

**Striving to live well with chronic neuropathic pain managed by a neuromodulation technology: A phenomenological exploration**

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### Introduction

Pain is a widely shared experience. It is, in fact, the main reason why people consult their general practitioner or go to the emergency department (Inserm, 2008; Jackson, 2009; SFETD, 2017). While acute pain is a healthy and useful warning signal that indicates that something is wrong with one's body, when it is chronic, that is, when it lasts for more than three months, pain has no warning function anymore. Rather, pain itself becomes the problem that demands attention. It is estimated that between 20 and 30% of the European adult population suffers from chronic pain (Bouhassira et al, 2008; Breivik et al, 2006; van Hecke et al., 2013; Queneau et al, 2018). Among them, one out of three people, i.e., 7 to 10% of the adult European population, suffers from neuropathic pain (Bouhassira et al, 2008; Colloca et al, 2017; Chenaf et al, 2018), which is pain caused by a lesion or disease of the somatosensory nervous system<sup>1</sup> (IASP, 1994; Colloca et al, 2017). Although it is a rather common neurological disorder, neuropathic pain is very difficult to treat with medication<sup>2</sup> (De Vos 2013). Indeed, besides analgesics having little effect on it (with the exception of certain opioids), less than 50% of the individuals who receive the most frequent treatments, which consist of repositioned drugs (mainly anticonvulsants and antidepressants), achieve a

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<sup>1</sup> Somatosensory 'refers to information about the body per se, including visceral organs, rather than information about the external world (e.g., vision, hearing, or olfaction)' (IASP, 1994). As for the somatosensory system, it 'allows for the perception of touch, pressure, pain, temperature, position, movement and vibration' (Colloca et al, 2017, p. 2).

<sup>2</sup> The difficulties related to pain management and treatment are not restricted to neuropathic pain. As observed by Harald Breivik and his colleagues in their survey of chronic pain in Europe, 'one-third of the chronic pain sufferers were currently not being treated' (Breivik et al, 2006, p. 287). Among those who received treatment, 40% 'had inadequate management of their pain,' be it neuropathic, musculoskeletal or other, with 'only 2% [...] treated by a pain management specialist' (Ibid.). Even more alarming, the French society for the evaluation and the treatment of pain estimates that 'more than 70% of chronic pain patients do not receive appropriate treatment for their pain, and less than 3% of them receive care in a specialised centre' (SFETD, 2017, p. 9, my translation).

significant reduction of their pain (Chenaf et al, 2018, Inserm, 2008). In this context, alternative forms of therapy are being researched and used to treat or manage neuropathic pain.

Spinal cord stimulation is one of them. Based on the gate control theory elaborated in 1965 by Ronald Melzack and Patrick Wall that postulates that pain can be (electrically) inhibited by non-painful stimuli (Rossi, 2003), spinal cord stimulation (SCS) is a neuromodulation technology that acts directly upon neural tissue. More specifically, composed of one or two electrodes implanted on the dorsal columns of the spinal cord and of a pulse generator (a neurostimulator) implanted under the skin of the lower abdomen or upper buttock, the technology administers electrical pulses that interrupt pain signals, thus reducing neuropathic pain perception (De Vos, 2013). In addition to these internal components, an external remote control enables the person living with SCS to regulate the intensity of the stimulation. While obstructing pain signals, the technology does not however cure the cause of pain: rather, it replaces pain perception by paraesthesia, a ‘more pleasant sensation’ generally described as tingling or pricking (pins and needles).

In this article, I aim to explore life with chronic pain as it is managed by spinal cord stimulation. More particularly, how is bodily intentionality affected and effected in such experience? If anthropologists, sociologists and philosophers have inquired into the experience of/with chronic pain as well as into the strategies and coping mechanisms that people living with chronic pain implement daily (Scarry, 1985; Baszanger, 1989; Jackson, 1994 & 2009; Richardson, et al. 2006; Zeiler, 2010; Le Breton, 2012 & 2016), fewer have attended to its ‘technological care,’ to use Mathilde Lancelot (2019)’s apt expression, especially when such care is performed by implanted technologies (Kaufman et al, 2011; Dalibert, 2014 & 2016; Haddow, 2018; Oudshoorn, 2015 & 2020). Both medical studies and the philosophy, anthropology and sociology of health underline how chronic pain severely impairs people’s lives, having a negative influence on almost all aspects of life: on one’s sleep and physical abilities, on one’s mental health and wellbeing, on one’s social and professional

life<sup>3</sup> – on one’s world (Jackson 1994 & 2009; Breivik et al, 2006; Bouhassira et al, 2008; van Hecke et al., 2013; Le Breton, 2012). Pain has famously been described by Elaine Scarry as a ‘destruction’ or ‘unmaking of the world’ (Scarry, 1985). That is, from a phenomenological perspective, being is always being in, as well as to, the world (Merleau-Ponty, 1945). In Drew Leder’s words, ‘the lived body [...] is an openness upon the world. It is a centre from which the rays of intentionality radiate outward’ (1990, p. 74). In everyday life, in the normal course of one’s life, one is rarely concerned with his or her pain-free body; rather, s/he is projected outside from it, towards the world. Bodily intentionality is thus characterised by agency — ‘I can.’ Conversely, in pain, one is no longer directed towards the world but called, instead, towards his or her painful body (-part). The latter becomes the object of one’s concern and attention, thereby impacting one’s perception and action (Zeiler, 2010, p. 336). Being a body-in-pain enacts a world in which one’s field of possibilities is hindered — ‘I can’ gives way to ‘I cannot’ — and such a world can be experienced as shattered and shattering. In fact, it has to be emphasised that ‘I can’ and ‘I cannot,’ or the degree of possibilities for the embodied subjects, can only be understood in relation to the latter’s *environnement* or lifeworld. In this respect, Iris Marion Young (1980) and Sara Ahmed (2007) have powerfully, and respectively, shown that women who live in a sexist society and are taught to protect and restrict their body might experience an ‘I cannot’ while a black person who lives in a white world might experience being ‘stopped’ (Ahmed, 2007, p. 61) or an ‘I cannot.’ Therefore, one’s degree of bodily intentionality does not reside solely in one’s body; rather, it is also affected and effected by one’s lifeworld. In (chronic) pain too, one’s ‘I cannot’ is not an exclusive property of one’s body<sup>4</sup>.

