Qualitative exploration of psychological factors associated with spinal cord stimulation outcome

Sparkes, Elizabeth; Duarte, Rui; Raphael, Jon H.; Denny, Elaine; Ashford, Robert L.

DOI:
10.1177/1742395311433132

Document Version
Publisher's PDF, also known as Version of record

Citation for published version (Harvard):

Link to publication on Research at Birmingham portal

General rights
Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

• Users may freely distribute the URL that is used to identify this publication.
• Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
• Users may use extracts from the document in line with the concept of ‘fair dealing’ under the Copyright, Designs and Patents Act 1988 (?)
• Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

Take down policy
While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.
Qualitative exploration of psychological factors associated with spinal cord stimulation outcome

Elizabeth Sparkes, Rui V Duarte, Jon H Raphael, Elaine Denny and Robert L Ashford

Abstract

Background and aim: Spinal cord stimulation (SCS) is a last resort treatment for chronic pain consisting of an implantable pulse generator connected to leads placed in the epidural space of the spinal cord. Effective in reducing chronic pain, however, efficacy has been found to decrease over time. Psychological factors affecting outcome of SCS have been investigated through quantitative methods, but these have failed to provide confident predictors. We aimed to investigate via a qualitative approach, the experience of SCS following 1 year of therapy.

Methods: Thirteen chronic non-cancer pain participants were interviewed. All participants had been trialled with SCS. The majority had gone on to full implantation with varying degrees of pain relief. Thematic analysis was employed to analyse the data from the interviews.

Results: Interviews resulted in findings that previous quantitative studies had failed to uncover. Two emergent core themes surfaced: ‘coping with pain’ and ‘SCS treatment’. The effect of emotion upon coping was recurrent. Participants divided the SCS experience into information provision, independence and unexpected experiences.

Conclusion: The findings provide context for the patients’ experience of SCS. This research suggests that improved preparation prior to SCS including information provision, CBT and contact with expert patients may be of value.

Keywords

Chronic pain, efficacy, psychological factors, qualitative analysis, spinal cord stimulation

Received 1 September 2011; accepted 24 November 2011

1Faculty of Health, Birmingham City University, Birmingham, UK
2Psychology Department, Coventry University, Coventry, UK
3Pain Management Department, Russells Hall Hospital, Dudley, UK

Corresponding author:
Elizabeth Sparkes, Faculty of Health and Life Sciences, Coventry University, Priory Street, Office JS242, Coventry CV1 5FB, UK
Email: aa8163@coventry.ac.uk
Introduction

Spinal cord stimulation (SCS) was developed as a clinical application of the gate control theory and introduced by Shealy et al. in 1967 as a treatment for chronic pain. A spinal cord stimulator consists of an implantable pulse generator connected to leads placed in the epidural space. The impulses are controlled remotely by the patient. SCS involves modulation of pain transmission by electrical stimulation of neuronal pathways in the spinal cord. By activating pain inhibiting mechanisms, the sensory experience of pain is altered, reducing intensity, frequency and duration of pain.

SCS has been in use for more than three decades and with more than 14,000 implanted annually worldwide; it is a commonly used pain treatment. Several randomized controlled trials and systematic reviews support the efficacy of this treatment. These randomized controlled trials are limited by the lack of adequate blinding to an interventional treatment with a paraesthetic sensation, and as a result possible placebo effects cannot be excluded.

It is common to test patients’ responsiveness to SCS prior to permanent implantation, nevertheless, 25% to 50% of patients selected as suitable for full implantation report loss of analgesia within 12–24 months following initiation of therapy. Theories for the decline in pain relief have focused mainly on the technical issues of SCS procedure such as position of the leads and electrical parameters as indicators for paraesthetic location; however, it seems intuitive that psychological factors would impact upon efficacy since pain is a multi-dimensional experience. Beliefs about pain and SCS treatment may impact upon behavioural responses and perception of pain therefore modifying treatment and pain outcomes. Previous studies using quantitative questionnaire methods have not found consistent psychological indicators for the prediction of long-term success of SCS. In a study of 100 patients investigating prediction of outcome using interviews conducted by a psychiatrist that explored psychiatric contra-indications, there was a high success rate achieved for selection for suitability. This raises interest in the potential value of interview for indicating suitability for SCS.

