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Long-term lived experiences of patients with chronic pain or angina pectoris treated with spinal cord stimulation: a qualitative study

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ABSTRACT

Objective To explore the short-term and long-term lived experiences of patients with chronic pain and angina pectoris with spinal cord stimulation.

Design An interpretive qualitative study with thematic analysis of one-off, semistructured interviews, following Braun and Clarke (2006).

Setting A multidisciplinary, publicly funded pain service in Auckland, New Zealand. Patients usually undergo a comprehensive medical, psychological and functional assessment and an in-house pain management programme before proceeding to spinal cord stimulator implantation.

Participants Participants implanted with a spinal cord stimulator between 1998 and 2019 who had their stimulator for ≥1 year, purposively sampled to increase the range of ethnicities.

Main outcome The themes identified from the interviews.

Results 24 participants with chronic pain of varied aetiology and a median (range) of 5.2 (2.4–23.2) years since stimulator implantation participated. 22 participants had the device in situ, and 2 had been explanted. Five main themes were identified: (1) embodiment: stimulator and body as one; (2) technical factors: batteries and type of stimulation; (3) improved well-being; (4) social connection and (5) healthcare system interaction. Most participants reported pain relief, but many had experienced complications and discomfort. They emphasised the importance of ongoing support from the pain service. Acceptance of pain, coping and embodiment emerged as common motifs across these themes. 21 participants were satisfied with their treatment.

Conclusion Within the context of a multidisciplinary pain clinic, despite some discomfort and various complications, most participants valued the ongoing reduction of pain achieved with spinal cord stimulation. Timely access to support from the pain service influenced their experience and satisfaction with their stimulators. Acceptance of pain and embodiment of the stimulator helped participants adapt to living with their stimulator, often over many years.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This study was adequately sized (n=24) for qualitative research and included patients who had lived with the stimulator for substantial periods of time (≥23 years).
⇒ We included participants with a broad range of aetiologies of chronic pain, including refractory angina pectoris.
⇒ Our findings come from a single, multidisciplinary pain service within a publicly funded healthcare system, which limits the generalisability of conclusions to other contexts.
⇒ The study was investigator initiated with no industry involvement, but two authors (AFM and ED) were involved in managing many of these patients (see 'Competing interests' section), and ED was present during the interviews, which might have introduced a positive bias.
⇒ Of 61 patients eligible to be contacted to take part in this study, 7 of 32 who were subsequently excluded had their stimulators explanted versus only 2 of the 24 who were interviewed: this may have introduced an element of positive bias.

INTRODUCTION

Chronic pain has been estimated to affect 20–40% of the global population.[1 2] Chronic pain can disrupt every aspect of patients' lives, including mental health, day-to-day activities and social and family relationships. Spinal cord stimulation has increasingly been incorporated into the management of chronic pain over the last 50 years.

A spinal cord stimulator is a neuromodulator implanted percutaneously or surgically, usually after a screening trial, to deliver electrical impulses through electrodes in the epidural space to manage chronic pain.[3 4] Spinal cord stimulation has been used for more than half a century worldwide[5] and for more than 20 years in New Zealand,[6] and is best conceptualised as an ongoing treatment extending over many years. Maintenance is required, complications need to be managed and patients must come to terms with their new body configuration, which now includes the device, with its effects.[7]

There have been many quantitative studies of this therapy,[8–11] but only a few studies have explored patient expectations of[12–14] and experiences with it,[15–17] and these have focused on chronic pain after spine surgery. Moreover, the longest treatment period previously evaluated qualitatively was an average of 48 months.[15]

We therefore sought to explore patient experiences of spinal cord stimulation in New Zealand over the short-term and long-term, including their satisfaction with the spinal cord stimulator and their perceptions of the extent to which it had improved their function.

METHODS

This interpretive qualitative study with thematic analysis is part of a larger mixed-methods study at The Auckland Regional Pain Service. In this article, we present the interviews and thematic analysis component of the project. We plan to submit a separate manuscript reporting the quantitative element of this study.

Setting

In New Zealand, almost all the spinal cord stimulation is provided through the public health service, often funded by the Accident Compensation Corporation (ACC) (https://www.acc.co.nz/). Patients usually undergo a comprehensive medical, psychological and functional assessment and an in-house pain management programme before proceeding to stimulator implantation. They are also provided with ongoing long-term access to follow-up and maintenance of their stimulators.

The research team included a specialist in chronic pain management and anaesthesia (AFM), two specialist anaesthetists (SR and JS), a clinical nurse specialist (ED), a medical qualitative research specialist (TJ) and a biomedical research fellow (MM). This project formed part of SR's doctoral research.

Inclusion criteria

Eligible patients included those who underwent a definitive spinal cord stimulator implant at The Auckland Regional Pain Service between 1 January 1998 and 31 December 2019, who were aged 18 years or over, and who had been implanted for at least 1 year. This time frame covers the period from the start of spinal cord stimulation at The Auckland Regional Pain Service to the time of starting this study, allowing 12 months from the implantation of a stimulator. Patients were excluded if recorded as deceased (in the Ministry of Health or Auckland District Health Board records).

Participant recruitment

Eligible patients were telephoned by ED and SR, and invited to participate in a one-off, semistructured interview. If interested, they were sent an information sheet and consent form via standard post or the internet (Research Electronic Data Capture software (REDCap)).[18 19] If willing to be interviewed, a telephone or video call appointment was arranged (figure 1).