When attending to chronic pain and chronic illness, ‘disruption’ is a recurring term or theme in academic work. Accompanied by an ‘intentional disruption’ (Leder, 1990, p. 73) or causing a ‘disrupted intentionality’ (Zeiler, 2010, pp. 337-339), chronic pain also constitutes a ‘biographical disruption’ (Richardson et al. 2006). Initially formulated in the context of chronic illness by Michael Bury, biographical disruption conveys that, in one’s life, chronic illness ‘mark[s] a biographical shift from a perceived normal trajectory through relatively

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<sup>3</sup> Epidemiological and medical research also frequently emphasise the socio-economic burden of chronic pain. Due to its impact on healthcare, absence from work and job loss, it is evaluated at more than €200 billion per year in Europe (van Hecke et al, 2013; see also Eschalier et al., 2013).

<sup>4</sup> I thank one of the anonymous reviewers for inviting me to make that point stronger.

predictable chronological steps, to one fundamentally abnormal and inwardly damaging' (1982, p. 171). It throws into confusion one's 'taken-for-granted assumptions and behaviours [and] the person's biography and self-concept' (Ibid., p. 169). For S. Kay Toombs (1987), this disruption caused by chronic illness presents itself as five losses: the loss of wholeness, of certainty, of control, of freedom and of the familiar world. Similarly, for Havi Carel, it materialises as 'bodily doubt,' where one's '[b]asic tacit beliefs about bodily abilities that were previously taken for granted are suddenly, and sometimes acutely, made explicit and thrown into question [...] [It] gives rise to an experience of unreality, estrangement, and detachment. From a feeling of inhabiting a familiar world, the ill person is thrown into uncertainty and anxiety' (Carel, 2016, p. 92). It is, in fact, one's sense of being-in-the-world that is affected — disrupted (Ibid.: 94).

Chronic illness, chronic pain, and accounts thereof bear substantial similarities. As it has been underlined, chronic illness frequently entails pain and suffering, while, conversely, chronic pain might stem from chronic illness, such as neuropathy (Bury, 1982; Charmaz 1999; Carel, 2016). Additionally, as Isabelle Baszanger (1989) draws attention to, their chronic nature means that they share two characteristics: duration and clinical management. Chronic pain, like chronic illness, is not short-lived, but rather 'lasts for months, years, or often a life-time [...] Instead of a cure, the chronic condition has to be managed day after day' (Ibid., p. 425). Living with chronic pain therefore requires adjustment and adaptation, but also the acquisition of new skills to live a life as 'normal,' as 'ordinary,' or as little hampered by the (bodily, social, material, and so forth) constraints that the condition entails, as possible (Carel, 2016; Winance, 2019).

Joseph W. Schneider and Peter Conrad<sup>5</sup> write that '[a] *bona fide* illness experience perspective must consider people's everyday lives lived *with* and *in spite of* illness » (1983, p. 9, quoted in Baszanger, 1989, p. 428, emphasis in original). Thus, to explore life with chronic pain as it is managed by spinal cord stimulation, this article will rely on fieldwork I realised in 2012 at a Dutch regional hospital. There, I interviewed 15 people living with the neuromodulation technology as well as the nurse and the neurosurgeon who take care of people (to be)

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<sup>5</sup> Schneider J. and Conrad P. (1983). *Having Epilepsy. The Experience and Control of Illness*. Philadelphia: Temple University Press

implanted with SCS. A former product developer of the St. Jude Medical SCS system that is implanted in the respondents' body was interviewed too. During fieldwork, I also had continuous contact and informal conversations with Judith Hart, a medical physicist, who was my gatekeeper and main informant. Finally, I observed an implantation procedure as well as a control visit. All the research participants verbally gave their consent to take part in this research, which received ethical clearance from the institutional review board of the hospital (as part of Hart's research). The interviews, that took place in April and May 2012, were semi-structured, realised in English, recorded upon permission and transcribed. To ensure the participants' anonymity, I use pseudonyms throughout the article.

The latter is structured in three parts. After having presented what it means to be living with, or in, chronic neuropathic pain in the first part, in the second one, I will attend to how chronic neuropathic pain, as it is managed by analgesic medication and spinal cord stimulation, is experienced. When doing so, particular attention will be paid to the way one's being in the world is affected in these different configurations. While living with chronic neuropathic pain and chronic neuropathic pain managed by medicine are characterised by 'I cannot,' SCS is experienced as a 'reworlding' marked by 'I can.' In the third and last part, I will show, however, that demanding work is necessary to achieve and maintain bodily intentionality and to live well with SCS.

