Living with Spinal Cord Stimulation: Doing Embodiment and Incorporation

Lucie Dalibert

(pre-print version; published in Science, Technology & Human Values:

doi:10.1177/0162243915617833)

Introduction

In the last decade, implanted technologies have received quite a lot of scholarly attention. Especially if they touch upon neurological functions, they have been seen as having profound implications for what it means to be human (McGee 2008; Verbeek 2008; 2011). Generally inscribed within broader discussions about the consequences and desirability of human enhancement, reflections on these technologies have taken the shape of rather speculative ethical judgments on 'hyped' technological devices, for example, brain-computer interfaces, deep brain stimulation, or thought-controlled prosthetic limbs (e.g. Sandberg and Bostrom 2006; Vedder and Klaming 2010). However, not only has Alfred Nordmann (2007) emphasised the deceit at play in speculative ethics, especially in its 'if ... then' argumentative structure, but this type of ethics also tends to ignore or erase the material grounds and realities in which (these implanted) technologies are embedded.

Remarkably, while the fields of science and technology studies (STS) and philosophy of technology have attended to the ways in which tools and technologies shape and (re-) configure our actions, intentions and subjectivities – our lives – they have scarcely accounted for implanted technologies and their ever more intimate relations with humans. Assuredly, the concepts of, for example, technical mediation and script shed light on the agentiality of technological artefacts (Akrich 1992; Ihde 1990; Latour 2009; 2005; Verbeek 2005), but they tend to be bounded by the temporality and configurations of use. It is the finite and definite interactions that take place between humans and handleable and detachable technologies – technologies-in-use – rather than the extensive and corporeal processes involved in one's life with implanted technologies that have occupied STS scholars and philosophers of technology (Dalibert 2014). In the few works that have explored implanted technologies, the latter are shown to be far from straightforward (Besmer 2012; Dalibert 2014; Kaufman et al. 2011; Lettow 2011; Oudshoorn 2015): the insertion of the implant (e.g. pacemaker, implantable cardioverter defibrillator, cochlear implant) under the skin amounts neither to its disappearance nor to its transparency, but rather entails new bodytechnology configurations and ways of being in the world. In the lineage of Haraway's (1991) famous figure, such configurations have been qualified as cyborg (e.g. Besmer 2012; Ihde 2008; Oudshoorn 2015; Verbeek 2008).

Notwithstanding its hermeneutic value, the cyborg has fallen victim to its own success: a material-semiotic figure that incarnates and illustrates the ontological intertwinement of humans and technologies and the increasing porosity between bodies and technologies/technoscience, the cyborg has become a linguistic trope. Thus detached from its material grounds, it flattens and reduces the myriad human-technology relations to a single all-embracing and amorphous term (Sobchack 2006). As a result, not only are the particularities and practicalities of lives and bodily experiences with implanted (and prosthetic) technologies made invisible, but people living with such intimate technologies are also "made to figuratively speak for a cyborgian existence" (Betcher 2001, 38). Feminist posthumanist scholars have emphasised the necessity of reckoning with the agency and materiality of humans and technologies, of bodies and technological artefacts, when attending to their relations (Alaimo and Hekman 2008; Barad 2007; Lettow 2011; Oudshoorn 2015). In this article, I will follow their enjoinment to explore what it means to be living with an implanted technology. In particular, I will examine how people live (and learn to live) with spinal cord stimulation (SCS), which is a type of neuromodulation technology.

Starting from the cases of Mrs. Bloemen and Mr. van Houten, I will introduce the implanted technology and I will try to understand why and how it can be experienced very differently (positively by one, negatively by the other). To do so, I will attend to what the technology does to bodies and inversely what bodies do to the technologies. This will contribute to understand the intimate relations and reconfigurations at play between humans and the implanted technology, as well as what it means to be living with SCS. I will show that while SCS (and its design) prescribe certain behaviours, two processes, embodiment and incorporation, which are dependent on gestures, bodily materiality, and one's embeddedness in relations and normative injunctions are vital for people to become and live satisfactorily with the neuromodulation technology. While bodies and the way they are experienced are reconfigured in particular ways by spinal cord stimulation, living and especially living well with such technology brings to the fore the relationality and intercorporeality of one's existence as well as the norms attached to who and what counts as fully humans.