The aim of this study was to explore the experience of SCS after the first year of treatment. Efficacy over time using quantitative methods has remained inconclusive and qualitative research may highlight important factors that previous questionnaires have failed to. SCS efficacy in this instance was determined by the patients’ subjective report of pain using a visual analogue scale. A qualitative methodology was felt to be appropriate for this study, as the purpose was not to generalize the findings to a wider population but to understand how participant’s experienced SCS and lived with chronic pain following SCS. Qualitative interviews allow for the collection of richer, more salient data, from which experience may be explained. Through the conduction of semi-structured interviews participants were enabled to focus on issues and concerns of importance to them, and how they made sense of chronic pain and SCS treatment within the context of their lives.

Methods

Clinical practice selection for SCS

SCS is a last resort treatment and hence several more conservative therapies have
previously been tried and proved ineffective, including spinal surgeries, pain management program, oral medication, injections and physical therapies. Patients referred to the pain department for possible SCS undergo multidisciplinary assessment in order to assess the different facets of pain and to determine patient suitability for SCS. The assessment team primarily includes a pain consultant, a psychologist and a physiotherapist. Patients are considered for SCS when they have neuropathic and/or ischaemic pain that is considered likely to respond to SCS and have had no response to more conservative treatment options. Patients are excluded on the grounds of being medically unfit for implant surgery, having unrealistic expectations of the treatment, lack of comprehension and unrealistic beliefs surrounding their pain.

Patients were directed to a website to read about SCS and given the opportunity to discuss with a nurse specialist. Several months later, patients undergo the operation. Under local anaesthesia with sedation, the SCS electrodes are implanted percutaneously and positioned to obtain maximal paraesthetic coverage of the painful area. Electrical parameters are set to obtain maximal pain relief and trialled for 1 week. During the days of the trial period if less than 50% pain relief is reported the electrical parameters are altered to try to obtain this. If superior to 50% pain reduction is reported consistently at the end of the trial week the patient proceeds to have a fully implanted SCS. If less than 50% pain relief is reported, the leads are removed.

Participants

Patients were invited to take part in the study from those who had undergone trial of SCS 1 year previously, none of whom refused to participate. Eligible participants were adults aged 18 or over who had undergone trial of SCS. All patients were white British and the sample was of convenience. During SCS treatment, all the pain management needs are dealt with at this particular centre. Follow-ups with the consultant, SCS technician and pain nurse take place every 3 to 6 months.

Recruitment took place between November 2009 and April 2010 at Russells Hall Hospital, Pain Management Department. Thirteen participants were recruited. Recruitment ceased when no new themes emerged from additional participants interviews using the qualitative research rule of data saturation. The criteria for determining that saturation had been achieved was repetition of previous identified codes and no new themes developing. This was agreed by ES, RD and ED. It was observed after ten interviews that no new themes were emerging. Three additional patients were then interviewed, revealing no further themes, therefore confirming saturation.

Ethical approval was granted by Birmingham, East, North and Solihull Research Ethics Committee and informed consent was obtained from all participants.

Semi-structured interview

The semi-structured interview schedule was derived from literature-depicting topics suggested to be important when assessing patients with chronic pain for treatments including SCS. As the interview was derived from this work a pilot study was not considered necessary. The topics covered in the interviews were as follows: pain description and experience; pain history; medication use; specific pain behaviours; SCS; patients’ concept (beliefs/expectations) of pain and pain treatment.

Semi-structured interviews were conducted by one independent researcher (ES) lasting between 45 to 60 min. During the interviews the researcher would regularly
ask the participant for clarification, to ensure the participant was being understood in the way which was intended by him/her. Interviews were transcribed verbatim and analysed to create an iterative process whereby subsequent interviews were informed by the analysis of previous ones. In combination with the interview, patients were asked to rate their average daily pain using a visual analogue scale (VAS). This score was used together with their pain score reported at baseline, prior to SCS trial, to compute percentage of clinical change.19