### **1. Living in chronic neuropathic pain: Inhabiting a world of shattered possibilities**

Living with chronic neuropathic pain means experiencing some body parts as distinctively painful. For people whose symptoms are treated with spinal cord stimulation, pain is located in the lower-back, legs and feet. Diagnosed with tools such as the 'Douleur Neuropathique 4 (DN4)' questionnaire, neuropathic pain is generally described as burning, painfully cold or electric-like shock sensations, which can be associated with tingling, pins and needles, numbness and itching (Bouhassira et al, 2004; Colloca et al, 2017). Other sensations, such as pain brought by brushing as well as reduced sense (hypoesthesia) upon touch or pinprick, can be experienced by people living with neuropathic pain (Ibid.). In contrast to its dry clinical characterisation, people experiencing it use much more vivid, visceral even, images to describe it.

The pain that I have in my feet is constant. I'm always in the South of France along the river, on pebbles with my bare feet. So you should imagine walking on that. But, well, I also have a lot of flashy shooting pain. In my feet and toes. And often I have cold feet (Mr Koopman, 53 years old).

A burning pain on the feet, like you're stepping on a rope constantly, constantly. I didn't sleep at night: 4 times a night, I had to go out of bed because of so much pain (Mr Mulder, 57 years old).

It's like walking on glass, on broken glass. It's ouch. So walking is full of pain. I can't walk on sand, on the beach: it doesn't work. When I go under the shower or go swim, the water hurts. [...] The pain is inside, all the time. [...] At home, I am always walking on slippers, shoes are not possible anymore. When I am in bed, the blanket is not on my feet, otherwise I can't sleep. I can't handle anything at my feet, everything hurts: socks, shoes, everything (Mr Meijer, 56 years old).

As expressed by these three men living with chronic neuropathic pain, the latter is ceaseless. There is no respite from it, even at night. All evoke the pain they feel in their feet through the action of walking barefoot on particularly unpleasant materials — pebbles, a rope, broken glass — and doing so constantly. Pain, be it burning or shooting, is also exacerbated through contact with matter and objects that are part of daily life — socks, shoes, a blanket, sand or water. Unavoidable, it is also conjured up as the impossibility to do certain things, nothing less than sleeping. Acutely felt in one's body (the feet in Mr Koopman, Mulder and Meijer's case), chronic neuropathic pain has significant repercussions on one's being in the world.

Recalling how life was before he was implanted with SCS, Mr van Houten, 61 years old, explains that

[w]hen I don't have this [SCS], I am in a lot of pain. I'm always lying in bed or I'm sitting in a wheelchair, all day. And I sit down, and I look outside, I don't do anything — maybe, yes, get some coffee, at home.

As it overwhelms Mr van Houten, chronic neuropathic pain also engulfs his world: it 'unmakes' it (Scarry, 1985) all the while it disrupts his bodily intentionality (Leder, 1990; Zeiler, 2010). That is, as previously mentioned, in good health and without pain, the body is experienced as an absent presence (Leder, 1990, p. 36-68). 'Most of the time, most of us, walk to the door without a thought. And as we walk, we think thoughts *without* a thought of the body that transparently makes not only out walking but also out thoughts possible,' writes Vivian Sobchack (2004, p. 190, emphasis in original). In other words, the lifeworld of healthy, pain-free people is a world characterised by agency — I can. Mr van Houten's experience is fundamentally different. Brought to the forefront of his consciousness and attention, that is, having 'dys-appeared' or having become an 'absent absence,' his painful body is experienced as a strange, disturbing presence: as alien (Leder, 1990). As Kristin Zeiler phrases it, 'I no longer experience that I am my body, but that I have a body' (2010, p. 337). Objectified, and even alienated, the body becomes a hermeneutical problem (Sobchack, op. cit). In this respect, Havi Carel's account of bodily doubt is illuminating to understand the extent to which chronic pain can throw existing trust in one's body and bodily abilities in disarray: as one lives and becomes aware of the failings of his or her body-in-chronic-pain, s/he starts experiencing 'anxiety on a physical level, hesitation with respect to movement and action, and a deep disturbance of existential feeling' (Carel, 2016, p. 96). Such realisation, and loss of bodily intentionality and agency in general, are experienced as highly distressing: it is with sorrow that Mrs Bloemen, 45 years old, remembers that 13 years ago,

[w]hen the children were 3 and 7 years old, we... with one of his aunts [she points to her husband] who's twenty years older than me, we went to the zoo in Rotterdam, and she took my children [her voice trembles as she fights back tears] to the playground because I couldn't do it.



Because pain is tying her to her ‘here-and-now’ body (Leder, 1990, p. 76), Mrs Bloemen is unable to perform movements and actions as well as to undertake activities that a much older woman can realise. In chronic pain, one’s lifeworld or habitual world becomes characterised by ‘I cannot.’

In it, space and time are constricted (Leder, 1990, p. 73-76). Mr van Houten’s horizon, for instance, is reduced to his home, while Mrs Bloemen’s stops at the playground’s borders. In chronic pain, with the painful body having become the thematic object of her attention, ‘[s]pace loses its normal directionality as the world ceases to be the locus of purposeful action’ (Ibid., p. 75). More practically, one’s spatial world becomes smaller. Even though it is not written in the context of chronic pain, Havi Carel’s account of the way lymphangiomyomatosis, a rare and progressive lung disease, affects her experience and apprehension of space, is highly valuable to understand how pain impacts one’s relation to space. She recounts that

[i]n illness, things grow heavier and further away. A distance I would once call ‘near’ or ‘a day’s walk in the countryside’ is now ‘far’ or ‘impossible.’ Small tasks like carrying groceries home or lifting a child require preparation, pauses, rest, and cause fatigue. Everything is hard. Everything is far. Everything is strenuous. My world, and the world of those who are close to me, has shrunk. For me, the trap is permanent. There is no release from it (Carel, 2016, p. 71).

