causing symptoms such as somnolence, nausea, dizziness and mood change; and they may interact with other drugs. A study of 151 patients' attitudes towards antineuropathic analgesics showed that for many fear of addiction (32%) and adverse side-effects (48%) were problematic⁷. Topical therapies such as capsaicin, NSAIDS and local anaesthetic may be used for peripheral nerve damage.

The CAM literature is generally unconvincing in terms of robust evaluations of its effectiveness. A small retrospective study of acupuncture suggested that it reduced neuropathic pain in patients with spinal cord injury⁸, but there were no controls and the placebo effect was not taken into account. A pilot comparison of healing touch and relaxation was inconclusive due to inadequate sample size and lack of randomization to each group⁹. Although CAM may have the potential to help this group, it is difficult to know which interventions would be worthwhile evaluating in a rigorous manner.

The use of psychological therapies and in particular, cognitive-behavioural therapies (CBTs) specifically for chronic neuropathic pain has received little attention. This approach takes account of patterns of thinking and behaviour that exacerbate and maintain pain and may also improve functioning regardless of how the pain feels. There are at least 34 randomised controlled trials involving sufferers of chronic pain which demonstrate the effectiveness of CBT in improving mood, physical functioning, independence, problem solving and reducing the use of health services. Unfortunately these contain little information about whether or not they have benefits for those with chronic neuropathic pain. Preliminary (non-RCT) evidence available concerning non-pharmacological interventions suggests that educational, cognitive and behavioural interventions may be effective for this group. A recent study of 27 people with neuropathic pain who participated in a 10-week comprehensive pain management programme showed that at 12 months they had lower levels of anxiety and depression and better sleep quality than at baseline¹⁰. It is likely that this group would benefit from educational and CBT interventions, though research is required to confirm this.

Patients may give up on health care professionals and develop their own ways of adapting to their pain. There is virtually nothing in the literature to indicate the nature of self-management of neuropathic pain. It is possible that strategies may be related to the three areas above (conventional medical interventions, CAM and behavioural approaches), and may also involve highly individual coping strategies.

Clearly, there are many different approaches to managing pain, and many inter-individual differences in what may be successful. This study aims to add to our understanding of approaches which might be useful for people living with neuropathic pain symptoms, by exploring their own accounts of dealing with the impact of the symptoms of neuropathic pain.

Method

This study aimed to explore how patients dealt with their neuropathic pain symptoms. A focus group method was used. This allows people to explore and clarify their views in ways that one-one interviews do not. Group discussions are particularly valuable when the researcher has a series of open ended questions and wants participants to raise issues of importance to them using their own vocabulary and in pursuit of their own priorities. The use of groups may be seen as inhibiting and that sensitive subjects may not be discussed, however, other researchers have found the opposite to be true. Group work can actively facilitate discussion as more extrovert participants may open the door and empower other more shy participants to speak out¹¹. Therefore the method is particularly suited to disempowered patient groups who may find it difficult to speak about their experience or those who wish to be critical of the care they have received. We believed people with neuropathic pain may be one of these patient groups.

Participants

The study was approved by the local Research Ethics Committee. A purposive sampling strategy designed to minimise difficulties in recruitment was employed.¹² Participants were recruited from an existing database of chronic pain patients who had previously participated in a study of neuropathic signs and symptoms¹³ and were identified as having these symptoms. Pain service staff kindly undertook the identification of potential participants on the researchers' behalf, since direct access to this information was not permissible under the UK Data Protection Act¹⁴. Sixty-five patients out of the 99 patients on the database were

identified as residing in the relevant postcode area. Sixteen of these were identified as either deceased or not well enough to participate leaving a total of 49 potential participants who were then sent study information packs which invited participation and included consent forms.

Twelve people agreed to participate and were organised into three groups of four participants and sent further information. Of these, 10 went on to participate in three focus groups. The first group comprised two men and two women; the second two men and one woman; and the third three women. Ages ranged from 24-60 years.

Due to the low response rate from the initial sample a second sample of 16 patients was identified from a different geographical area. Only one person responded therefore it was not possible to convene an additional group.