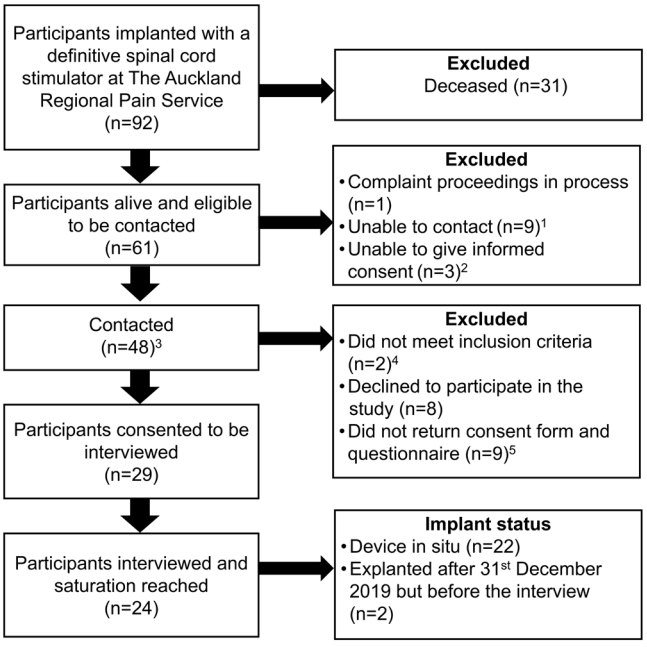

Figure 1 Recruitment of participants. [1]Because patients' contact details were not updated at the Auckland District Health Board (n=3), or we were unable to establish contact after four attempts despite leaving voicemail messages (n=6): of these, four had been permanently explanted before December 2019. [2]Because of dementia or disorientation. [3]Māori participants (n=3) were recruited and interviewed first. [4]These patients had transferred to a different pain service. [5]Of these, three had been permanently explanted before December 2019.

Data collection

SR conducted the interviews between May and September 2022 via telephone or Zoom. ED, who knew all the interviewed participants, was present to address any clinical queries, but did not participate in questioning.

The interviews were semistructured with open-ended questions (see online supplemental material 1), and field notes were taken. Prompts and probes were used to encourage participants to expand their responses. Participants were free to pause the interview or withdraw without reason. Interviews were audio recorded then transcribed. Participants were offered the opportunity to receive and edit their transcript. De-identified participant characteristics were captured using REDCap.

Sample size

We determined our sample size according to the principle of data saturation (ie, the point at which further interviews do not produce new themes or codes).[20 21] Guidelines suggest that 16–30 interviews are usually needed for this.[22–24] We planned to conduct and analyse 17 interviews,

and then continue until no new themes emerged.[25] Saturation occurred after 23 interviews, but one more participant had already been recruited and was interviewed.

The 61 patients eligible for interview (see figure 1) included more patients of European ethnicity (~80%) than expected in the general population of the catchment area. Given the importance of adequately including Māori (the Indigenous people of New Zealand) in research, we first approached all the Māori patients in this cohort, and then the other non-European patients. We then recruited the remaining participants in random order using random numbers generated by MM using R statistical software (4.2.3).[26]

Data preparation and analysis

Audio recordings were transcribed verbatim with notes on non-verbal cues, such as laughter, crying and pauses. Potentially identifiable information, such as personal and place names, was censored, and participants were assigned pseudonyms. Participants were sent copies of these transcripts to check, and some made modifications to them. The transcripts were then organised and analysed in NVivo-R1 (2020) QRS International software.

We adopted Braun and Clarke's six-stage inductive thematic analysis approach[20] to identify themes (online supplemental material 2). Participants were not approached for feedback on the results.

Patient and public involvement

This study was discussed in its early stages with Taia te Hauora, our Department's Māori research advisory committee. The intention to publish was included in the information provided to participants before they consented to participate.

RESULTS

Out of 61 patients who had a definitive spinal cord stimulator implanted at The Auckland Regional Pain Service between 1 January 1998 and 31 December 2019 and were still alive, 50 (82%) were European, 6 (10%) were Māori, 2 were Asian (Indian), 1 was Pacific peoples (Fijian), 1 was MELAA, that is, Middle Eastern/Latin American/African (African), and 1 identified as Others. From these, 24 patients (42% female; 58% male; 0% other) were interviewed (see figure 1). Of these 24, 3 (12.5%) were Māori (a fourth Māori patient declined to participate and the remaining two could not be contacted) and 21 (87.5%) were European. Of the patients of other ethnicities, one could not be contacted, and the remainder did not return consent forms. The interviewed patients had first undergone implantation a median (range) of 5.2 (2.4–23.2) years earlier. The median (range) age at interview was 59 (30–75) years. Participants had varied aetiologies of pain, such as chronic pain after spine surgery (n=8); complex regional pain syndrome (type-1=2; type-2=2); chronic post-traumatic pain (n=3); spinal cord injury (n=2); chronic posthernia surgery pain (n=1); chronic primary low back and leg pain (n=1); chronic chest pain of unknown cause after cardiac stenting (n=1); bilateral knee stump pain (n=1); unilateral phantom leg pain (n=1) and chronic refractory angina pectoris (n=1). One participant had chronic pain after spine surgery and unilateral phantom leg pain.