Where once accessible places have become out of reach, doing anything now demands planning. This changed state of affairs not only involves herself but also her loved ones, those who share her life (e.g. her partner, children, friends). As pain (or illness) is chronic, there is however no break nor turning back, which also affects one’s relation to time. A certainty is that pain is not only present — and constantly so — today, but that it also lasts and requires that one attends to his or her bodily sensations throughout the day, before and when engaging in particular activities (Zeiler, 2010, p. 336). In echo of Carel, Mrs Bloemen recounts that ‘before [living with SCS], I really have to think about what I am going to do today. Now I just do it.’ As for the future, as one no longer trusts his or her body, it is foreseen, and feared, that

it might hold a worsening of the pain (Le Breton, 2016, p. 132). Finally, if such dread pervades future plans as well as present considerations, pain also colours one's past, insofar as 'while knowing intellectually that we were once not in pain we have lost the bodily memory of how this felt,' explains Leder (1990, p. 76). Bodily doubt envelops one's present and future as well as one's past.

With chronic pain offering no respite days and nights but tainting one's existence and undoing one's world with disrupted bodily intentionality, bodily doubt and a constricted space-time, quest for a treatment or a solution to restrain or ease its effects becomes an important part of one's life (Baszanger, 1989, p. 428). Chronic neuropathic pain is progressive, as Mrs Jansen, 63 years old, reminds us:

You have the feeling that you are reasonably healthy, weirdly enough, because everything happens so gradually and you get so used to the pain, so you go one step further and then you think, well this [increase of pain] I can also still take.

When pain becomes eventually unbearable, alleviating it becomes one's, or rather one's and one's partner's focus.

Mr Meijer: I was only searching for pain reduction.

Mrs Meijer: He was in so much pain, everyday, every hour. So much pain... It was the solution to be implanted.

The men and women I interviewed all mentioned not only the different medical professionals, hospitals and specialised pain centres they have visited and consulted, often in different parts of the country, but also, for some, the clinical trials in which they took part. Implantation with spinal cord stimulation occurs after a long journey with pain and various pain medications. The technology is indeed used as last resort in cases of refractory chronic neuropathic pain (Colloca et al, 2017).

Living in chronic neuropathic pain, that is, constantly experiencing burning, shooting, painfully cold or electric-like shock sensations is disruptive. It has significant repercussions

on one's being in the world, as one's bodily intentionality is hindered and one's projection in the world shattered. Seized by bodily doubt, one's existence endures a constriction of space and time and a reduced agency. One's lifeworld is marked by 'I cannot.' In this context, people look for remedies against their pain, and it is only after medication proves ineffective that spinal cord stimulation is offered as a last resort treatment. It is against this backdrop — i.e., the experience of chronic pain and the experience of chronic pain managed by drugs — that what it means to live with chronic pain managed with spinal cord stimulation has to be understood.

## **2. Managing chronic pain with medication and spinal cord stimulation: From a world of 'I cannot' to a world of 'I can'**

Eliminating or at least reducing pain so that it becomes endurable is a lasting endeavour for people living in chronic pain. As aforementioned, they do not experience that they *are* but that they *have* a body (Zeiler, 2010). In pain, there is a fracture between the body as object, i.e. *Körper* (Husserl, 1952), and the body as subject, i.e. *Leib* (Ibid.) or *corps propre* (Merleau-Ponty, 1945). Chronic pain not only amounts to an 'I cannot,' but also corresponds to the impossibility to be the body one has (see also Slatman, 2016; Slatman & Widdershoven, 2010). Such inability is however not limited to the experience of chronic pain. Rather, it extends to life with chronic pain as it is managed by medication.

When asked if he was taking some forms of medication before being implanted with spinal cord stimulation, Mr van Houten indicates that

Yes, very much. Morphine, yes.

LD: And how did you feel about it?

Mr van Houten: Oh... Like [he laughs] I don't know where I was: I couldn't drive a car, nothing. [Silence] [...] The medications you take, you're *gevoel* [Dutch: feeling] [...] Your mind is not clear with the medication.

If medication reduces pain perception, it does not restore one's bodily intentionality and projection towards the world. The opacity with which the world is experienced when chronic pain is managed with medicine is not the exclusive preserve of opioids. Indeed, Mr Koopman recalls that

I used some medicines, [...] a type of antidepressant [that], as a side effect, [...] can fight the pain. [...] But my mind was flat, so to speak. And I did not noticed that so well, but my wife and the people around me who noticed said it, and that is an unpleasant experience to hear afterwards... So then I said resolutely: I quit. And that is what we did.

The hazy, disabling effects of pain medication are perceived by oneself as well as others. It is Mr Koopman's wife and loved ones who became first aware of the behavioural changes that were occurring with him when he was taking antidepressants, and who told him about it. As he is not the only one being affected by medicine, it is in fact not just 'I' but 'we' who quit taking it. The way analgesic drugs impact others and upset loved ones all the while it does not restore intentionality ('I can') is quite salient in Mr and Mrs Meijer's exchange:

Mr Meijer: My former neurologist told me 'I will give you a morphine pump.' I didn't like it. Because today it's 10 CC, tomorrow 20, 40, 50, you know. Lying on the couch all day, I don't like that. I have been looking for such a long time [to find a solution for the pain]. [...] Before the technology, I was taking 21 pills to reduce the pain and was getting a little bit mad because of the medicine. [...] The medicine has such an influence on your brain that... I can't work. I could be there but no thinking. I have a financial job so I have to make a lot of calculations. But my colleagues said 'don't do that.' You don't know if you're doing it right. That was a hard period.