The focus groups

A comprehensive review of the current literature was undertaken. MB (a researcher with knowledge of neuropathic pain) and VS (background in psychology and no previous knowledge of pain conditions) generated themes from the available literature and developed the focus group schedule. This used a series of open ended topics for discussion (see Box 1, items 1-4) supported by prompts (if needed) designed to encourage conversation between participants rather than participants directly answering the questions of the researcher. The schedule focused on their experiences and the impact of neuropathic pain on their daily lives (reported elsewhere) and how they dealt with their symptoms (reported here). Focus groups were held in geographical locations close to participants' homes, to minimise inconvenience for them, and taxis were provided for those who had difficulty in travelling.

Analysis

The audio-taped discussions were transcribed verbatim. Data from the transcripts were organised using QSR NVIVO version 2. Three different researchers then undertook independent analyses of the data, in order to minimise any personal biases in interpretation.

These were VS (psychologist, as above); IR had a background in nursing, and no specialist pain knowledge; and SJC had specialist knowledge having been involved in pain research for 10 years.

First, a thematic analysis¹⁵ was undertaken by VS. She had primary responsibility for transcription and a simple first-level analysis of themes emerging from the discussion. This involved reading and re-reading the transcripts until she was familiar with the content. Themes emerged within and between groups, and interactions between themes were identified.

Reliability of coding was assessed through independent re-analysis of the data (by IR). In two cases disagreements in how similar themes were labelled were resolved through discussion between VS and IR. If unresolved, consensus would have been sought through discussion with the wider research team. This produced a basic framework of themes generated from the data, with more specific categories within each.

At this point SJC then read the transcripts in relation to the agreed framework. Her focus was on the identification of potential omissions in coding and possible misinterpretation of the data. No meaningful changes emerged from this. Inductive processes were then used to identify patterns between and within themes, producing a theoretical model of key processes within participants' lives. Model development was an iterative non linear process, with two draft models being discussed and amended by the research team before agreeing the final model (Figure 1).

The qualitative findings are presented as descriptive summaries and interpretations of key emergent themes, illustrated by data extracts from the transcripts (Tables 1-3). Quotes have been anonymised to maintain participant confidentiality.

Results

The focus groups ran smoothly and all participants took part readily. They tended to spark off each others stories about their experiences. This was particularly the case when describing their frustrations with health care professionals which they were initially reluctant to describe. There were no difficulties with dominant group members taking over the discussion and all three groups reported how much they had gained from the supportive attitudes of other group members at the close of discussions.

Dealing with the impact of neuropathic pain symptoms was a dominant issue for these people. The most commonly mentioned strategy was the use of medications, both legally and illicitly; and there was also use of complementary and alternative medicine; and resting or retreating. Many had made attempts to accept their situation. The themes and categories identified in the transcripts are presented in tables 1-5. Quotes are numbered in the text, cross-referenced to the tables.

Use of medications (Table 1)

Patients relied on medication as the primary method of dealing with their symptoms. They reported numerous attempts to find pain relief through the use of prescription medications including anti-depressants, anti-epileptics, anti-inflammatories and opioid and non-opioid analgesics. Patients were mainly prescribed amitriptyline and gabapentin with two participants being prescribed pregabalin. In most cases patients indicated that medications were ineffective in relieving pain and problematic in terms of side-effects. Diminished cognitive ability, attention and memory impairments, were the most prevalent side-effects particularly associated with gabapentin and anxiety associated with amitriptyline. Tolerance to opioids was reported in several cases and addiction to long term prescription medication was mentioned as a concern.

Ineffective treatments

Patients shared their past treatment histories, allowing familiar and unfamiliar treatment options to be aired. Many described how they had exhausted treatment options and acknowledged that there were no further options available and shared their experiences of treatments that had not been successful (Q1-3). In general a poor level of relief was reported (Q4). Patients were acutely aware that there was little hope of finding a successful cure and that treatment was predominantly about obtaining as much relief as possible (Q5). One patient reported refusing a treatment option she was not comfortable with. She was reluctant to initiate treatment with morphine as this was perceived to be the final treatment option and she felt that she should have something in reserve if things became even worse (Q6).

Patients found themselves in a cycle of treatments where they moved between classes of drugs, within classes of drugs and between different treatment modalities. They were often well informed about their drug regimens and very interested in new treatments that were available. There was a degree of ambivalence among patients about this continual cycle: it offered hope and often patients expressed that they felt that some hope was better than none. However, they described experiencing deep disappointment when no significant improvements were obtained. For some this had happened repeatedly.

Dealing with side-effects, tolerance and addiction

The positive effects of medications were often marginal and for many the side effects were difficult to manage. Finding suitable treatment regimens and optimal doses was often a case of trial and error. Patients appeared confident when requesting to change certain drugs or reduce their doses to avoid particular side effects (Q7).