All patients were implanted percutaneously at The Auckland Regional Pain Service until 2015, when a neurosurgeon interested in neuromodulation joined the team and selected patients could undergo open implantation. Thus, 21 of our participants were implanted percutaneously and 3 were implanted surgically.

22 patients had their device in situ at the time of interview. Two patients had been explanted after December 2019, after 47 months and 13 months of implantation, one due to inadequate pain relief following lead replacement, and the other due to leg weakness with bowel and bladder dysfunction. At the time of the interview, 17 participants were using their stimulators and 5 were awaiting a battery replacement procedure. All interviews took 60–90 min, except one that took 120 min. Field notes were analysed in one case, where the audio recording was corrupted and incomprehensible.

Themes

Participants made it clear during their interviews that for us to understand their experiences with the stimulator we needed to understand their lives prior to implantation. Chronic pain had disrupted their personal, professional, and social lives and was considered an obstacle to achieving previously held personal goals. This disruption is the context from which participants experienced their stimulator. Most participants experienced their stimulator as a transformative step towards reforming and reclaiming their identity and capabilities. Nevertheless, two reported having elected to have their stimulator explanted after December 2019. Our analysis identified five themes (figure 2): (1) embodiment: stimulator and body as one; (2) technical factors: batteries and types of stimulation; (3) improved well-being; (4) social connection and (5) healthcare system interaction. Each theme had two to five subthemes.

Theme 1—embodiment: stimulator and body as one

Embodiment refers to the relationship between body and mind, whereby the physical body and its sensory experiences play a fundamental role in shaping our thoughts, feelings and actions. Similarly, our thoughts, feelings and actions inform how the body is experienced. Embodiment also refers to the blurring of boundaries around additions to the physical body, such as through piercings, prostheses, implants or spinal cord stimulators. Participants described experiences consistent with embodiment, such as the stimulator shaping their bodily experience. Participants expressed hopes that the stimulator would reduce their pain and, by extension, enable them to restore their prior sense of selfhood and rebuild their movement and sense of wellness (Box 1, subtheme 1.1). This may

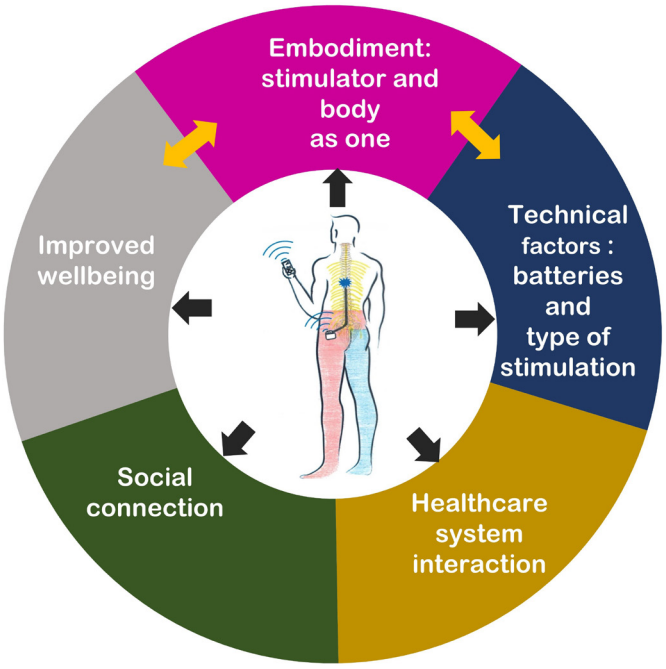

Figure 2 Thematic map showing the main themes identified from the interviews. The bidirectional arrow represents the theme of embodiment: stimulator and body as one is linked to the themes of improved well-being and technical factors: batteries and types of stimulation, in terms of how the stimulator enabled them to rebuild their life and how technical factors impacted participants' perception of the device.

be interpreted as viewing the stimulator as a means to regain a previously lived life. Thus, participants' expectations and attitudes towards the device influenced the ways in which they considered the stimulator would shape their bodily experiences. In addition, time spent living in chronic pain before receiving a stimulator influenced participants' hopes. For many, these hopes were realised, and they described their stimulator as a 'life-changing' or a 'lifesaver'.

Participants described adapting to the implant. Initially, they felt the stimulator as a 'foreign' object and its electrical impulses as 'strange' and were conscious of the pulse generator as a 'lump'. Over time, they became accustomed to their stimulator. Participants learnt to avoid activities or environments that were incompatible with their device or caused them avoidable discomfort (Box 1, subtheme 1.2). Avoidance of things that might inflict harm to the body or implant was seen as key to the process of embodiment and living successfully with the implant.