Data analysis
Interviews were analysed using thematic analysis20 facilitated by QSR NVIVO 8.0 data management software. The process followed the six-stage protocol as described by Braun and Clarke.20 Interviews were transcribed and carefully read to allow familiarization. Initial open coding of the data began after familiarization; specific features identified within the transcribed interviews were assigned suitable code names. This process was repeated to ensure a rigorous exploration of the data. Codes were organized into themes; themes were checked to adequately describe the coded data extracts. Themes were determined by the relevance, prevalence and importance (clinical implications) of the data. Coding results were reviewed independently by a second researcher (RVD) also involved in pain research and disagreement was resolved through discussion to increase credibility of the results.21

Results
The participants consisted of six males and seven females with ages ranging from 32 to 70 years (mean 45.4 years). Two participants had failed the trial and had not proceeded to full implantation of SCS. At 1 year follow-up for those proceeding to full implantation of SCS, eight participants reported less than 30% pain relief from SCS and three participants reported at least a 30% reduction in pain after implantation of SCS. Pain topography included back, anus, legs, ankle and feet. Time in pain prior to implant ranged from 2 to 21 years (mean 18.2 years).

Analysis of the interviews revealed themes in two domains, which were categorized into seven sub-themes:

Coping with pain
- helplessness, controlled by pain;
- frustration and anger;
- responsibility for pain relief; and
- acceptance of pain.

SCS treatment
- information provision;
- regaining control; and
- unexpected experiences.

Coping with pain
Living with chronic pain induces a mixture of emotional responses including frustration, anger, sadness and fear. Often the lack of a distinct diagnosis leaves individuals feeling helpless and unsure of the future. These intense emotions often impact on an individual’s ability to cope and continue with daily life; it was very evident that participants wanted to express the helplessness they experienced. All participants disclosed feeling helpless and controlled by pain to some degree. Coping and pain was a significant theme among all participants. Regardless of whether their pain was managed, emotional coping was still of importance.
Feelings of helplessness and being controlled by pain: ‘I’m stuck in a hole’

Feelings of helplessness were described almost unanimously. Patients who experienced both successful and unsuccessful SCS expressed feelings of helplessness; however, those who had not obtained successful relief from SCS made more regular reference to an inability to cope.

‘...It’s just like I’m stuck in a hole and I don’t... don’t know how to get out of it’. (Interview 5)

Often participants described how they focused on what they were no longer able to do; there was a sense of the mental torture that was experienced.

‘...I can just sit there thinking like well I could be dancing like and you can’t, you sit there, it’s terrible’. (Interview 2)

Participants described that they could not find a way to move on or cope with the pain when it became extreme. Often an external locus of control was described in relation to any possibility of the pain improving, waiting for someone to cure their pain. An external locus of control is understood as an individual belief that an improvement will only be achieved via external factors independent of their individual control or ability. It became clear that there was a strong sense of feeling out of control. One woman in her fifties who had been out of work for sometime due to pain remarked:

‘...I’ve resigned myself you know this is as good as it gets and erm, short of somebody coming up with a miracle cure then well that’s it’. (Interview 11)

There was a sense that participants felt helpless due to the very nature of the control that pain had over their lives. The ability to be able to carry on was often related to medication use, this dependency was evident among many participants.

‘...You can’t live a normal life when you are constantly in pain because your whole life revolves around taking the next pain killer’. (Interview 1)

The concept of feeling controlled by pain was also evident in the inability to follow certain goals individuals had for their lives. One woman described how she had been advised against having a child, as it was suggested that her pain would not be controlled whilst pregnant.

‘...he’d said “I would be extremely concerned if she got pregnant with you know the, the metal work, the amount of pain that’s she in, the fact that she’s, you know she’s still suffering because we’re not going to be able to manage the pain properly because you’re going to have to stop taking various things”’. (Interview 12)

Frustration and anger: ‘I just explode’

Frustration and anger in response to the control that pain had over individual’s lives was a recurrent experience for the participants. There was the sense that pain could occur at any moment and without any expected triggers.