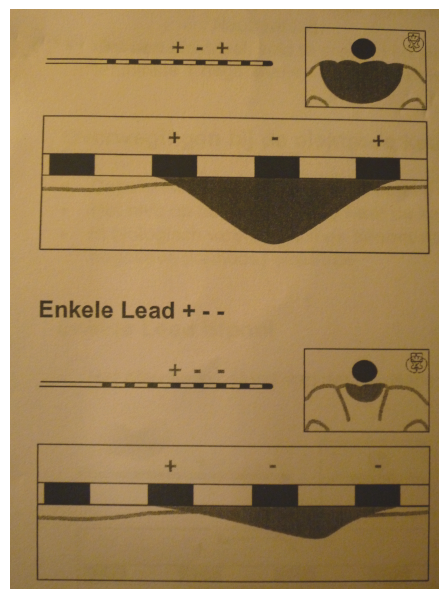
Mrs Meijer: We didn't go out then, because he was tired. He was always lying on the couch or in his bed because of the pills, and because of the pain of course. It was not a normal life then.

Chronic neuropathic pain and its management with pain medication unmakes Mr Meijer and his wife's world — their world. It prevents them from living a 'normal life,' one that entails leaving the house and having social connections and activities, hence living like 'everybody else' (Winance, 2019). It is not just the intentionality of the pain sufferer that is disrupted but that of his or her loved ones too. 'I cannot' becomes 'we cannot.'

In all three accounts, pain medication is associated with unpleasant experiences and memories. Not only is their body-in-pain experienced as other, but with medication they also feel that they are not themselves. This resonates with Jean-Luc Nancy's account of his experience with heart transplantation and immunosuppressants. 'An intruder is in me, and I am becoming a stranger to myself,' writes Nancy (2008, p. 167), before explaining that '[y]ou no longer recognize yourself: but "recognize" no longer means anything. Very soon, you are just a wavering, a strangeness suspended between poorly identified states, between pains, between impotences, between failings. Relating to the self has become a problem, a difficulty or an opacity: it happens through evil or fear, no longer anything immediate – and the mediations are tiring. [...] I end/s up being nothing more than a fine wire stretched from pain to pain and strangeness to strangeness' (Ibid., p. 169). The rift that takes place within the body-in-pain, with the impossibility to be the body one has, seems to be exacerbated with pain medication, with one's sense of self being jeopardised or dis-articulated (Charmaz, 1999, p. 364). Such an experience strongly colours the way spinal cord stimulation is perceived by people living with chronic neuropathic pain, especially as the technology is implanted in case of refractory chronic pain. People living with spinal cord stimulation have, therefore, experienced the disabling effects of pain medication without the promised pain relief.

If chronic pain and analgesic medication can be apprehended as biographically disruptive, being implanted with spinal cord stimulation appears as a rebirth or a reconstruction. Reconstruction happens in at least two respects. First, through the implantation of the SCS system, one's subjective experience of chronic pain is objectivised and legitimised. In this respect, Baszanger points out that in each medical encounter, 'the evaluation and legitimation of pain – the question of credibility – arises because pain is a sensation that can be directly perceived only by the person who feels it' (1989, p. 427). That is, others, including

physicians, have to rely on the person's subjective experience and the way s/he expresses it to appreciate the presence and intensity of pain. As the neurosurgeon implanting the neuromodulation device expressed it during one of our discussions, 'there is no person in the world who can objectively measure if somebody has pain: we have to believe that somebody has pain.' In this context, the existence of pain is rendered questionable (see also Jackson, 1994, p. 213). Screening tools, such as the DN4, and rating scales contribute to objectivise pain by turning it into an operational medical object (Baszanger, op.cit.). Yet, to the extent that there might not be an identifiable lesion, doubt can still be cast on its reality. As the electrode array is positioned on the spine, as the electrical field of stimulation is mapped, and as the burning and shooting pain felt in one's lower back, legs and/or feet is replaced by a tingling sensation, pain is objectivised.



**Figure 1:** Two ways of mapping the electrical field on the dorsal column of the spinal cord and interrupting pain signals with the electrode (photo taken from textbook belonging to Anna Maes, the specialised nurse at the regional hospital where fieldwork was realised)

Paradoxically, neuropathic pain materialises through its disappearance, or rather, replacement by paraesthesia. The (technologically-induced) validation of chronic neuropathic pain can be experienced as a recognition of the credibility of the sufferer's claims, hence as a reparation.

Second, SCS is experienced as a 'reworlding' (Besmer, 2012).

It [SCS] changed my life. What I can do and how I feel [...] Now I can go outside, I can go shopping, I can take care of my husband. And when I don't have this, [sigh] yeah, then I can do nothing. [...] I can say now I ehm, I belong somewhere again. I'm now part of the life (Mr van Houten).

I have been very active after [the implantation]! [Both he and his wife laugh] I went swimming again, I went working again, at 100%. I became a board member of [a patient association]. It changed my life 100% (Mr Meijer).

SCS enables both men to engage in activities and make (new) projects. As it allows them to project themselves in the present and the future, it enables them to be part of the world — of life — *again*. As such, the neuromodulation technology 'rebuilds' their bodily intentionality and projection towards the world. Their lifeworld is characterised by 'I can.' After years with disabling chronic pain and pain medication, this regained agency is lived as a relief and an achievement. In this respect, when asked whether SCS improved her daily life, Mrs Bloemen answers that

Yes. Yes. A lot. I can walk better, longer. Ehm... Vier [four], vijf [five]... Four, five years ago, we did go back to France: we've been there 25 years ago, with my parents, and the first time there we climbed the mountain that we could see from the camping. Five years ago, we did it again! We didn't make it quite to the top [her voice fills up with emotion] but it was ehm, yeah overwinning [Dutch].