Mrs. Bloemen, Mr. van Houten and Spinal Cord Stimulation

To begin this exploration of what it means to be living with spinal cord stimulation, I will present two "cases," or rather, the ways in which the neuromodulation technology is experienced and lived by Mr. van Houten and Mrs. Bloemen. These two cases, while highly contrasting, are exemplary of processes at play for the people living with SCS that I interviewed.

Mrs. Blomen and Mr. van Houten are two of the fifteen persons living with SCS that I interviewed as part of my philosophical empirical study² of intimate relations between humans and technologies (see Dalibert 2014). In addition to these interviews where at times partners, spouses or children (generally a daughter) were present, I held others with the nurse and the neurosurgeon who, in the local Dutch hospital where I have been allowed to conduct fieldwork, deal with people (to be) implanted with SCS. I also interviewed a former product developer of the St. Jude Medical neuromodulation system that is implanted in the respondents' body and had continuous contact and (informal) conversations with Ilse Hart, a medical physicist, who has been my gatekeeper and main informant during my fieldwork. From my observations (of, for example, an implantation procedure in the surgical room and during some control visits in the examination room) I kept a journal. All the respondents have verbally given their consent to participating in this research, and the latter received ethical clearance from the ethical review board of the hospital (as part of Hart's research). All the interviews took place from April to May 2012 and were semi-structured, recorded upon permission, and transcribed. To ensure the participants' anonymity, I use pseudonyms.

Mrs. Bloemen (45 years old) and Mr. van Houten (61 years old) have been living with spinal cord stimulation since 2009, Mrs. Bloemen because of chronic pain due to diabetic neuropathy – she learnt she was diabetic when she was nine – and Mr. van Houten because of chronic pain due to failed back surgery syndrome - he worked in construction. In fact, SCS is a type of neuromodulation technology that is used as a last resort treatment of chronic pain³ caused by various types of neuropathy or failed back surgeries. It modulates nerve activity through the delivery of electrical energy directly to a target area, here the dorsal columns of the spinal cord. The continuous administration of electrical pulses interrupts pains signals, thereby reducing neuropathic pain perception⁴ (in one's back, legs and feet). That is, SCS does not cure the cause of pain but replaces pain perception by another, "more pleasant," sensation called paraesthesia⁵ (which is usually described as tingling). Surgically implanted in the body, it is an invasive technology. During surgery, which is performed under local anaesthesia with the patient lying prone on the operating table, the percutaneous lead, which is six centimetres long, five millimetres wide and consists of eight flat electrode contacts (St. Jude Medical), is placed with the help of X-ray images into the epidural space (figure 1). Then, the neurosurgeon connects the lead to a pulse generator (located outside the body) and the nurse programs it. The stimulation settings are defined and adjusted in coordination with the patient and his or her needs. That is, the patient, who is awake, provides information on whether the dorsal column is stimulated at the right side(s) and level(s): the electrical field on the dorsal column should excite the nerve

fibres that innervate the painful area, and the paraesthesia brought about by the stimulation should completely cover the painful area. Once the stimulation program is set, the surgery can come to an end. Patients usually stay overnight and go home the following day. There is a consecutive trial period of several days: only if the trial period is successful – i.e. only if a patient experiences significant pain relief – the external pulse generator is converted into a smaller one which is implanted under the skin of the lower abdomen or upper buttock during a second surgery. In the Netherlands, most of the implanted pulse generators are still non-rechargeable, thus have to be surgically replaced three to seven years later (figure 1).



Figure 1: the percutaneous lead, the pulse generator, and their respective position

The electrode lead and the pulse generator – the implanted parts – are not the only pieces of technology that constitute the neuromodulation device. It also counts external components: a remote control and a coil (figure 2). People living with SCS can use the remote control to adjust the stimulation amplitude or to switch between stimulation programs. To do so, they must not only plug the coil into the remote control by means of a wire, but they must also position and maintain it over the pulse generator (i.e. on their lower abdomen or upper buttock) so that the latter can connect, via radio frequency, to the remote control. However, while they can use the remote control to choose between different programs and change the stimulation amplitude when or if their pain varies during the day – the augmentation of the stimulation amplitude increases the sensation of paraesthesia, and inversely – they cannot modify or redefine the program settings, which can only be done by the nurse during control visits.