‘...I get frustrated, you know because sometimes I don’t know what I’ve done extra to cause the extra pain you know, I know if I’ve been on my feet a lot you know, I can expect to ache more, I know if I’ve been busy at home, I can expect to ache more but some days it’s a case of well, what have I done you know so, I get frustrated, I get angry with myself that I can’t sort it, you know but it’s there and it’s not going to go, so...’ (Interview 10)

The sense of helplessness leading to frustration continues in the amount of reliance on others that is developed due to pain. Participants often described how frustrating it was not being able to be independent and involved in family life. One male participant aged 44 years displayed feelings of guilt that he relies heavily on his wife, leading to angry outbursts.

‘...Well like I said, my wife has to do most, everything for me. Like I said I had my independence before but now she’s got
everything on her plate, plus everything else. It just mounts up, you know what I mean, it’s like anybody else I assume, but at the time like it gets so far and then I just explode’. (Interview 2)

Responsibility for pain relief
Frequently patients made reference to responsibility for pain relief lying with the doctors. One younger woman who considered herself very active before the onset of chronic pain described waiting for something to cure her pain.

‘...Erm, still hoping that somebody else invents something else or something else, you know every time I come here and play with the computer I’m always thinking well I don’t know what they’ve done with that computer programme since they were last there, there might be something new and brilliant’. (Interview 12)

There was also evidence of losing faith in doctors when anticipated pain relief was not obtained. Participants on occasions displayed anger towards doctors not ‘curing’ their pain. The sense that it was external responsibility for pain relief appeared to increase angst and anger.

‘...Well first off I thought doctors will help me, then, I lost faith in them’. (Interview 1)

There was a general sense that participants focused on external sources as responsible for their pain relief. One participant described feeling that her family and friends also thought not enough was done to help her reduce the pain.

‘...I think they get, maybe get, sort of annoyed. Cos the quality of life that I had, I no longer have. Everything is restricted for me. I feel they think, they feel more should be done for me. That’s the only sort of thing that comes across to me. They think that more could be done for me’. (Interview 7)

Acceptance of pain
There was mention of acceptance from some of the participants. This was more common from those who reported ≥ 30% pain relief from the SCS. The sense was that acceptance came from realizing that the pain could not be beaten but managed as a normal part of their lives.

‘...It’s just something that, something that lives with me, I you know, I don’t live with it, it lives with me, it’s what I am trying to make of it is that I know I am not going to beat it but you know, I’ve got it, it’s under my umm, you know my control to an enth, to a degree’. (Interview 3)

‘...I’ve learnt to live with it, it’s an everyday thing, it’s normal for me’. (Interview 9)

SCS treatment
Separate issues arouse when describing the experience of SCS. Access to information was something that participants regularly felt they needed more of. It became quite clear that those who were satisfied with the knowledge they had about SCS had researched on their own via internet resources. There was a desire from participants to speak to individuals already with an SCS before participation in the trial. The trial and initial experience of the SCS introduced body image concerns for the majority of the women participants. Women disclosed that they experienced dissatisfaction with their individual perceptions of their bodies (body image) in relation to the SCS being implanted and the wires visible during the trial. Also scarring due to the implantation was described by some women as upsetting. There was also discussion that health professionals did not seem to recognize the traumatic experience of the trial. Those that achieved successful pain relief described regaining some control, independence and a reduction in helplessness.
Access to information, professionals and expert patients please!

It became quite evident that those who felt relatively satisfied had taken it upon themselves to research SCS via the internet as well as receiving information from health professionals.

‘...I started doing some homework then, you know, on the internet to find out exactly what it was, what it did, erm then I was referred here, sat and talked it through with the consultant who was you know, very informative’. (Interview 10)

‘... So when I came in yes I did find, feel I had enough information because I’d made it my business to find out’. (Interview 11)

One participant who had been in pain for 20 years, and was unsuccessful in receiving satisfactory analgesia with the fully implanted SCS, described how she was not completely aware of what was actually going to happen when she went in for the SCS trial.

‘... Yeah and I think in the future I would be a bit more pushy and I would ask a few more questions about what they are actually giving me’. (Interview 1)

This was in complete contrast to another participant who had obtained successful pain relief. The experience was described as much improved when comparing to other places where he had sought treatment.

‘... They’re caring people, and everything that I had done, everything was explained well in advance, I knew what was going on whereas, what happened at other places it’s not been like that, you’re kept in the dark sort of thing’. (Interview 9)

On occasions participants reported that they received contrasting information and advice. Participants made reference to feeling confused about the right action to take with their SCS device.