Mr Bloemen: A victory.

Mrs Bloemen: A victory. Yeah, that I could do that. And ehm... yeah... it felt all right.

With her body-in-pain significantly less, if not no longer, at the forefront of her attention and awareness, that is, no longer an absent absence (Leder, 1990), Mrs Bloemen is able to undertake previously unimaginable actions, such as climbing a mountain. It is, for her, a victory. It is, in fact, a hard-won one. Bodily intentionality and agency have been regained

after a prolonged and straining journey as well as through much efforts. Indeed, as I shall describe shortly, ‘I can’ is not a straightforward result of implantation. Rather, it demands work.

Life with chronic pain managed with (strong) analgesic medication is associated with ‘I cannot.’ As in pain, one cannot be the body one has, and one’s sense of self is severely disrupted. Implantation with spinal cord stimulation gives way to a reworlding. That is, one is able to project oneself in the world. The latter is again marked by ‘I can.’ As we will see, such outcome is however neither effortless nor absolute.

### **3. Living well with spinal cord stimulation: A hard-won achievement**

Spinal cord stimulation replaces pain perception with a ‘more pleasant’ sensation, namely tingling or pins and needles<sup>6</sup>. Although the technology is implanted, its disappearance under the skin does not mean that it disappears from one’s awareness. For the SCS system to become ‘transparent’ (Ihde, 1979), that is for the technology and its effects not to be brought to the forefront of one’s attention and experienced as bothersome or disabling, living with SCS, and even more so living well with such technology, demands long-term work and a particular attentiveness to one’s sociomaterial environment. If SCS enacts a lifeworld of ‘I can,’ the latter results from training and sustaining activities and efforts, all the while it remains quite precarious.

SCS creates new sensations which can be quite disorientating for its users. After implantation, the sensations elicited by SCS are unfamiliar and awkward, and one is highly aware of them. As developed elsewhere (Dalibert, 2014 & 2016), making these sensations one’s own is the result of a reflexive exploration process, through which one (playfully) experiments with the technology. It is by varying the intensity of the stimulation, performing bodily movements and assessing the resulting sensations that progressively SCS becomes embodied, that is, rendered (quasi-) transparent at the sensory-kinetic level (Ihde, 1979; Merleau-Ponty, 1945). As such, embodiment demands a renewed and sustained attentiveness to one’s body. Over

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<sup>6</sup> Stimulation with frequencies below 30Hz evokes distinct tingling sensations. New stimulation paradigms, however, with intermittent or continuous stimulation frequencies of 500Hz and above are believed not to cause any paraesthesia at all and to achieve good results as well (De Ridder et al. 2010; van Buyten et al. 2012).



time however, such process of ‘adjustment’ (Winance, 2015) no longer requires reflexion: rather, people living with SCS have acquired know-how and become habituated to the technology. Yet, to live *well* with SCS, the latter must not only be embodied (in one’s body schema) but also incorporated (in one’s body image): besides no longer drawing attention to itself, it must be seen and experienced as a part of one’s body. To achieve that, one must be able to identify with one’s technologically transformed body, that is, ‘to appreciate and accept both the strange body part’s visual features [...] and its haptic, affective aspects’ (Slatman & Widdershoven, 2010. p. 75). Doing so, or in other words, being the body one has, is hardly accomplished alone. Loved ones as well as social norms play a key role here, insofar as they can hinder or, on the contrary, facilitate identification and incorporation (see Dalibert, 2014 & 2016).

Embodiment and incorporation, two processes that enable people to regain bodily intentionality and agency, and live well with spinal cord stimulation, are not realised once and for all in the weeks and months following implantation. Bodies implanted with technology must be ‘sustained’ in the long term (Oudshoorn, 2015 & 2020). While sustaining bodies in chronic neuropathic pain is generally realised by humans, i.e. family, friends, (health-) care professionals, in the case of SCS, it also entails a distinctive technological care. For SCS to optimally replace pain perception with paraesthesia, the pulse generator has to be properly programmed. After implantation, people have one or two programmes set by the nurse or the physician in charge. With time, however, they require new adjustments of the device. Throughout time and depending on one’s activities, postures and tiredness, pain’s intensity and one’s sensitivity to it and to paraesthesia might change, as well as the way one’s feet, legs and lower back are affected during the day and at night. Therefore, regular control visits are organised at the hospital to check whether the technology is working correctly and whether people experience appropriate stimulation for their pain. Yet, fine-tuning the device so that the electrode’s 8 contact points create the right electrical field to interrupt pain signals and induce paraesthesia in the desired body parts is a complex endeavour. Fine-tuning requires the collaborative and coordinated actions of the person living with SCS and the programming nurse or physician.

I was able to assist to such a ‘dance of agency’ (Pickering, 1995) between SCS and its human users (the person implanted and the person programming the device) during the control visit that I observed. There, Judith Hart, who connected a programmer (a small PDA) to the patient’s pulse generator in order to fine-tune it, explained:

- Judith Hart: On one lead, there are 8 points. [...] They can all be positive, or negative, or neutral. So I have lots of possibilities and we have tried almost everything with Mr. Koopman.

- Mr Koopman: Yes and we have, ehm, since I experience pain especially under my feet, you must also try to stop that tingling right there, but we haven’t achieved that yet.

- LD: It is hard to reach?

- Judith: Yes and maybe not even possible...

[...]

- Judith [starts recording values for each contact point on the lead] The first is 500. [To Mr Koopman] You can tell when something...

- Mr Koopman: Yes, is there something coming now?

- Judith: Yes.