Figure 2: the remote control together with the coil and the leather case

For Mrs. Bloemen and Mr. van Houten – and for most of the persons living with spinal cord stimulation that I interviewed – the implantation procedure was a very demanding, not to say traumatic, experience. But the critical, even vital, role of the neuromulation technology in relieving the pain they have been experiencing for decades in their legs and back has compensated or made them forget this upsetting event. As he explained to me when I met him, Mr. van Houten is very happy with SCS.

It changed my life. What I can do and how I feel. ... When I don't have this, I am in a lot of pain, I'm always lying in bed or I'm sitting in a wheel chair, all day. And I sit down, and I look outside, I don't do anything — maybe, yes, get some coffee, at home. And 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 is grateful for the neuromodulation technology that has not only become part of his body but has also enabled him to do things and to be part of the world – of life – again. In fact, he is so content with it that, as he told me later in the interview, he would like to have a zipper put in his back so that the world could see his implant, which he calls a pacemaker for his legs and back. In contrast, even though she would not have it removed nor turned off for the world since it is a big help for minimizing her pain, Mrs. Bloemen is unhappy with her neuromodulation device. She does not like it because she cannot read the screen of the remote control (she lost sight in one eye because of diabetes and barely sees with the other), and the buttons are too small for her to use. While she acknowledges that SCS has changed her life, enabling her to simply be and "do things" in the world (e.g. go shopping with her daughter or for walks with her family), it does not feel as part of her. In fact, her neuromodulation device

distresses her because she can neither touch it nor look in the mirror at her lower back without feeling or seeing the pulse generator's shape, and she finds it all the more abject because her husband can also see it and touch it (even if under her skin).

Mr. van Houten's and Mrs. Bloemen's different and unique experiences with spinal cord stimulation hint at the fact that living with such an implanted technology is not an uncomplicated matter but rather entails a singular becoming with and the materialization of particular bodies. However, how to account for the differences (between e.g. Mrs. Bloemen and Mr. van Houten) in experiencing the neuromodulation technology and more generally the transformation of bodies with SCS? What does it do to bodies?

Pre-scribed Behaviours and Somatechnologies

When I asked people living with spinal cord stimulation, including Mrs. Bloemen and Mr. van Houten, to show me how the neuromodulation technology works, they drew my attention to the remote control. By pressing the latter's buttons and following the screen display, they can increase or decrease the stimulation amplitude. As such, the remote control appears to be people's interface with the neuromodulation device. By its "technological presence" (Kiran 2012), it shapes the actions of people living with SCS. Be it actually used or not, the presence of the technological device mediates one's actions, technical mediation referring to "how [technological artefacts] mediate the relations between humans and their world, amongst human beings, and between humans and technology itself' (Verbeek 2005, 11). The interaction with the SCS system through the use of the remote control is "scripted," or even "pre-scribed," behaviour. As conceptualised by Madeleine Akrich (1992) and Bruno Latour (2009), technologies can have "scripts" inasmuch as they can prescribe certain actions, just as a movie script does. The scripts embedded and conveyed by a technological artefact therefore invite or suggest certain actions while they inhibit or discourage others (Verbeek 2011, 19). Indeed, while the intensity of the stimulation, hence the paraesthesia and pain can be influenced, steered even, by one's posture and bodily movements - a central aspect that I will discuss later - the presence of the remote control affects – discourages – this bodily activity.

In fact, after the implantation procedure, people are instructed by the neurosurgeon and/or by the nurse in charge not to do certain movements – e.g. to bend their back or carry heavy bags – for a few months to prevent the lead from getting displaced. It can be said that this advice materializes in, or in Latour's (2009) idiom, is delegated to the remote control. It is by means of the latter that one is invited or directed to modulate the stimulation amplitude (and to switch between programs). Furthermore, from the screen display, information about the current

stimulation program (in the form of a human shape whose electrically stimulated parts of the body, e.g. back, right and left legs, appear as coloured in black) and the amplitude of the stimulation (in the form of vertical bars of increasing size) can be accessed and further interpreted as depicting one's level of pain and paraesthesia and vice versa.⁶