The implantation procedure is awkward: patients must be prone to access the spine and awake so that they can give feedback on the sensation. This was demanding for many participants, and it was traumatic for one participant, whose first procedure had to be discontinued because of airway obstruction (Box 1, subtheme 1.3). Subsequent complications (such as infection, lead fracture, leg weakness, inadequate pain coverage, stimulation of non-painful areas and uncomfortable electric

Box 1 Themes 1 and 2

⇒ **Theme 1—embodiment: stimulator and body as one**
This theme had five subthemes.
⇒ **Subtheme 1.1: hope to regain capabilities and selfhood**
Selected quotations

It [expectation] depends, like I said, on the person's journey in the life where they're at because someone that's freshly diagnosed, they want cure, one hundred percent [….] for me, it worked, but I was at a later stage of my journey than a lot many [….] with it [stimulator], I knew that I could live a different life to what I was currently living.(Ethan)

⇒ **Subtheme 1.2: adapting to the implanted stimulator**
Selected quotations

When they first put it in, it was very far in your thought, and you were hanging on to an electric fence. But now, after so many years of having it there, you know, sometimes you don't even know it's on. (Alexander)

⇒ **Subtheme 1.3: navigating through complications and side effects of the stimulator**
Selected quotations

I got an infection which [the pain physician] wasn't very happy about [[(laughs)]]. It's been two weeks in hospital or a week in hospital, trying to get rid of the infection. It wasn't too bad. Gave me a bit of pain. But everything I know, even with those complications, yeah. It was, it's worth it.(Richard)

⇒ **Subtheme 1.4: acceptance**
Selected quotations

I can't stress enough that anybody that's getting a stimulator needs to be aware that it is not the be all and end all fix. It is a step in your recovery to your new life, you will never get your own life back. (Ethan)
If it'll functional long enough, it will outlive me, let's face it [….]. And then one day when I switch off, it'll switch off. Yeah, that's how I see it. (Nora)

⇒ **Subtheme 1.5: stuck in limbo**
Selected quotations

Since the simulator died [[(laughs)]], I've spent more time bedridden because I can't function other than to get up to go to the toilet, get up go to the bath. I very rarely leave my house [….] So, I don't do any shopping. I don't go out to the public. I don't go visit family [….] I just would like vegetate in the bedroom. (Nora)
I need the stimulator changed. I need the battery changed [….] I want to get better, and I want to be a dad again, and I want to take my son fishing, and I want to open a business, and I want no offs. (Richard)

⇒ **Theme 2—technical factors: batteries and types of stimulation**
This theme had two subthemes.
⇒ **Subtheme 2.1: perspectives on the battery position and type**
Selected quotations

It is in my back. For me, I would have preferred it in the front [….] because I am in the wheelchair, and every time you lean forwards, it falls off [….] so, if it is stuck to my front, I'll be able to see everything. (William)
If I had been offered a non-rechargeable one now, I probably would have gone with that, just the simple fact that it makes it a little bit easier not having to remember to check on it and charge it. (John)

Continued

Box 1 Continued

⇒ **Subtheme 2.2: different stimulation programmes**

Selected quotations

> There are different programmes which targets my legs more than my pelvis, and then there are programmes that target my legs and going up into my pelvis [….] when it's really sore, I'll change the programme to cover the pelvis, which previously was probably just covering my legs. (Isabella)
>
> With the silent mode, I don't notice it at all, it might be once in every couple of months, I might feel something in silent mode, [….] it is very softer tingling. (James)
>
> I prefer the tonic mode because I guess you can feel it [….]. It is a pleasant sensation rather than the unpleasant one, whereas the silent one doesn't always appear to work all the time. (Emma)

Note: additional quotes are provided in online supplemental material 3.

shocks) sometimes created pain or discomfort, making participants aware of the presence of the device and disrupting the embodiment process. However, the benefits of the treatment lightened the memory of these upsetting events, and they accepted the stimulator despite its limitations.

A crucial subtheme was acceptance. Acceptance was described in terms of enduring pain, limitations and unusual experiences of the stimulator, and health service delivery waiting times (eg, to have batteries changed) (Box 1, subtheme 1.4). A positive outlook and a sense of acceptance seemed to promote a stronger sense of embodiment.

Some participants faced challenges when their stimulator stopped working (eg, due to battery depletion or complications), leading them back to constant pain and medication use (Box 1, subtheme 1.5). Participants reported undergoing revision procedures (such as lead or pulse generator replacement, lead repositioning) to manage complications. In addition, participants whose stimulators had stopped working were ready to undergo further revisions to continue using their stimulators. Disruption caused by delay in maintenance or replacement could negatively affect embodiment of the stimulator.

The theme of embodiment was strongly connected with themes 2 and 3 (figure 2).

Theme 2—technical factors: batteries and types of stimulation

The leads and pulse generator of the stimulator are implanted, whereas remote control is a hand-held external device. Both rechargeable and non-rechargeable implantable pulse generators contain a battery. Stimulation is delivered in various electrical patterns, including 'tonic', 'burst' and 'high-frequency'. Tonic stimulation is generally perceptible to the patient as tingling (paraesthesia), whereas newer stimulation patterns are not usually perceptible. At the pain service, the predominantly implanted devices can provide tonic and burst stimulation patterns.

Their stimulator provided participants with a sense of control over their pain. The remote control, location and type of the pulse generators, and different stimulation patterns influenced embodiment of the stimulator. The ability to customise the programme for pain and activity using the remote control with preset stimulation parameters enhanced embodiment by allowing participants to feel more in control and connected to their stimulators (Box 1, subtheme 2.2). Many participants noted that they were unaware of the implant while it was functioning in the background until the battery was exhausted, although the need to monitor battery status and regularly recharge their devices made participants with rechargeable stimulators more actively aware of their stimulator than participants with non-rechargeable ones.