Cognitive impairment was particularly associated with gabapentin at the higher doses. Patients were prepared to sacrifice pain relief in order to retain clarity of thought. Patients described feeling unsafe if they were not alert. In addition memory loss was common (Q8-9). Two patients had changed from gabapentin to pregabalin and reported that whilst the pain

relief was no different the doses were less as were the side effects so that was more tolerable (Q10).

Where high doses of tricyclic antidepressants were used, problems were associated with missed doses leading to feelings of anxiety (Q11). Lethargy was a distressing side effect (Q12) as were loss of libido and urinary problems. One patient also described an involuntary twitch that had developed following initiation of gabapentin.

Some patients also expressed concern that their medications had become less effective over time and that they had become addicted to these drugs (Q13-14). One participant mentioned that although addiction might be a problem, it might be preferable to the alternative of not using a particular medication (Q19).

Seeking prescribed medication and other medical treatments

Patients questioned why there were still no specific neuropathic pain medications and why their symptoms were been treated with drugs developed for other conditions, namely depression and epilepsy. They were generally very well informed about their medication and other treatments and appeared to be realistic about the purpose of therapy. They were also keen to remain informed about possible developments, accessing information from a variety of sources such as medical texts. In addition the focus group sessions provided a forum for patients to share information among themselves (Q15).

Patients described that sometimes making progress was a more a matter of luck than process and gaining initial access to the desired services was often difficult (Q16). Some patients had then undergone quite drastic surgery in search of a cure for their pain and others had even requested limb amputation. Generally such treatments were either unsuccessful or denied due to being inappropriate or not likely to provide relief.

Use of non-prescribed drugs

In addition to prescribed medication, several patients reported using non-prescribed drugs, such as alcohol, cannabis or medications obtained illicitly, such as diazepam. Cannabis was

reported to provide some temporary pain relief and it also aided relaxation, which patients reported gave them a break from dealing with the pain. However, negative side-effects were also noted as a result of smoking cannabis (Q17-18).

One patient described how he had taken other people's medication and street prescription drugs (Q19). The side effects of illicit drugs were recognised, but the distress at not being able to find relief was immense, so the pros and cons of using these drugs had to be weighed up.

Alternative strategies (Table 2)

Categories were structured according to the types classified by the National Center for Complementary and Alternative Medicine¹⁶.

Use of CAM manipulative and body-based methods

Patients described that they had tried a number of alternative therapies including reflexology, acupuncture and self-hypnosis (Q20). None was reported as providing any relief (Q21-22).

Use of CAM mind-body techniques (resting and retreating)

Most patients described a pattern of disengagement, both mentally as they focused inward to cope with their pain, and physically as they retreated to places of rest (Q24-26). Some patients described how they successfully used distraction to take their mind off their symptoms (Q23). The desire to be able to relax was mentioned by several patients who believed that if they could just get enough sleep they would be better able to cope (Q27). No longer being able to relax in bed and it be a place of comfort was described as the loss of a luxury by some patients (Q28).

Considering suicide

For one patient, the alternative to not coping was an attempted suicide and she was not the only person who admitted to feeling that desperate (Q29-30).

Adjusting to the situation (Table 3)

Acceptance

Being told to 'live with the pain' was associated with a lack of adequate support from health care professionals. Patients were living with the pain, but many had not adjusted or accepted living with the pain. Most patients described having gone through periods of complete despair and for some this was still very much the situation. For those who did appear to cope better with the pain, they described having accepted the situation, recognised limitations, engaged with life despite the pain and had a desire not to give in to the pain (Q31-33).

Some patients described how the energy they had for struggling had diminished over the years so although they were not resigned they did not expend the same amount of energy on fighting their symptoms as they had earlier in their patient career (Q34). Lack of hope, lack of forward motion was not acceptable to many patients and they said they would rather continue to try than resign themselves to defeat (Q35). Patients expressed fear at not coping with their symptoms and questioned the alternative to not coping (Q36).

Identifying pain triggers

Making sense of the pain experience was important for these patients and they expressed despair at the unpredictable nature of the pain (Q37-38).

Increasing pain tolerance

Furthermore, patients believed that their tolerance to pain had increased as a result of living with their neuropathic pain symptoms, as normally painful stimuli or events were no longer considered to be as painful as they would prior to living with NP (39-40).