However, while the remote control shapes – mediates – the actions and perceptions of people living with spinal cord stimulation, it also tends to disable some bodies (from using it). As previously mentioned, Mrs. Bloemen, who suffers from diabetic neuropathy which weakens her hands and caused blindness of one of her eyes, barely uses the remote control because of the small size of the screen and buttons as well as because of the latter's rigidity. Designs matter for use/ability (Oudshoorn and Pinch 2003) and the liveability of technological artefacts. As a former product developer for St. Jude Medical told me, SCS with its remote control and coil is "a nice example of a horrible system [that] is really patient unfriendly ... [I]f you put the antenna [i.e. the coil] not on the right spot, it's not working anymore, [and] it looks bulky." Therefore, while interaction with the remote control (connected to the coil positioned on the pulse generator) is the scripted and prescribed behaviour, it can be disabling or, as it is conventionally named, "user-unfriendly."

The remote control is not the only piece of technology that acts and has an effect on one's becoming with spinal cord stimulation. The implanted lead and pulse generator also do things – e.g. they generate and deliver electrical currents that modulate nerve activity. Assuredly, the remote control (connected to the coil) has been the respondents' immediate response to how they relate to the SCS system and as such appears to be people's interface with the neuromodulation device. Nevertheless, the tendency to focus on handle-able and usable (and overwhelmingly detachable) devices might also be an artefact of STS and philosophy of technology. Concepts such as technical mediation and script are informed by and shed light on interactions and temporalities of use, hence on temporally finite human-technology relations (Dalibert 2014; Oudshoorn 2015; see also Lettow 2011; Verbeek 2008). Yet, implanted technologies do not stop acting and mattering once they are inserted into the body and (seemingly) disappear from view. Rather, they have to be understood as somatechnologies, that is, as technologies that act on and intervene in bodies, as technologies that cannot be understood outside of their intimate relations with bodies (Lettow 2011; Sullivan and Murray 2009). Concerned with the ways in which technological artefacts mediate the relations between humans and their world, the concepts of script and technical mediation are silent about the ways in which these technological artefacts might transform bodies and the relations between someone and his/her body. While they enable us to apprehend how technologies affect our actions in and

perceptions of the world, they tend to ignore the matter of intimate human-technology relations: bodies. As the next sections will show, with implanted technologies, it is first and foremost bodies that are reconfigured, thereby profoundly affecting one's being-in-the-world. If the intimate relationships taking place between people living with spinal cord stimulation and the neuromodulation technology are to be understood, both people and the technological device in their *materiality* and as *agential* entities have to be accounted for.

Gestures, Embodiment and Becoming with Spinal Cord Stimulation

Spinal cord stimulation is an implanted technology. Or rather, two of its components, the lead and the pulse generator, are implanted under the skin, respectively positioned on one's spine and at the level of one's lower abdomen or, in rarer cases, upper buttock. As aforementioned, to resort to the remote control to modulate the stimulation amplitude or to switch between programs is scripted or even pre-scribed behaviour. However, in one's relations with SCS, the remote control is not necessarily central. The relationships are more intimate. The intensity of the stimulation, hence paraesthesia and pain, can be influenced and steered even, by one's posture and bodily movements - even though the presence of the remote control affects (inhibits or discourages) this bodily activity. Bodily gestures are crucial for the becoming transparent of SCS: for its embodiment (Ihde 1990). In Ihde's acceptation, embodiment is one instance of technical mediation: it refers to the technology being perceived as a "quasi me" while extending one's field of perception. Embodied, the technology neither attracts attention to itself nor is experienced as bothersome. Rather, it becomes (quasi) transparent at the sensory-kinetic level: it is embodied in the body schema (Merleau-Ponty 1962). If this transparency is the desired state - and the indication of a successful use - of a technological device, how it is done by bodies with the technology tends to be absent from Ihde's conceptualization. Yet, as concerns the neuromodulation technology, disappearance under the skin does not equate to a de facto transparency. Implantation does not mean nor amounts to embodiment - or incorporation, as shall be addressed later.