- Mr Koopman: Yes... I feel something.

- Judith: Where?

- Mr Koopman: Ehm... in... at the top of my lower back and in my buttocks.

- Judith: So, and at the end?

- Mr Koopman: Yes... because it reaches... it is going to the left... The concentration is particularly at my calves.

- Judith: Ok, that’s good.

[...]

- Judith: I can give you this program for now... Do you feel it now?

- Mr Koopman: Yes.

- Judith: Yes? Gently? And now? Now if I increase it? Then it becomes a pleasant tingling?

- Mr Koopman: Yes... Yes, I think I like this.

- Judith: Then I am at least increasing this one, so that the right side is added a bit.

- Mr Koopman: Did you decrease it now?

- Judith: I adjusted it now like you said, I think that makes a good baseline.

- Mr Koopman: Put it lightly higher.
  - Judith: Higher?
  - Mr Koopman: Yes.
  - Judith: Umm... like this... It's back up again now.
  - Mr Koopman: Yes, it is ok now.
  - Judith: Like this? Then I'll save it like it is now.
  - Mr Koopman: Yes... It's good like this. That is the neutral program, right?
  - Judith: Yes.
  - LD: So that is the baseline, in a way?
  - Mr Koopman: Yes, that's like the ideal position.
- [PDA makes a beeping sound]
- Judith: And now you can go in any direction [increase or decrease].

The stimulation creates new sensations. Similar to what is demanded of them during implantation, during control visits, people living with SCS have to assess the new sensations that are created by the device. They have to be attentive to their bodily feel as the physician is acting on the stimulation parameters, so as to report the paraesthesia's location, type and intensity to her. While their sensory experiences guide the physician's actions, she reciprocally directs them with her questions, e.g., 'do you feel it now?', 'like this?' Challenging for people living with SCS, fine-tuning is also difficult for the physician, whose understanding of what constitutes the right settings might be even so slightly at odds with what her patients experience. Although essential, the adjustment process is also highly precarious — and not only because stimulation might not be able to induce paraesthesia in all painful areas. Anna Maes explains that after fine-tuning and stimulating for 30 to 45 minutes,

that's enough. People tend to not feel at all or feel everything... tingly. And that's not because they feel the tingly feeling everywhere, but they don't know where to feel what, where the tingly feeling is at. So you can't have it located. That's the experience I have. Yeah, most of the patients say, I don't know, I don't know where that is: it seems to be here, but then again it seems to be there, [Anna points at different parts of her legs and feet] and that's difficult, yeah, to explain.

Fine-tuning, due to the intense self-awareness it requires, can be overwhelming for patients. Eventually, they cannot make sense of their sensations, which jeopardises the adjustment procedure. In her illuminating account of fine-tuning pacemakers and implantable cardioverter defibrillators, Nelly Oudshoorn (2015 & 2020) writes about the importance of these regular adjustments to create a ‘body-technology alliance.’ Such a process is not only essential for the technology to be experienced as transparent, hence embodied at the sensory-kinetic level, but it is also key in fostering ‘resilient cyborgs’ (Ibid.), that is people who can cope with the challenges entailed by being and having a technologically transformed body.

Such body-technology alliance is fragile. Fine-tuning enables the technology to remain transparent and to maintain bodily intentionality. However, despite optimal settings, embodiment, incorporation and bodily intentionality can be disrupted. Paradoxically, while living well with SCS necessitates that one becomes attentive to his or her technologically transformed body in order to create a body-technology alliance, it also demands a particular ‘disentanglement work’ (Oudshoorn, 2020: 118) from other devices and people that can be potentially disruptive, if not harmful. People living with the neuromodulation device have to be attentive to the actions of others, be they human or nonhuman, especially how they might interact and interfere with the proper functioning of the technology as well as with their bodily agency. Speaking about the remote control that enables her to modulate the stimulation, Mrs Bos, 61 years old, explains that

I always keep it in this [she points to a small leather case]. I always put it back in here as well because the grandchildren are walking around and if they see something with buttons... They are crazy with buttons [she laughs] So no, the remote goes behind bars [Dutch expression which means that it is properly tucked away]!

Disentanglement work does not only mean being watchful of others’ interactions with the remote control but also anticipating the interferences between one’s technologically transformed body and other devices. If in high-income countries, we live in environments

filled with technological devices, the density and ‘the texture of [the] “technosphere” within which we undertake our daily affairs’ (Ihde, 1979, p. 7) is more intensely felt by people living with neuromodulation (as well as, in general, implanted and prosthetic) technologies (Dalibert, 2014). Whether it is when one’s entrance or exit from a shop triggers (metal) detection gates to beep — Action and Kruitvat have become infamous shops for people living with SCS in the Netherlands (interview with Judith Hart) — or when one has to go through airport security, one is reminded not only of the technological nature of his or her lifeworld, but also of his or her intimate entanglement in it. As I could hear it during a conversation that I witnessed between Anna Maes and Mr Smit (one of her patients), despite the fact that people living with SCS are advised to turn off their neuromodulation device before going through airport security and are provided with a card that they can show when passing through detection technologies, ‘passing,’ as able-bodied, is precisely what is precluded here. Screening devices become ‘outing’ and disabling technologies, whose beeping attracts others’ gaze on oneself. Interfering with SCS, they expose one’s bodily difference to public view. One is interpellated as different, disable, other than normal. In this context, the technology that, a minute ago, was experienced as being part of oneself is now experienced as an object of the world (Winance, 2010). Rosemarie Garland-Thomson (2011) has proposed the concept of misfit to account for such disabling practices. When bodies are sustained and enabled by their sociomaterial environment – largely construed by Garland-Thomson as comprising not only of buildings (and the accessibility thereof) as well as natural surroundings, but also of technological artefacts and other humans – one can speak of a fit. Conversely, when the interaction between a particular body and the sociomaterial environment is not harmonious, a misfit happens. In Garland-Thomson’s words, ‘[a] misfit occurs when world fails flesh in the environment one encounters – whether it is a flight of stairs, a boardroom full of misogynists, an illness or injury, a whites-only country club, subzero temperatures, or a natural disaster’ (Ibid., p. 600). Misfits call into question the possibility of being the body one has: one’s body is no longer an absent presence but rather dys-appears while one’s bodily intentionality is disrupted. ‘I can’ fades into ‘I cannot.’