Participants' views about the best location of the pulse generator were determined by physical comfort and by its accessibility for recharging (Box 1, subtheme 2.1). 12 participants had their pulse generator implanted in a buttock. Some participants disliked this location because they experienced pain when sitting on chairs or because (according to one participant) activating it in public was awkward. They would have preferred an anterior position, which would make access for recharging easier. However, some with an anterior pulse generator noted difficulties if the stimulator was below or on the belt line.

Participants' preference for the type of pulse generator was governed by aesthetics (ie, a smaller generator produced less protrusion), battery life, ease of recharging, and frequency of recharging and battery replacement. Some participants preferred rechargeable stimulators and adapted their schedules around recharging. Others preferred, or would have preferred, non-rechargeable devices, noting that rechargeable stimulators do not provide pain relief during recharging, imperfect positioning can lead to difficulty in recharging and old batteries can overheat while recharging (Box 1, subtheme 2.1).

Participants' preference for different stimulation patterns was influenced by comfort, particularly when the stimulator was used for a longer duration (10–12 hours), during activities and during body movement (Box 1, subtheme 2.2). 12 participants had tried burst stimulation, and of them, 8 preferred burst and 4 preferred tonic stimulation. Of the 12 participants who had never tried non-perceptible stimulation, 2 expressed interest in it as they found the tingling uncomfortable.

Theme 3—improved well-being

Most participants (n=19) reported that their stimulator reduced pain and thereby enabled them to regain some ability to undertake routine activities and live more independently. Moreover, many participants (n=15) reported that it increased their capacity to engage in physical activities, although with limitations. These limitations often hinged on the unpredictable nature of pain and coexisting medical conditions (Box 2, subtheme 3.1). 19 participants reported that their stimulator reduced their reliance on medication,

Box 2 Themes 3 and 4

⇒ **Theme 3—improved well-being**

This theme had four subthemes.

⇒ **Subtheme 3.1: improvement in activities and mobility**

Selected quotations

I couldn't even make the bed, and before the stimulator, standing at the sink was a problem [….] I looked awkward even when I was sitting. So, you know, activities around the house now with the stimulator in, there's nothing I can't do. (Alexander)

I actually ended up using a wheelchair [….] There was pretty much no physical activity before the stimulator [….] now, I am able to go for a long walk on the farm or do, you know, cycling class or pilates classes. I am able to run [….] I am able to do pretty much everything what everyone else can do. (Eleanor)

I use meditation regularly, and I make sure of that [….] I'm probably better at listening to my body than what I was. I am more aware that, you know, sometimes you have to make decisions rather than trying to do everything, and so I think I've got I think those skills were really developed at that course and things that I still use in every day in life now, yeah. (Isabella)

⇒ **Subtheme 3.2: pain relief with the stimulator**

Selected quotations

It has made a difference [[(pause)]] because initially, I used to have to go in and trim the nerves back and I'd had to have an operation [….] I just turn my stimulator on now and control it that way. (Jack)

It [Spinal cord stimulation] makes me feel fine. Although it [pain] doesn't go away altogether, it has lessened it a whole lot to deal with [….]. So, I don't have to put all the chemicals in my body from the analgesia. (Raya)

⇒ **Subtheme 3.3: improved sleep and appetite**

Selected quotations

Before I didn't sleep. My biggest fear was, you know, I died before I had the chance to say goodbye to everybody [[(laughs)]] [….] but, when the stimulator came on board, and the pain started subsiding, I relaxed a bit more. And so, I slept a bit more. (Nora)

With the stimulator, I was probably getting hungry because I was doing more exercise. (Richard)

⇒ **Subtheme 3.4: changes in work life and finances**

Selected quotations

⇒ I didn't have my job anymore which was the big part of who I was [….] So, yeah, the stimulator has enabled me to have a work-life [….] I just used my nursing skills in a different way and was able to get work relatively quickly really. (Eleanor)

⇒ **Theme 4—social connection**

This theme had two subthemes.

⇒ **Subtheme 4.1: rebuilding relationships and social life**

Selected quotations

Before the stimulator was put in my sons sort of stayed away from me, and that was pretty hard [….] when the pain was high, I got a bit short-tempered. Now I'm not [….] I'm going back to where I used to be. I have got a lot closer to my sons than I was before, what's really made the house a lot happier. (Eric)

⇒ **Subtheme 4.2: support from family and friends**

Selected quotations

You're lucky if you've got family to prop you up. You're even luckier if you've got friends that help prop you up [….] He [my friend] and his partner at that time called me up and said, 'we need you here [….]'. I went to help them and gradually worked my way back into the workforce that way. (Ethan)

Note: additional quotes are provided in online supplemental material 3.

and of these, 6 reported fewer pain-related hospital visits since receiving it. The reduction in reliance on pain medication had important implications for participants' sense of identity. Participants continued to use some pain relief medications along with their stimulator, and this made some of them feel stigmatised. Some participants derived limited pain relief with their stimulators, but, despite this, most preferred it to medication, although one preferred medication and behavioural modification to stimulation (Box 2, subtheme 3.2).

Many participants reported improvement in sleep quality, sleep duration and appetite with their stimulators. Improved appetite was attributed to reduced medication use (and hence the associated side effects) and improved exercise capabilities (Box 2, subtheme 3.3). Some participants reported being able to return to work, although after recalibrating their goals. Some participants who experienced work-related or financial stress reported that this increased their pain (Box 2, subtheme 3.4).

