

Supplementary Material 3 - Additional Quotes

Theme 1—embodiment: stimulator and body as one

In this theme participants described how their bodily experiences were shaped by the stimulators, and what it means to be living with an implanted stimulator. This included participant's expectations from the treatment, learning to live with their stimulator, and showing the positive attitude of acceptance while enduring the side effects, complications, and limitations of their stimulator.

This theme had five subthemes.

Subtheme 1.1—hope to regain capabilities and selfhood

Selected quotations

I just needed to get rid of the pain [...], and I just wanted to go away from taking so many painkillers. It wasn't me [...]. That was my expectation to go off painkillers to have a normal sit down on the toilets and go like a normal person when you have number two to not experience pain. (Aurora)

You've got your life back through technology, [...] it's just amazing technology. (Alexander)

Subtheme 1.2—adapting to the implanted stimulator

Selected quotations

The only other experience I can relate it to take the light bulbs out and stick your finger in the socket and you would get, this really intense tingling feeling current through your fingers, which I guess is exactly what the stimulator is doing to you anyway [...] it is uncomfortable [...] but it's less uncomfortable than the pain. (Mateo)

Part of my old job was I used to do crack testing, and it's done with electrical waves. And the first time I went in the room after having the implant put in, it was really weird feeling so [...] I saw the manager and got myself out of doing that part of my job because [...] my body doesn't seem to like that room anymore. (Eric)

I voluntarily turn off and we just we check it all the time to make sure if I go past the scanners [...] it was at the airport, people getting little bit worried that's all because it looks like a bit of a weird thing the box unit does. Why this is here, what is this for? Once you explain, oh, well, that's quite interesting. (Eric)

Subtheme 1.3—navigating through complications and side effects of the stimulator

Selected quotations

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It was the fifth of September on Father's Day [...] all of a sudden, I couldn't feel my feet, my legs and my waist, and it all went numb, and I had pains unbelievable [...], so I turned up the implanted stimulator, and it made it worse [...] this pain was just crippling [...] I managed to turn it right off [...] well, of course, I couldn't pee. I couldn't. I mean, you know, my bowels wouldn't work naturally. So, I had to have a catheter, yeah, and after two days, I flew to [name of a city], and took the stimulator out. (Lucas)

We had a flat line situation and had to bring me back, ended up with collapsed lungs or the lung quite a bad way [...] [(laughs)]. So, that was a bit of a scary buzz. (Eric)

That's frustrating on its own, you know, like having something that's inside you trying to fix you, and that's only working half, you know, it's like having a brand-new car, and the engine is only running on half the cylinders. (Logan)

Subtheme 1.4—acceptance

Selected quotations

Sometimes you just have bad luck, and as a person, if the implant is malfunctional I'm just going to keep positive [...] you can't sort of blame anyone. This is one of those, like, it's just like walking out [in front of] a bus on a street, you know, sometimes you had bad luck, and it was just an implant malfunction. (Lucas)

Theme 2—technical factors: batteries and types of stimulation

In this overarching theme, participants described their perspectives on and preferences for the location and type of pulse generators and different stimulation patterns. This theme had two subthemes.

Subtheme 2.1—perspectives on the battery position and type

Selected quotations

It's an awkward position to turn on and off, and I get lots of funny looks if I'm out in public trying to turn it on. It's like why is this guy sticking his hand up his butt for. (Mateo)

As before this was right on the beltline so, every time that I was sitting down or standing back up, you know, it would stick out. And that was really frustrating. (Nyra)

I would not recommend that [rechargeable pulse generator] [...] I was in lying in bed for three to five hours because it just wasn't connecting, only because the stimulator wasn't positioned properly. (Nyra)

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I was just coming along, because after a while year actually I forgot it was there, you just like live the normal life, but you had to charge it charge it up I think every two weeks, but it definitely didn't worry me. I'd charge it when still in the house, while it was getting charged do office work or vacuum the house or cook. (Lucus)

Subtheme 2.2— different stimulation programmes

Selected quotations

It [stimulator with the remote control] almost works like your best friend is sitting in your pocket (Emma)

If I leave it [tonic stimulation] on all the time after a while it starts to irritate me rather than help me. So yeah, it [burst stimulation] just makes it a little bit easier because I don't get that feeling of being annoyed. (John)

Ninety percent of the time, I don't even notice the stimulation. I like the feel of it because it gives me a sense of security psychologically to know that it is functioning. (Oliver)

Theme 3—improved well-being

In this theme, participants described improved well-being in terms of pain relief, improvement in physical activities (e.g., exercising, biking, running, and gardening), activities of daily living (e.g., showering, grooming, eating, driving, and shopping), appetite, sleep quality and duration, and return to work after receiving the stimulators. Participants described using medications and coping strategies along with their simulator to manage pain. The coping strategies included taking breaks between activities, planning and prioritising activities, avoiding strenuous activities, seeking help or support, using distraction techniques, exercise, and meditation. This theme had four subthemes.