Discussion

Overall, the participants presented a mostly unsuccessful view of their experiences of managing neuropathic pain, a model of which is presented in figure 1. They actively sought

management strategies which fell into three main areas: attempts to self-manage using alternative strategies; conventional medical interventions; and the need to accept the pain and adjust to their situation. However, they also indicated a cyclic pattern of seeking new ways (mostly ineffective) to control their pain and a need for help in adjusting to a life in pain at the point when professionals ran out of management options (figure 1). The dotted lines and shaded boxes indicate the potential for additional support designed to help pain sufferers to accept and live with their pain.

Figure 1 shows that participants placed a great emphasis on proactive help-seeking, with repeated attempts to find some way of relieving their pain. Their attempts to self-manage depended on strategies such as resting and retreating, the use of distraction (partly effective) and a range of complementary therapies (ineffective). Despite repeated disappointment in the orthodox medicine and CAM approaches tried, they continued to express a willingness to try any possibility. The reasons for this were not clear, but possible explanations include; feeling the need to be doing something (anything) to try to avoid the pain; hoping that a different intervention might help them; or they may have been driven by desperation.

There was an apparently repeating cycle of these attempts to find ways to control their pain, through both conventional and alternative treatments. This pattern has been observed among other groups with pain (eg Calnan et al¹⁷). In our study, each attempt tended to be either partly successful; unsuccessful; and/or accompanied by unpleasant treatment side-effects, leading to further attempts to find other solutions. For many the lack of success led to despair, with them running out of energy to continue searching for solutions, and occasionally even thoughts of suicide.

This cyclic pattern is a familiar aspect of many types of persistent pain, but for those with neuropathic pain there appeared to be an obvious gap in their care. When professionals' efforts to control the pain were fruitless, patients were often told that they would need to 'learn to live with the pain' but little or no support was provided (shown by shaded boxes, figure 1). Unfortunately, it appears that in many pain clinics, the presence of neuropathic

pain provides an exclusion criterion for entry into such programmes, since they are thought not to be effective for this group. The evidence for this, however, is scarce.

Psychological therapies comprise an approach to improved coping and/or acceptance of chronic pain. Coping is a concept which is not always clearly defined in the pain literature. It is variously described as behaviour exhibited in response to pain regardless of the result; behaviour of this kind which successfully reduces the impact of pain; and the intentional attempt to adapt to pain or manage one's own negative response to pain.¹⁸ It has been suggested that 'narrowing of focus onto this one particular class of behaviour, ie coping, may have inadvertently led us away from other conceptualisations of how patients adapt to chronic pain'.¹⁸ Acceptance of chronic pain is another option, which can be defined as living with pain without reaction, disapproval or attempts to reduce or avoid it.¹⁹ It involves being realistic about the pain, ceasing to struggle with it, and engaging in positive day-to-day living. From the data it appeared to be only when all their attempts to find external ways of reducing their pain had failed, that psychological mechanisms for trying to live with the pain were actively mobilised. The patients in this study reported having tried to use nearly all of the traditional approaches with little or no success. The unpredictable nature of neuropathic pain and the bizarre clinical features such as allodynia and dysesthesia caused patients their greatest distress. Most participants did not appear to have overtly accepted aspects of living with their pain, although this was not pursued specifically in the focus groups. It is not clear whether the complex characteristics of neuropathic pain would make this condition amenable to behavioural acceptance strategies, but preliminary research testing the effect of education and CBT suggests that it may have therapeutic effects¹⁰ and larger studies would be of value.

While the benefit of acceptance has been demonstrated for some chronic pain patients, little information is available concerning chronic neuropathic pain. For this group it appeared to be a last resort, but it may be an approach with considerable potential to help sufferers at an earlier point in the trajectory of treatment. A comparison of coping with acceptance in 230

patients with chronic pain suggested that acceptance was a more successful strategy, being associated with less pain, disability, depression, pain-related anxiety and other positive factors.¹⁸ Three common features of acceptance have been identified: acknowledgement that a cure for the pain is unlikely; a shift of focus away from pain to non-pain aspects of life; and resistance to any suggestion that pain is a sign of personal weakness.¹⁹ Whether these features would be similar for neuropathic pain sufferers is unknown. It may be that they have more difficulty in shifting their focus from the pain, due to its unpredictable and unpleasant nature. Trying to engender acceptance of pain too soon may be too burdensome for many patients and may encourage under-treatment by health care professionals.