‘... and you ask questions, “oh yeah” blahblahblah, you ask somebody else, they tell you something completely different and just confused all the time’. (Interview 2)

There was an almost unanimous desire to have the opportunity to speak to an SCS patient before having the trial themselves. Participants described feeling disappointed when they did not get the opportunity to talk to someone who already had an SCS.

‘... I actually asked if I could speak to somebody who’d had the stimulator but that never happened erm, but I did come up and speak to one of the sisters here and had a chat with her but, I found that useful, but I was a bit disappointed not to speak to somebody who’d err, who’d had a stimulator’. (Interview 11)

Speaking to an expert patient was seen as a factor that would have greatly improved the information provision among many of the participants.

‘... Even if it is you know getting in touch with someone who has had it done. You know like myself, so somebody coming in and you know they have no experience of it whatsoever and then to be put in touch with somebody who has had it done and for them just to have a chat about it’. (Interview 3)

Independence and regaining control

Participants who were obtaining successful pain relief made regular reference to regaining control over their lives. There was mention of improved ability to cope, although pain was not eliminated completely, participants were able to reduce medication and still manage their pain. One lady who worked as a bar maid had managed to maintain her job throughout her experience of chronic pain.

‘... The implant has helped greatly because I’ve been able to reduce the medication that I’m taking, but err yeah it’s just there all the time you know, there’s good days and bad days but never very good days when it goes away’. (Interview 10)
It was clear that the SCS gave participants some freedom back. The ability to go out and walk everyday was something that one participant had greatly missed. ‘...I think it’s given me a little more independence back, because I do go out walking every day, umm and I think that’s where I have lost the weight. Umm so I think yeah from that side, you know, it’s given me independence, you know’. (Interview 3)

Participants clearly felt an increased ability to be able to carry out their lives. The SCS gave the participants security that when pain became unbearable, use of the SCS would enable them to carry on. ‘...I think now that I’ve got the implant, I can cope with the pain more. It’s not as severe when the machines running. I look forward to the day to begin. Whereas before I didn’t want to wake up in the morning because I knew I’d get the same thing to look forward to everyday. I know it’s still there now, and it’s, it’s not nice but I know I can go and do something about it when it gets bad. I can go shut myself away in the room, put the machine on and the helps there’. (Interview 9)

**The unexpected experiences of SCS**

There were several issues for patients that emerged along the lines of unexpected experiences. The majority of participants did not expect the trial to be so painful and felt unprepared for the experience. It also became evident that participants felt health professionals were not aware or empathetic of the experience during the trial and the subsequent feelings after the trial.

**The uncomfortable trial.** The majority of participants found the trial painful and often participants declared that they had not expected the experience to be quite so uncomfortable. Individuals explained that they were prepared to be uncomfortable but were completely unaware of how painful the experience would be for long periods of time. ‘...I knew what you know, I was going to feel some discomfort, pressure, pushing but I didn’t expect to feel the pain that I did. You know erm, whether they normally put people to sleep I don’t know, whether they give more local, leave it a little bit longer, I don’t know, but for me it wasn’t a good experience’. (Interview 10)

‘...When I spoke to him (consultant), when he said about it, I asked him, he said I should be awake and I said well is it very painful, he said it’s uncomfortable which I expected, but it was very painful when it was hitting the nerves’. (Interview 13)

Participants made reference to feeling that health professionals on the wards during the trial in hospital were not empathic of their experience during the operation. Ambivalence could be noted by some patients as they wanted to express their gratitude for the SCS but at the same time felt a need for acknowledgment for the difficult experience. ‘...“lots of people would love to be in your position” was one of the phrases that was used and I was sort of saying I’m so grateful I am in my position but actually right now this is the way I feel about it’. (Interview 12)

‘...Whilst actually in hospital having it done, I did get the feeling that some of the nurses didn’t quite understand the severity of the operation that we’d had’. (Interview 8)

**Body image ‘I wasn’t expecting that!’** Women disclosed negative body image issues in a number of areas related to the SCS. There was a sense of shock described by some of the female patients regarding when the SCS was fully implanted. The idea of a machine being implanted into their body caused some concern, as did the visibility of wires during the trial. They were also not expecting scars caused by the implantation itself, which some found upsetting.
‘...the only shock I had was the size of the scars. I wasn’t expecting that. The big scars, you know that don’t you, and on your back, you’ve got all the scars on your back, so I think for some women, I think that might be a major problem’. (Interview 1)

One woman was really disturbed by the presence of the ‘holes’ in her body where the wires were for the trial period. She discussed how unprepared she was for this. She also pointed out how she was unable to look at the physical change, scarring, on her body for two months.