Two participants reported regaining movements in the upper limb, and one reported progressing (with physiotherapy) from being in a wheelchair before stimulation to walking, and even running (Box 2, subtheme 3.1). Many participants reported using coping strategies learnt over time or through the pain management programme along with their stimulator to manage pain.

Improved activity and functionality often translated to improved well-being or enhanced quality of life. Embodiment of a spinal cord stimulator is deeply intertwined with improvement in the overall well-being of participants. By controlling pain, the stimulator enabled participants to lead a more fulfilling life, thus fostering a strong sense of embodiment.

Theme 4—social connection

Many participants reported positive changes in their mood, memory and ability to think clearly after receiving their stimulator. As pain was better controlled and mood was stabilised, these improvements were noticed by their family members, further reinforcing the positive impact of the stimulator on their lives. These participants reported improvements in family dynamics and interpersonal relationships, leading to increased happiness among family members (Box 2, subtheme 4.1). One participant reported that a coexisting psychological condition hindered socialising ability. Many expressed their gratitude towards people who had supported them emotionally and financially to rebuild their lives (Box 2, subtheme 4.2).

Theme 5—healthcare system interaction

Interactions with the healthcare system influenced participants' experiences with their stimulators. Prior to implantation, most participants (n=18) attended a pain management programme, and the information received at the pain service before receiving their stimulators helped alleviate their fears about the procedure. Many participants (n=15) said they appreciated the care and regular follow-up they received at the pain service. However, five felt that the pain service had not met their expectations as they had not received the promised regular follow-ups and ongoing care, and the responsibility for receiving regular follow-up was placed on the participants rather than the pain service. This had left them anxious and feeling like they might have been forgotten. For those residing away from the Auckland region, follow-up visits presented greater challenges, including financially (Box 3, subtheme 5.2).

Waiting times had a distinct bearing on participants' narratives of acceptance. At the time of participant interviews, a typical waiting time at the pain service for a spinal cord stimulator implant was 12 months, and for a revision procedure was 6–18 months (Box 3, subtheme 5.1). Participants identified various reasons for the delay in the procedure, which included funding difficulties and the ACC approval process, the recent COVID-19 pandemic, nursing shortages and a perceived lack of cooperation between ACC and the pain service.

Participants' views on the usefulness of the pain management programme were mixed. Some participants learnt coping strategies through the programme and formed social connections with other chronic pain patients. Others did not find the programme beneficial, reporting that it offered little new information and was not tailored to their individual needs. Participants who travelled to attend the pain management programme reported difficulties associated with being away from home, such as poor sleep. One participant was angry as he had not received ongoing psychological support and physiotherapy despite asking for it after the programme (Box 3, subtheme 5.3).

Box 3 Theme 5

⇒ **Theme 5—healthcare system interaction**

This theme had three subthemes.

⇒ **Subtheme 5.1: jumping through hoops—process of stimulator insertion and maintenance**

Selected quotations

It took me three years to get this stimulator in my back. I think if I had to fight any more probably I would be a dead person. (William)

I have been in the fortunate position that ACC [Accident Compensation Corporation] has covered those costs, and if I was not an ACC case [[(pause)]] [….] The cost would just been ruinous. (Mateo)

I don't think they [ACC] know what it [chronic pain] means. They sent me to psychiatrists and all sorts that saying it was in my head and when we knew it wasn't in my head. (Eric)

It's just a shame really that more people don't get the opportunity to have this device. (Noah)

⇒ **Subtheme 5.2: ongoing care and support at the pain service**

Selected quotations

As far as the simulator was concerned, it was annual reviews, and replacement and upgrades when suitable. (Mateo)

I had that surgery, which was exquisitely painful [….] I needed a bit more [information], I think because I felt like I'd been in a boxing match where everything that hurt was on my back, and I hadn't expected that. (Flora)

I found that the hardest thing, especially with this is having going to Auckland [….] and that is actually quite frustrating at times. Especially if there is a problem, and you need to see them, you can't just go to a doctor and to see them eventually, you got to fly out. (Nyra)

⇒ **Subtheme 5.3: experience with the pain management programme**

Selected quotations

Boot camp [pain management programme] is the best thing before anyone gets a stimulator [….] they need to learn how to do mind over matter. Yeah, they need to learn what's happening in their bodies. They need to learn that pain is not going to kill you, which is all taught at the boot camp. It's the building block to starting their new journey of life.(Ethan)

After the three week course, I was to my mind kind of essentially abandoned in the physical therapy side of it. That makes no sense [….] they talked about psychological aspects or whatever, but then at the end of the three weeks, that's it, 'Oh, thanks, nice to see you, here's your little book. Bye. Now you are by yourself.' Wow, holy crap, how are you supposed to do that? (Mateo)

Note: additional quotes are provided in online supplemental material 3.

Other questions

Thinking back to when you were deciding whether or not to get the stimulator treatment, and given what you know now, would you make the same choice of getting this treatment?

21 participants said they would undergo stimulator insertion again despite the discomforts of the procedure. Three participants said they would choose to have a stimulator again only if no alternative treatments were available, and one said she would only choose this if the non-rechargeable battery could be made to hold power better.