Subtheme 3.1—improvement in activities and mobility

Selected quotations

I can't lift boxes that are past my head or grasp things quite small because of the physical problems with my arm rather than the pain. (John)

I've got nerve damage in my right arm, so the pain was actually stopping me from moving my wrist, so I couldn't move it. But since I've had the stimulator put in, I've actually got some movement back in my wrist. So that's been quite amazing to me how it's worked. (Eric)

Subtheme 3.2—pain relief with the stimulator

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It was good because the serious ones had disappeared, you know, I wasn't getting them as often as I used to. And so, for me, it was kind of like, this [stimulator] is a blessing in disguise because I was not frequenting the hospital, whereas at one stage, I was in and out of hospital for one year; every week, I was in hospital [...]. And that I attribute to having the stimulator on board. (Nora)

A lot of the times they think you're drug seeking, so you don't get much help at all. And that's, very frustrating [...], I have just a short little list of medications that I take [with spinal cord stimulation]. (Logan)

I think I rank drugs the biggest tool, psychological knowledge and behaviour modification be number two. The stimulator would be number three in the toolkit that I use. (Mateo)

It [medications] made quite a large difference to my life. I was on a lot of medication to try and control it, which sort of turned me into a zombie in a way [...] In the long run, it did stop me from working [...] and with the stimulator now, I still have quite a lot of medications, and some of those opiates, so it does sort of slow me down a little bit, and I'm not working at the moment. (John)

Subtheme 3.3—improved sleep and appetite

Selected quotations

The stimulator is extremely good at helping to interfere with intense pain and take it down to a level where I can actually sleep. Most of the time, I can get four or five hours of solid sleep at night, and that's something that wasn't happening before. (Emma)

Subtheme 3.4—changes in work life and finances

Selected quotations

I can probably undertake my responsibilities [at work] a lot better with the stimulator than without it. (James)

They [Accident Compensation Corporation] only paid 80% of the minimum wage, and I had bills from a business, tax bills, and everything. So, the stress of the finances comes back in again. So, you couple stress with pain [(laughs)] doesn't it go badly. (Ethan)

Theme 4—social connection

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In this theme participants described improvement in family dynamics, personal relationships, and social life after receiving the stimulators. This was further influenced by the support they received from their partners, family members, friends, and employers who have supported them to rebuild their lives. This theme had two subthemes.

Subtheme 4.1—rebuilding relationships and social life

Selected quotations

Since the stimulator was put in, it just yeah changed everything because, I have been able to get out, and you know, just things as simple as sitting and having coffee with someone in a café is all now very doable without freaking out whether my pain was going to get out of control [...] because the pain wasn't there anymore and I very easily was able to control the pain if I feel it was raising just by increasing my stimulator. (Eleanor)

My pleasure life is non-existent. My choice. I just have a fear of people. That has nothing to do with the stimulator [...] I have PTSD. (Nora)

Theme 5—health-care system interaction

In this theme participants explained their experiences with the pain service and ACC with respect to their stimulators. These include their experiences around the process of stimulator implantation and maintenance procedures and the pain management programme. Also, it includes their experience with the pain service in terms of perspectives on information received before the stimulator implantation, expectations, follow-up, and ongoing care. This theme had three subthemes.

Subtheme 5.1—jumping through hoops - process of stimulator insertion and maintenance

Selected quotations

I have been told that surgery is delayed because of COVID now, so to be honest, [...] Yes, I do get frustrated. But then I can't do nothing about it. It's out of my hands. Like it's a battle waiting on ACC for approval, but then COVID has been a big factor. (Nyra)

The biggest downfall for anybody in pain is ACC. They cause so much stress [...] you cut that out, and you will cut out so much stress for these people [...] it's been ten years of me talking about it, I'm still almost in tears. Can you imagine what it was, like ten years ago for me? (Ethan)

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Subtheme 5.2—ongoing care and support at the pain service

Selected quotations

I have flown up a couple of times to Auckland [...] maybe three or four years since I last saw them [...]; we had phone consultation but not on a yearly basis. Once I got it in, I was on my own [...] It's nice to have people to talk or find out how you are going. I should not have to be doing walking all the time with the phone books. And that's probably now where I am anyway. (William)

I went down to Auckland and met [stimulator nurse] and [pain physician] I've walked away from there more positive than I had with anybody else. (Nora)

Subtheme 5.3—experience with the pain management programme

Selected quotations

I thought it was dust. I thought it was a waste of time, their time and mine [...] I have had the problem and having things done for, probably thirty-plus years at that time. I knew quite a lot of it. (Flora)