‘...so, probably the worst thing was how freaked out I was. Erm, first of all, I suppose I hadn’t really realised after that first stage of the operation that you’d have like, what in my head always looked like, I’ve got holes in me, you can go from the outside to the inside and that’s just wrong and that kind of shook me up a bit but it was actually when I, after the second one where erm, I could feel the thing and even though it was all stitched up I probably couldn’t look, oh yeah I probably couldn’t even turn round and look at where the scar was or anything for about two months’. (Interview 12)

Discussion

This study explored patients’ experiences of SCS with the aim of providing a descriptive analysis of the findings. To our knowledge the findings in this study have not been reported previously. Typically, psychological factors experienced by SCS patients have been investigated via questionnaires.22–25 The interviews have enabled some wider areas of interest that have not been investigated by questionnaire studies to be explored. These findings may be important to consider when preparing individuals for SCS. Two core themes were generated through thematic analysis of 13 interviews, coping with pain and SCS treatment.

Coping with pain encompassed the sense of helplessness that patients experienced in response to chronic pain, alongside other negative coping strategies (passing responsibility to doctors, feeling controlled by pain and frustration and anger). The theme SCS treatment comprized the three main topics patients focussed on when discussing SCS. These included information provision and a desire for contact with expert patients; regaining independence when SCS was successful; and also the unexpected experiences of the treatment (e.g., painful trial and body image concern).

Emotional coping and a sense of helplessness was experienced by all patients in response to pain, more so by those who had not achieved successful relief of pain through SCS. The recurrent theme of the effect of emotion upon coping was evident throughout the findings. The data suggest that some participants were hoping for a ‘miracle’. This is an example of negative coping, indeed, helplessness and negative outcome expectancies have been found to be related to uptake of passive pain coping strategies.26 Passive coping includes aspects such as inactivity and an over-reliance on medication with patients absolving themselves of personal responsibility for the reduction of pain. Passing responsibility to others can adversely affect individual’s lives.27 The results demonstrate how some of the participants experienced an inability to move past the pain, resulting on a focus of what cannot be done rather than what can be achieved. There was also evidence of responsibility being passed to external sources for reduction in pain. Findings of helplessness in response to pain, was not new knowledge. However, further demonstrates the importance of enabling patients to develop and use active coping strategies which may impact on treatment outcomes.

The sense of feeling controlled by pain was very evident. Pain is a conscious process with internal and external factors
influencing the experience. Individual interpretations of the painful experience interact with the affective component of pain. The attention and evaluation given to the pain experience appears to be central to the perception and subsequent experience. Cognitive behavioural therapy (CBT) may be helpful in reducing the negative attributions and increasing active coping, which may lead to a further reduction in pain when being treated. CBT may encourage a move away from feelings of lack of control and a move towards acceptance, potentially influencing outcome of treatment.

The results highlighted acceptance of pain, more so by those with successful pain relief. Acceptance has increasingly become an important consideration for successful pain management. Acceptance can be understood as not employing avoidance, fear of movement beliefs or control behaviours, continuing with an individual’s life and following personal goals. Appropriate CBT can also assist in increasing acceptance of pain and a reduction in fear avoidance behaviours, which may also improve treatment outcomes.