Would you recommend the stimulator therapy to a friend with similar chronic pain to you?

21 participants said they would recommend spinal cord stimulation to others with similar pain conditions, and 4 participants reported having done so. This underscored the perceived overall positive effect this therapy had had on their overall well-being. Two participants said they preferred and would recommend a dorsal root ganglion stimulator over a spinal cord stimulator.

DISCUSSION

In this qualitative exploration of 24 patients' lived experiences with spinal cord stimulator, we identified five themes: (1) embodiment: stimulator and body as one; (2) technical factors: batteries and type of stimulation;

(3) improved well-being; (4) social connection and (5) healthcare system interaction. That 22 of these participants would recommend spinal cord stimulation to others and 21 would have a stimulator again suggests an encouraging level of satisfaction with the therapy. This view was informed by their diverse personal experiences with stimulation therapy, including complications, difficulties with navigating the healthcare system and the ongoing care provided by the pain service. Embodiment, acceptance and coping emerged as the prominent motifs throughout the themes.

Consistent with previous research, our findings indicate that this therapy can improve the well-being of patients with chronic pain[16 27–32] and decrease the frequency of pain-related hospital visits.[33 34] Many of our participants experienced complications, side effects, repeated revision procedures and administrative delays. Nevertheless, our participants were largely accepting of their situations and acceptance has been shown to reduce pain, promote adaptation and improve quality of life.[35] Their overall well-being also required the use of coping strategies (learnt through a pain management programme or experience), acceptance and balancing the use of medications with stimulation. Acknowledging and accepting the complications, side effects and restrictions imposed by their stimulator was also important. Previous researchers have noted the positive influence of acceptance of pain[17] and of coping strategies for managing pain in conjunction with spinal cord stimulation[16] and explored the constraints and challenges associated with spinal cord stimulation[13 15 16]; our participants emphasised the importance of acceptance of their stimulators within these constraints.

The observation of benefit lasting many years in some participants is in contrast to some previous reports that describe pain relief with spinal cord stimulation declining 2–5 years after implantation.[16 28 29 32 36–38] These (and indeed all of our) conclusions need to be tempered with reference to the study's limitations, detailed below. Of the previous studies, the only study with qualitative data was that of Witkam *et al*,[16] who explored the experiences of 11 patients with chronic pain after spine surgery managed with spinal cord stimulation at the Radboud University Medical Centre, Nijmegen, The Netherlands. These authors noted that although the stimulator provided pain relief and improved overall well-being, 8 of 11 patients reported a decline in the pain-relieving effect of the stimulator 1 year after definitive implantation. However, the reasons for this were not identified. Many authors have addressed the question of long-term efficacy of spinal cord stimulation. For example, a systematic review by Turner *et al*[32] summarised data on diminution of efficacy over time in studies up to 16 May 2003. The evidence presented was at best only suggestive, with questions about statistical significance. No detail was given about maintenance or troubleshooting of device-related problems, although these issues were mentioned. Aiudi *et al*[38] studied 62 patients who received spinal cord stimulation at the Massachusetts General Hospital in Boston, USA. They concluded that pain scores increased over time, but their results showed that there were two groups of patients: 42 who did not experience loss of efficacy and 20 who did. They did not detail the approach to follow-up and maintenance of the stimulators, but acknowledged that technical problems (such as device migration or malfunction) might have been a factor in loss of efficacy. Nissen *et al*[36] reported quantitative data on a detailed long-term follow-up of 175 patients who received definitive spinal cord stimulators for chronic pain after spine surgery at the Kuopio University Hospital in Finland between 1 January 1996 and 31 December 2014. 'Three out of four' of these patients experienced long-term efficacy, up to 18 years in some patients. They described high rates of revisions (comparable to ours) and the need to remove stimulators in some patients for reasons such as infection or as a requirement for MRI, as well as for inadequate pain relief in 34 patients. Witkam *et al*[16] have provided an excellent discussion of the issue, concluding that predictors of long-term efficacy are still unknown, and that factors influencing this are likely to include habituation, psychosocial and technical. Thus, our results may reflect the willingness and ability of The Auckland Regional Pain Service to address technical causes of failure such as lead movement or breakage or the requirement for a new battery, without financial barriers to patients, and also its integration of spinal cord stimulation into a wider, multidisciplinary programme of pain management.

Importantly, the participants who reported long-term benefits had needed ongoing support with battery replacements, troubleshooting and revision procedures. They expressed their willingness to have further procedures to maintain this long-term benefit and frustration over delays in getting these revision procedures. Over the period of this study, a number of technological improvements have occurred in the devices available for spinal cord stimulation, notably improvements in lead design and the advent of high frequency (not used in Auckland) and burst stimulation modalities.[39] We have not sought to explore the benefit of the former. Some participants commented on burst stimulation, but numbers limit any firm conclusions about the advantages or disadvantages of this innovation.

In New Zealand, spinal cord stimulation is publicly funded. This enables patients to receive stimulation who would not otherwise be able to afford it, but, with competing demands on limited resources, some participants reported long waiting times for assessments or procedures. Fewer patients are selected for stimulation in New Zealand than in many other countries. This may reflect differences in available resources, incentives associated with various funding models and approach to patient selection. There is a balance between overtreatment (sometimes driven by financial incentives in privatised health systems) and ensuring adequate access to a useful therapy for a serious condition such as chronic pain. Nevertheless, we think our results provide grounds

for increasing and improving the resources available for this therapy in New Zealand.