The repertoire of cognitive-behavioural therapies available for chronic pain has increased substantially over the past 30 years. Although many have been effective, it is neither clear why some patients do not benefit, nor how to match particular patients to particular treatments.²⁰ There is huge scope, therefore, for exploring the effectiveness of different cognitive-behavioural therapies with patients who have persistent neuropathic pain symptoms. It is interesting to note that despite the respondents in this study openly discussing many psychological difficulties in coming to terms with their pain, none of them referred to psychologists or the use of psychological therapies in their search for pain relief. The findings of this study reinforce that even though a “plethora of pain management programmes are in place for individuals with chronic musculo-skeletal pain little is available for people with chronic neuropathic pain”.²¹ This is also supported by the findings of Daniel et al.²² She found that existing pain management programmes did not meet the needs of people with neuropathic pain and suggested that more tailored programmes may be required.

Even though some of the participants had reached an understanding that they had to live with the pain, they had clearly suffered due to the lack not only of psychological but also the absence of the social, emotional and practical support required to do so. Patients were reluctant to accept their situation, as they equated it with giving up and yet the pattern of

medication trials and the constant battle with their symptoms had a negative impact on their lives, inducing feelings of hopelessness and anxiety for the future. This is supported in the literature, where it has been suggested that 'ongoing investigations and treatment trials may ... reinforce an unhelpful somatic focus, passivity and disability at the risk of overlooking opportunities for such patients to accept their conditions and develop more of a self-management approach'.²³ Recognition of when a patient has reached the point of accepting that they have to live with their pain might allow for provision of targeted psychological support and/or therapy, although it may be of more benefit to start such therapies earlier in the process.

In conclusion, how individuals manage their chronic neuropathic pain is poorly understood, and requires further exploration. While it is not possible to generalise from this small sample to the much larger population of people living with the symptoms of neuropathic pain, their narratives have convincing face validity which may be recognised by clinicians working with this group. The group studied here showed some similarities to those with chronic pain of nociceptive origin, but it is likely that the bizarre and unpleasant nature of neuropathic pain produces additional problems. The findings suggest at least three key areas for future research:

1. A larger study to validate the theoretical findings presented here. In particular more detail of the process of seeking out and testing different types of pain management intervention, a more complete account of individual approaches to self-management of pain, and more information about needs for support in adjusting to a life in neuropathic pain.
2. Evaluation of different types of support required to live with pain, in particular, psychological (including CBT), emotional, social, practical etc and by whom, how and when it might be provided.
3. Quantitative investigation of the behavioural/psychological processes associated with neuropathic pain which would allow the design and testing of treatments specifically for neuropathic pain.

People with persistent neuropathic pain undergo long-term suffering for which there are few, if any, effective remedies; the development of self-management techniques alongside the continued development of orthodox interventions is essential to provide realistic hope that suffering can be made manageable for this group; and an increased focus on supporting patients who may be willing to accept their pain is needed.

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Table 1: Themes, categories and quotes – Use of medication: Ineffective medications

Theme	Category	Quotes
Use of medication	Ineffective medications	<p>(Q1) My pain doctor says that there's nothing else, if this doesn't work there's nothing else, nothing in the pipeline to try and help. It's just a case of suck it up and get on with it basically. It's never going to go away - all they're trying to do is get something just to take the edge off it.</p> <p>(Q2) I'm a bit disappointed though ... I've had probably about two and a half year of physio, I've had acupuncture I've had everything. I've had the injections. I'm on these gabapentin and what have you ... I was disappointed</p> <p>(Q3) ... I was four years trying all different types of medication to try and control the pain ... they weren't any good really...</p> <p>(Q4) I've had the TENs machine I've had everything they can think of and unfortunately at the end of it they've turned around and said sorry.</p> <p>(Q5) There is no hope, Dr X has said to me all we can hope is we can just take the edge off it. He says we're not going to get rid of it, you've got it.</p> <p>(Q6) last time I went [to the pain clinic] I was advised to go on morphine. And because I refused - I said well, I don't want to go on that because it seems like a last resort. And he said well it is really, and I don't want to go on it and I've never heard from there since. So whether they think my pain has magically disappeared itself I don't know, or whether [it's because] I refused to go on the morphine.</p>

Table 1 continued: Themes, categories and quotes – Use of medication: Side-effects, tolerance and addiction