Unexpected experiences came to light in the interviews. Patients felt on occasions that they were not prepared for the painful experience of the trial. Disclosure of the possible amount of pain experienced from this procedure could serve to increase anxiety prior to trial. There is therefore a tension that clinicians must manage. Some participants also alluded to feeling that health professionals on the hospital ward were not aware of the difficult experience of the trial. Ensuring staff are aware of the procedure may be important to improve care. The trial and initial experience of the SCS introduced body image concerns for the majority of the women participants, which was apparently something they were not expecting. It was not, however, mentioned by any of the men. Body image is not merely personal perception of the body, but is mediated by social and cultural context. An altered body image may undermine the confidence people feel in the presence of others, and the way in which they feel they are perceived, and in this study it would appear to have affected women more than men. These aspects need further consideration during information sessions.

Information provision was a topic that generated several considerations for clinical practice. There was a desire among the participants for the opportunity to discuss SCS treatment with expert patients. Some participants reported a lack of information; those who felt they had enough information had often researched the subject themselves, usually via internet. A question/answer session may be helpful in determining if patients are well informed about what an SCS procedure involves. Cognitions impact upon the pain experience and therefore interact with response to treatment. Feeling confident and knowledgeable about the treatment, thus increasing self efficacy may enhance outcome. Ensuring patients are appropriately informed and enabling discussion with an expert patient may prepare them for potentially unpleasant experiences.

For those who achieved successful pain relief, a sense of regaining control was experienced. The possibility to obtain relief at any given moment provided participants with confidence that they could indeed continue with their goals in life and no longer be controlled by pain that often occurred without warning. This was connected with an understanding that SCS treatment was not a cure for pain. Ensuring patients are aware that SCS is a treatment to enable increased pain management and not cure chronic pain seems imperative for realistic expectations.

**Strengths and limitations**

The study recruited participants sequentially upon reaching one year following SCS trial.
No participants declined participation in the interview. A particular strength to the study is the non-involvement of the researcher in the treatment process. This encouraged participants to speak openly. The cohort included patients who had failed the trial; those who had full SCS implantation receiving successful pain relief and those not receiving successful pain relief from SCS. Interestingly, themes generated were common across all participants. Participants, who were receiving satisfactory pain relief from SCS, expressed feeling more control over pain and expressed improved coping and acceptance of pain. The nature of this qualitative study does not allow conclusion as to whether improved coping and acceptance led to increased efficacy of SCS or improvement in pain enabled improved coping and acceptance.

Limitations of the study include the setting; participants were interviewed in an office on the hospital site, which could inadvertently have influenced the interviews by having pain management staff in the close vicinity. Moreover, the participant group was white British and therefore the findings lack an element of transferability to other patient populations. The centre where the study was conducted serves a mixed demographic area with some of the participants from deprived areas and others from more affluent areas. The sample was relatively small, although new themes ceased to emerge indicating saturation. A more ethnically diverse, multicenter-based sample has the potential to lead to verification or to allow further findings. The data were collected from a single centre and findings may be specific to this centre, especially when considering information provision. This centre, however, follows the British Pain Society national guidelines; therefore, all patients were assessed by a multidisciplinary team including a psychologist, physiotherapist, consultant and specialist pain nurse prior to SCS treatment. The findings may be influenced by how successful the treatment was. Negative attributions may therefore be influenced by the outcome of the treatment. Interviews prior to 1 year following initiation of SCS treatment may allow further insight into this aspect.

Conclusion

The current study provides a context for understanding the experience of SCS from a patient’s perspective. The findings may contribute to the practical implications for preparation for SCS. Enabling patients to learn active coping strategies and reduce maladaptive coping through CBT may lead to improved outcome. Information provision needs consideration, particularly regarding the potentially uncomfortable experience of the trial and body image concerns raised by the women. Additional information via an expert patient may be of value, to cover issues of what to expect and ensure correct levels of understanding and expectation are achieved before treatment. Further investment in preparation prior to SCS surgery is warranted. Additional investigation is needed as to whether such changes in preparation for SCS lead to increased efficacy from SCS. This study provides new areas for more rigorous exploration. Use of the emerging themes to develop a questionnaire and subsequently validation could also be considered.

Acknowledgements

The authors are grateful to Mr. Ben Newton, Dr. Gail Steptoe-Warren and Mrs. Christine Grant for their critical appraisal of an early version of this manuscript.

Conflict of interest

The authors report no conflict of interest concerning the materials or methods used in this study or the findings specified in this paper.
Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

References