Living well with spinal cord stimulation is an intricate matter. If it is experienced as a reparation and a rewording, this state of affairs is neither effortless nor absolute. Assuredly,

SCS enacts a lifeworld marked with 'I can,' but the latter is not without particular limitations or specific constraints. Embodying and incorporating the neuromodulation technology and the distinct sensations it creates demand work. They also require regular fine-tuning, which necessitates finding a delicate balance between different agencies. Fine-tuning can also be experienced as overwhelming for the person living with SCS who has to be extremely attentive to one's bodily feel. Finally, with SCS implanted in one's bodies, one is intimately entangled with his or her sociomaterial environment, which renders him or her subject to disabling misfits where 'I can' risks collapsing in 'I cannot.' Living well with chronic pain managed by SCS requires being able to create resilience in navigating these hurdles. It is a hard-won achievement.

## **Conclusion**

In this article, I have explored life with chronic neuropathic pain as it is managed by spinal cord stimulation. Relying on a phenomenological framework, I have addressed how chronic neuropathic pain unmakes one's world, as well as the world of one's loved ones. As it ties its sufferer to his or her here-and-now body and fills him or her with bodily doubt, one's projection towards the world and ability to act and make projects is hindered. One's lifeworld is marked by 'I cannot.' In this context, people look for remedies against their pain. Before being implanted with SCS, people living in and with chronic pain have taken strong analgesic medication, be it opioids, anticonvulsants, antidepressants or more. If their life with chronic pain managed by medicine was no longer saturated with pain, not only was their intentionality still disrupted but their sense of self was also severely compromised. In chronic pain as well as with chronic pain managed by medication, it is not just one's lifeworld that is affected but also the lifeworld that is shared with loved ones. 'I cannot,' which characterises these two experiences, extends into a 'we cannot.' An account of what it means to be living with spinal cord stimulation cannot dispense with these previous experiences. This is so for at least two reasons. First, they form the backdrop against which SCS is experienced as a reparation and a reworlding. The intensity with which one feels that s/he is now part of the world, or of life as Mr van Houten would have it, is intrinsically linked to the extensive disabling effects of chronic neuropathic pain and its management with medication. Second, although they are in the past, life with chronic neuropathic pain and life with chronic neuropathic pain managed

with analgesic drugs are however not distant memories but inform present and future considerations — and fears. This is an aspect that was not developed in the body of the article but that deserves to be touched upon in this conclusion.

Even when chronic pain is satisfactorily taken care of by SCS, chronic pain is still there in one's present and one's future. More precisely, the technology keeps pain perception at bay by replacing it with paraesthesia, but it is not a cure, while the future holds the possibility that SCS will eventually stop working. The frailty of one's body is matched with the frailty of the technology: electrodes are fragile and can break — one of the contact points on the electrode implanted in Mr Koopman's body actually broke a few days before his control visit — with little if no option to change or repair them. This colours the horizon of people living with chronic pain managed by SCS. Likewise, the 'repair' that people experience with SCS should not be conceived as the restoration of a former, pain-free existence. As Havi Carel explains in the context of chronic illness, 'it is impossible to return to the naïve (and, in retrospect, gullible) state of confidence once was in before. There is no turning back once genuine bodily doubt has been experienced; one's basic orientation in the world has changed and the possibility of catastrophic bodily failure is now part of one's experiential horizons' (2016, p. 95). This 'loss of innocence' is shared by people living with SCS.

In this article, I also showed that while people experiencing chronic neuropathic pain strive to live a 'normal life,' to live well with spinal cord stimulation demands particular and constant efforts. A well-programmed pulse generator, hence fine-tuning, is essential not only to be able to get habituated to the technology but also to be able to identify with one's technologically transformed body. Yet fine-tuning is a delicate and demanding exercise, for both the physician and the person living with SCS. Furthermore, people living with SCS have to navigate their intimate entanglement with other devices, which might result in misfits. The 'I can' enabled by SCS is therefore not absolute, but can give way to 'I cannot.' Importantly, what these disabling sociomaterial encounters reveal is that one's 'I can' and 'I cannot' should not be seen as resting with one's body, abilities and impairments. Rather, they are also dependent on one's embeddedness in power relations and socio-cultural norms (Dalibert, 2016). With chronic neuropathic pain and SCS, 'I can' and 'I cannot' are particularly linked to

‘compulsory able-bodiedness,’ (McRuer, 2006), which values and posits able-bodies as the norm and unavoidable injunction. The latter affects how one can live, and all the more so live well, with chronic neuropathic pain managed by spinal cord stimulation.

Finally, the people living with SCS that I interviewed were relatively young, being between 45 and 63 years old. Therefore, it is to be expected that they will age with the device. This raises questions about the vulnerabilities they will face as the technology will also grow older with them and might malfunction or be damaged. They invite researchers to investigate what it means to be ageing with chronic neuropathic pain and an ageing technology.

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