Spinal cord stimulation creates a distinctive tingling sensation that replaces (chronic) pain perception. The embodiment of SCS demands habituation to these new sensations – e.g. paraesthesia and reduced pain. The first days and weeks following the implantation are characterized by experimentation with the technology, what it does to one's body, and what one's body does to SCS.

[T]he first, two, three days, yes, yes all day you're just playing with it. Yes. What is possible? Can I drive the car? ... When you're sitting down and you put it on: oh, that's very nice. And then you go stand up: iuuuuuh! Yes? ... You put it higher: aaah, it's not possible! And then you must learn. Higher: what can you do? I put it on, and I try, I feel this. Or a little lower ... [W]hen I have a lot of pain, I put it higher. But when I lay down and put my arm up, you can djijuuuu! My ears go a bit [laughing and scratching them]. You cannot lie down: you must put it lower... It stimulates much more and then your toes are buh-dut-dut: you put it too high (interview with Mr. van Houten).

While Mr. van Houten's account illustrates the difficulties that exist in talking about one's body and sensations, it exemplifies the process that is at play. And indeed, when learning to live with spinal cord stimulation, play is important. By changing the intensity of the stimulation, performing certain bodily movements, and assessing the resulting sensations, one playfully experiments with the neuromodulation technology. This "dance of agency" (Pickering 1995) between people and the technology resonates with Carrie Noland's reformulation of the concept of "tâtonnement," or "groping," proposed by paleoanthropologist Leroi-Gourhan, where "[[]âtonner] conveys the sense of exploration, whether physical or cognitive: testing out a path not yet cleared or devising a sequence not yet inscribed" (Noland 2009, 105-106). It is through such groping, which is characterized by the playful enactment of bodily movements and the simultaneous attentiveness to one's technologically affected bodily materiality, that the technology becomes embodied (i.e. experienced quasi transparently). Indeed, as Mrs. Jansen (63 years old) who has been living with SCS since 2005, explains,

[i]n the beginning, I thought I will never get used to it, because you constantly feel that trembling in your legs. And also, if you travel and you sit in the train, and the train or the bus drives over a bump, you feel that extra. [..] But at some point you feel it no more. ... At one point I sat down and I thought: "oh, yes, that thing is still on, I didn't feel it at all today."

Eventually – relatively quickly – one becomes accustomed to the new sensations elicited by SCS. They become imperceptible, transparent.

Furthermore, the bodily movements composing one's groping with the neuromodulation technology soon become structured and purposeful: they become gestures, an "organised [form]

of kinesis through which subjects navigate and alter their worlds" (Noland 2009, 4). It is through them that one comes to intimately relate to the implanted technology. Besides the fact that some, if not most, of the people I interviewed never use the remote control to change the stimulation amplitude, other interact with, or rather steer the stimulation by using their bodies – by performing certain gestures. Mrs. Jansen describes how the device works for her in these terms:

Well, you feel it directly. Yes, uh, that's how I feel it right now. The feeling goes on through the legs and back here: I feel it. And then, if I am lying down, or if I pull my head back, I feel it very clearly. If I have pain in my legs, I do like this [she pushes her head backwards] then it vibrates very strongly for a moment and then the pain decreases.

Having become attentive to and deeply aware of the ways in which the technology affects her body and, inversely, the ways in which her body affects the technology (i.e. the generated stimulation), she directs the stimulation and paraesthesia through her gestures. The technology is made close and familiar; it becomes intimate.

As people experiment and learn to live with spinal cord stimulation, they are moved by the implanted technology. They perform new gestures, thereby enacting a different body. With the neuromodulation technology, not only are bodily movements created and/or transformed, but one's kinaesthetic experience and bodily sensations are also reconfigured. This enactment of particular gestures and correlate kinaesthetic and sensory assessment of the effect of the stimulation is a groping process. As developed in the next section, the latter engenders a renewed appreciation of the way one's body is present for oneself, which entails a renewed awareness of one's bodily materiality.