Theme	Category	Quotes
Use of medication	Dealing with side-effects	<p>(Q7) I went jowly and everything. It's one of the side effects and it wasn't doing me any good. So I said take me off it I said. And the weight went down when I came off it and I said I've put loads of weight on when I was talking to Dr X about it and he said yeah, its one of the major side effects of it.</p> <p>(Q8) I'm glad you said that about the gabapentin with the memory ... when I first started taking it I'm thinking I can't concentrate I couldn't read a book, I still can't read a book really and it's a bit blurry ...and I had to make a decision at one point to sort of reduce the gabapentin a little bit and have more pain just to be able to... A bit more clarity I won't say brilliant, but a little bit more clarity, yeah.</p> <p>(Q9) I didn't feel safe. [taking a high dose of gabapentin] ... but yeah I feel better now I'm not taking as much. But my concentration, that's something I really suffer with.</p> <p>(Q10) he mentioned this new drug that was waiting for approval, called pregabalin which is a derivative of gabapentin but you don't have to take as much and there's less side effects. And he said try it, see how it works.</p> <p>(Q11)...the amitriptyline - I find that if I don't take that the next day I'm like anxious and I think something's going to happen that fear of something happening so I have to take them as well so whether or not I'm hooked I don't know [if] it's helping me.</p> <p>(Q12) I'm really lethargic, really slow until I get into the afternoon, when I feel quite normal and then I take the tablets again and I go back down.</p>
	Acknowledging tolerance and addiction	<p>(Q13) I think you get used to it because my co-codamols do take the pain away but because I might take, it's like just taking I don't know sweets I suppose now, I think I have got, it helps or I wouldn't take them but I don't think they are as effective as they were when I first started.</p> <p>(Q14) I mean I'm probably addicted to fentanyl that I have all the time, by this point taking for at least 4 years now.</p>

Table 1 continued: Themes, categories and quotes – Use of medication: seeking other medications

Theme	Category	Quotes
Use of medication	Seeking prescribed medication	<p>(Q15) If I take something it's mainly because I've gone to my GP and said I want to try this because I've been through medical books and I've searched through and thought right this says it controls muscle spasms and so on I'll try popping some of them and I'll actually go, because it's not nice to go and have someone just say well go and crack on with it just get on with it.</p> <p>(Q16) It's breaking through the initial barrier to find somewhere where you can go ... it's always there, it's just out of reach, like a kiddie in a sweetshop you know, but you never know.</p>
	Use of illicit drugs	<p>(Q17) To help me I do smoke weed...that makes a big difference to me</p> <p>(Q18) It does help but in a way I'm not sure if it helps because it just keeps me still I can sit and kind of relax for a bit but then you end up doing it all the time and then the side effects start to affect you in other ways. I got to the point when I'd wake up in the morning, come down stairs and smoke straight away like seven o'clock in the morning and then you start to think oh what am I doing, this isn't right, this isn't the way to live your life and then say by the time you come to the evening now I've started getting paranoid and panicky.</p> <p>(Q19) I take valium to try and stop muscle spasms but they won't prescribe them too many valiums because of the addiction of it. Although, that annoys me because it might not be good to be addicted to valium but if it helps me, you know I know that there is people out there who've been taking them for 30, 40 years but they won't give me any more of them... I use cannabis but that has side effects as well ..., you get paranoid and everything's like rolling out of control so at the moment I zip between doing nothing and then just grabbing a hand full of valium and I mean it is crazy I've taken other peoples prescriptions, I've taken bloody tablets I've bought off the street, anything.</p>