In 2018, the ethnic distribution of New Zealand population were European (70.2%), Māori (16.5%), Asian (15.1%), Pacific peoples (8.1%), MELAA (1.5%) and Others (1.2%).[40] This suggests that non-European patients (notably Māori) may be under-represented among those receiving a spinal cord stimulator. It is difficult to draw firm conclusions on the basis of small numbers, but, if this is the case, it would be consistent with many other examples of inequity in healthcare in relation to Māori,[41–43] notwithstanding obligations in New Zealand under the Treaty of Waitangi.[44]

Our interviews raised interesting philosophical considerations. The theme of embodiment is consistent with the wider phenomenological literature.[45] For example, some participants had experienced disintegration between their body and self with chronic pain and saw spinal cord stimulation as a mechanism for reintegration, transforming from what Gadow calls an 'object body' (ie, disintegration between body and self) to a 'lived body' (ie, neutral state of experiencing body and self as one).[46 47] These states can be understood as extreme ends of embodiment. Most of our participants identified with these notions, but others instead perceived their stimulator as a useful tool that created a heightened awareness of their body. This diversity is consistent with earlier reports.[7]

Our findings align with and support seminal theories concerning technology in the body, such as cyborg theory[48] and posthumanist studies,[7 49] as well as theories of fitting and misfitting from studies of patients with disabilities.[50] As with cyborg theory, the intimate relationship between technology and the human body was central to our findings. Sustaining their newly hybrid body required our participants' active involvement. After the implantation, our participants gradually learnt how to use the stimulator, became aware of the ways in which bodily actions or the environment could affect it and learnt to avoid things that caused discomfort or danger (such as MRI). Participants described their implant interacting with electromagnetic devices in airports, stores and the work environment. One noted unpleasant experiences with security control staff where the responsibility for receiving clearance was placed on the participant rather than the facility (Box 1, subtheme 1.2). This is an example of structural discrimination implicit in the built environment, in which those who are not able-bodied are deemed 'misfits'.[7 50 51] Our participants' experiences suggest that living with a spinal cord stimulator is complex, and that embodiment takes time. Embodiment requires patients to alter their sense of where their body begins and ends (ie, the device is now part of me), and is influenced by factors, including the location and type of the pulse generator, complications and delays in revision procedures. Future research into the relationship between embodiment and satisfaction with stimulation could inform strategies (such as counselling) to support future patients undergoing this therapy.

This study has strengths and limitations. Our findings come from a single centre within a particular publicly funded healthcare system in a multidisciplinary pain service that ensured ongoing maintenance and follow-up, which limits their generalisability to other contexts. The data presented here are qualitative: quantitative data from the same cohort of patients will be reported separately. Of 61 patients eligible to be contacted to take part in this study, 7 of 32 who were subsequently excluded had their stimulators explanted versus only 2 of the 24 who were interviewed: this may have introduced an element of positive bias, and our conclusions may not be generalisable to those who do not continue to use their stimulators. The study was investigator initiated with no industry involvement, but two authors (AFM and ED) were involved in managing many of these patients (see 'Competing interests' section), and ED was present during the interviews (to manage unexpected clinically relevant findings), which might have introduced a positive bias. However, neither AFM nor ED was involved in the data analysis, the other authors were independent of the pain service and three authors (JS, MM and TJ) had the explicit task of guarding against potential bias.

This study was adequately powered for qualitative research and was relatively large for a qualitative study. It included patients who had lived with their stimulator for longer periods of time (≥23 years) than in any previous reports[12 13 15 16] (the longest previous report we could find was 4 years[15]). Also, the study included participants with a variety of aetiologies of chronic pain, including refractory angina pectoris, in contrast to previous reports that included only patients with chronic back and or leg pain.[12 13 15 16] It describes a broad range of their experiences of the challenges, benefits and complexities surrounding the use of spinal cord stimulators.

Our findings have direct implications for clinical practice (some of which have already been mentioned). Through the themes identified in this study, clinicians could gain a more nuanced understanding of patients' expectations, complex experiences and preferences, and thus provide more empathetic, patient-centred care. Our results add weight to the importance (already widely appreciated, notably at The Auckland Regional Pain Service) of understanding that a stimulator is part of an overall strategy for managing chronic pain and not a definitive, stand-alone treatment (this is integral to the approach at The Auckland Regional Pain Service). Furthermore, they underline the importance of long-term follow-up and maintenance of stimulators. Improving long-term access to the spinal cord stimulation service for patients outside of Auckland would help improve care and help reduce the burden of chronic pain in New Zealand.

Future qualitative research should explore the experiences of patients whose stimulators are explanted, to better understand why spinal cord stimulation therapy fails to provide worthwhile net benefit to some people.

CONCLUSION

Within the context of a multidisciplinary pain clinic with careful patients selection, and regular follow-up and maintenance, and despite some discomfort and various complications, most of our participants valued the ongoing reduction of pain achieved by spinal cord stimulation. Timely access to support from the pain service influenced their experience and satisfaction with their stimulators. Acceptance of pain and embodiment of the stimulator helped participants adapt to living with their stimulator, often over many years.

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