Living with Spinal Cord Stimulation and Becoming Intimate with One's Materiality

As Merleau-Ponty formulated it, "the body is the fabric into which all objects are woven" (1962, 235), and being is always being in as well as to the world. Being a body-in-pain, however, enacts a world in which one's field of possibilities is hindered and hampered, a world that is even experienced as shattered and shattering. Being a body-in-chronic-pain (un-) makes one's world (Scarry 1985). As Drew Leder (1990) phrases it, in pain the body "dys-appears." In the normal course of events, the lived body is characterized by a primordial absence, or rather absence and presence are intertwined in the lived body: absent presence, the body is characterized by ecstasis

(Leder 1990, 21-22). Derived from the Greek *ek-stasis*, the lived body whereby we are-in-the-world "stands out." That is, its "very nature ... is to project outward its place of standing" (*Ibid*, 22). Ecstatic, the body is experienced transparently – it is absent. But in (chronic) pain or in sickness, the lived body is characterized by a secondary absence – a "dys-appearance." Dys-appearance characterizes the body's absent absence. That is, the body is no longer experienced as transparent, as the (back-) ground of our being-in-the-world, but it is rather brought back into the foreground of our awareness.

With spinal cord stimulation, the body's absent absence and more generally how it is present to oneself is precisely what matters. For the somatechnology to become (i.e. be experienced as) transparent, implies getting in touch - becoming intimate - with one's bodily materiality. SCS not only puts bodies in motion – i.e. enables them to move – but also creates bodily sensations – the feeling of vibration as the electrodes fire onto the spinal cord and that of paraesthesia progressively replacing the pain. These sensations render the lived body nontransparent. However, if it is not experienced as an absent presence (as disappeared), it is no longer experienced as something alien or other than oneself (dys-appeared, as in chronic pain) either. As people living with SCS attend to and become more intimate with their bodily materiality, its agency, and that of the implanted technology, they start experiencing the neuromodulation device as transparent and their body as no longer an incapacitating "absent absence" (Ibid). A degree of opacity remains however, as complete intimacy need not be achieved - e.g. one does not need to be aware of the blood being pumped in his/her heart and circulating through his/her veins - but to live (satisfactorily) with SCS, one must become familiar with and progressively habituate to one's nerve activity as it is being modulated by electrical current and affected by one's movements and gestures. While the dys-appeared body in chronic pain is incapacitating, in paraesthesia it is enabling, which has SCS being experienced as a "belong[ing] somewhere again, [as being] part of the life," to use Mr. Van Houten's words. As such, with spinal cord stimulation, the body can be said to "eu-appear." The term is borrowed from Kristin Zeiler who, in contrast to the Greek prefix dys that is negatively connoted, uses "eu to highlight the experience of the body as well, easy or good" (2010, 338). Through attentiveness to one's body-with-technology-and-in-paraesthesia, the body is experienced positively. When playfully experimenting with the technology, what it does to one's body, and what one's body does to the technology (e.g. the stimulation), or when doing particular gestures to steer the stimulation, awareness of one's eu-appearing the body is reflective; it becomes pre-reflective when ones grows accustomed to the tingling sensation for instance. In both cases, it creates a feeling of empowerment – I can.

Furthermore, living with the neuromodulation device not only brings about a "re-worlding" (Besmer 2012) through this transformed bodily mode of being; it also materializes singular bodies. As the electrodes fire and stimulate the spinal cord's nerve fibres at a certain amplitude and frequency, the burning and shooting pain felt in one's lower back, legs, and/or feet is replaced by paraesthesia (tingling sensation). In fact, as the electrode array is implanted and positioned on the spine, and as the field of stimulation is mapped, pain is, to a certain extent, realized. That is, spinal cord stimulation objectivises – makes visible or concrete for oneself and to others – the experienced pain and thereby enacts the body-in-pain. This realization might also contribute to feeling empowered by the technology (see Jackson 1994, 210-222). Simultaneously, as the paraesthesia covers and replaces the painful sensation, the body-in-paraesthesia comes into being. Equipped with SCS, the body becomes multiple, to borrow Annemarie Mol's expression (Mol 2002).