Table 2: Themes, categories and quotes – Alternative strategies

Theme	Category	Quotes
Alternative strategies	Use of CAM manipulative and body-based methods	<p>(Q20) I mean I've even had reflexology of the feet and everything because it controls all parts of the body and it gets where you'll have a go at anything.</p> <p>(Q21) I've tried acupuncture, massage healing I've tried everything ... I have tried quite a lot of alternatives and nothing...helps – nothing seems to, it seems to have it's own will..</p>
	Use of CAM mind-body techniques: Resting and retreating	<p>(Q22) I've got self hypnotism books at home trying to hypnotise myself and I'm reading and I'm thinking this is just bloody ridiculous but I still go through the whole book and still sit there for weeks on end and I couldn't do it.</p> <p>(Q23) I just took myself out in the garden which I like to get in the greenhouse and that and even though I was still hurting my mind wasn't on it as much.</p> <p>(Q24) You just close in don't you? It's just I get tunnel vision, I don't hear people talking to me.</p> <p>(Q25) I go to bed ... just leave me alone. Maybe six or seven hours later or over night or sometimes even forty-eight hours. Just leave me alone.</p> <p>(Q26) ... it's a way of coping. ... it tires your body out you know, coping with the pain all the time, so you will try and lay down and get up and then you can cope.</p> <p>(Q27) But half of the time if you could relax you would have less pain.</p> <p>(Q28) Another big thing is I have a lot of problems sleeping. I have to have about two cushions under my knees and if I turn over I have to have cushions in between my legs and then I'm awake at about six o'clock every morning and I ...can't lay in bed anymore... Yes, laying in I can't lay in, laying in until ten o'clock its like, are you having a joke?</p>
	Considering suicide	<p>(Q29) I have no life whatsoever you know and I've tried topping myself, and then I thought what about – I did try and I laid there just thinking about my grandson. And I thought how can you do that, my only grandchild, I love him dearly and he's going to find out that his grandma committed suicide. So I just had glass after glass of salted water and I puked that much...</p> <p>(Q30) I understood what he was saying, there really was nothing they could do and he said to me "look people have to cope with pain, take some tablets and cope". And at that point, I were at my lowest you know, and I said 'but I feel that I can't live with it' and if I hadn't have had my family, the way I felt that day I could have quite easily have come home and ended it...</p>

Table 3: Themes, categories and quotes – Adjusting to the situation

Theme	Category	Quotes
<p>Adjusting to the situation</p>	<p>Acceptance</p>	<p>(Q31) And it's got to, where I am at the moment that, I've got to just sort of admit to myself that I can't do what I could do before and just accept you need to take the tablets and you need to readjust your life around this pain and so I've got to manage it</p> <p>(Q32) I mean I've accepted now that the pain - it will come and go.</p> <p>(Q33) When it gets at its worse its like anything is preferable to sitting and doing nothing and just going through this because it's really it's that feeling that I'm not going to be able to cope with this and it's what's on the other side of not coping?</p> <p>(Q34) I think the longer you've got it as well because I had more fight in me earlier on it's been fifteen years and touchwood these last two years have been a bit better so because for such a long time you've just been round and round and round you think I just can't be bothered with it</p> <p>(Q35) If there's always something else to try at least you've got forward motion you're not just static.</p> <p>(Q36) It's what happens if I don't cope? There's no one to go at, there's nothing to take there's nothing to do so what? You know it gets scary.</p>
	<p>Identifying pain triggers</p>	<p>(Q37) Bang it just hits and like, oh Christ what have I done and I'm trying to think what have I done to set it off and you go back and you spend, I mean I nearly drove myself mad at first coz you're just questioning it all the time but why? Why is it happening? Why?</p> <p>(Q38) That's what it's like when mine comes back and I've done nothing and so you can't prevent it you know - it's like a switch it just comes on.</p>
	<p>Increasing pain tolerance</p>	<p>(Q39) Because you've had it so long I would say that my pain threshold is just really really good</p> <p>(Q40) When I had either side of the wisdom tooth pulled it didn't hurt at all, when I got tattooed I didn't feel a thing and all them things that used to hurt you don't even register as pain anymore. It's just feeling because in comparison it's, it's nothing.</p>

Box 1: Key topic areas used in the focus group schedule

1. Experience of symptoms

'As a group, thinking about the last few months what are the main symptoms you have you experienced?'

2. Talking about symptoms

'How have you or do you explain these types of symptoms to other people?'

3. Reactions of others

'How do or have others reacted when you have described your symptoms?'

4. Dealing with symptoms

'What ways of coping, if any, have you found to help you live with these types of symptoms?'

5. Impact of symptoms on family life

'Thinking now then about these [group of] symptoms, what influence do you feel they have on your family life?'

6. Impact of symptoms on social life

'Do these symptoms influence your social life in the same ways as they influence or family life or do they have a different influence on your social life?'

7. Impact of symptoms on working life

'Lastly, do or did these [group of] symptoms have any influence on your working life, if so in what ways?'

8. Positive changes

'Finally, we've covered many of the problems and challenges of living with these types of symptoms day to day. We'd like to know, have any of you have had any positive experiences of these symptoms, or as a result of living with these types of symptoms?'

Figure 1: Model of participants' experiences of managing their neuropathic pain