To summarize, while implanted and close to bodies, spinal cord stimulation (SCS) is not straightforwardly and directly an intimate technology. Rather, it becomes intimate as it is embodied, embodiment being a process *done* by bodies and technologies. For the somatechnology to become transparent, movements and gestures are crucial: one learns to live with SCS through a groping process. Living with the neuromodulation technology also entails becoming attentive to (and empowered by) one's lively materiality and what one's body can do. Bodies' transformation with the somatechnology constitutes a re-worlding. However, even though being attentive to the materiality and agency of both bodies and spinal cord stimulation is necessary for apprehending what it means to be living a neuromodulation technology, the focus on embodiment is not sufficient to explain the striking difference that exists between Mrs. Bloemen and Mr. van Houten in how *liveable* and satisfactory the technology is for them. Whether spinal cord stimulation is considered to be part of their body is key here: processes of incorporation are also at play with somatechnologies.

Incorporating Spinal Cord Stimulation and (Failing at) Doing Able-Bodiedness

Besides living with somatechnology involving the latter's embodiment – i.e. the becoming transparent of spinal cord stimulation at the sensory-kinetic level (Sheet-Johnstone 2005) – and its becoming intimate, the question concerning whether or not SCS is lived as part of one's body has been a recurrent issue in my fieldwork. Interestingly, the implanted technology's incorporation – etymologically meaning "brought within the body" (Leder 1990, 31) – is entangled with relationality: it is a highly relational process. Done with others (both humans and

nonhumans), incorporation is also linked to the enactment of humanness. In fact, informing the incorporation of SCS – and possibility thereof – is the question of which bodies materialize and especially matter as putatively human with somatechnologies. Attending to this process is necessary to understand how the neuromodulation technology can be positively or negatively experienced even though it significantly reduces pain perception in both cases.

Besides Mr. van Houten sharing that he considers spinal cord stimulation to be part of his body and Mrs. Bloemen expressing that she does not, when asked if she thought the device has become part of her, of her body, Mrs. Jansen answered that "that's a part of me now! It's a part of me. Yes. I mean. just as the eyes see indeed" (interview with Mrs. Jansen). In fact, conceiving of the neuromodulation technology as being part of one's body is linked to living satisfactorily with SCS. Incorporation, however, is not only an active process of identification with one's transformed body by somatechnology, but is also done with others, especially loved ones (Slatman 2012; Slatman and Widdershoven 2010; Sobchack 2010).⁸

As Jenny Slatman and Guy Widdershoven have showed in the context of living with transplanted hand(s), (re-) identification with one's transformed body or "[b]eing able to be the body one has implies ... being able to appreciate and accept both the strange body part's visual features ... and its haptic, affective aspects" (2010, 75). This capacity, however, is also dependent on loved ones' ability to re-establish an intimate relationship with the transplanted hands in Slatman and Widdershoven's account: they are incorporated with, and to a certain extent by, others. This process particularly resonates with spinal cord stimulation. In this respect, it is in relation with her grandson, and more specifically in relation with her grandson's admission and validation that SCS is neither a strange nor a threatening thing but rather part of his grandmother that Mrs. Baten (61 years old) reasserts her acceptation of the neuromodulation as part of her body. As she recalls, her eldest grandchild

knows about it [SCS]. He saw it once and he thinks it's ok ... He was part of the process back then [when the technology was implanted], he was ten, so he was part of it and he first takes a peak and then it's all mighty interesting, but once they have seen [it], it's ok, it becomes a part of grandma. That's the way it is.

Likewise, Mrs. Bloemen's strong rejection of SCS as a part of her body cannot be apprehended outside of her relations with her son and husband.

As previously mentioned, Mrs. Bloemen lives with spinal cord stimulation because of chronic pain due to diabetic neuropathy. While she is no longer diabetic as a result of a pancreas

(and kidney) transplant, her son is, and she blames herself for his condition: "I feel guilty, because he has it and I'm not anymore [tears]." Mrs. Bloemen's non-acceptance of and failed identification with SCS is highly affective and entangled with her son's body, but not only. During our interview in which both her husband (HMB) and Ilse Hart (IH) – whom she knew from her visits at the hospital – were present, Mrs. Bloemen (MB) explained her relationship with the neuromodulation technology by referring to her organ transplants:

I told Ilse [Hart] my son asked when I was transplanted if I thought it was ehm strange to have organs from somebody else in my body, and I said no, I get them and they're mine now. [Trembling voice] Ehm that feels like part of me. The stimulator, no. It still is an instrument.

- LD: And this because? For you, how or what makes the difference?
- MB: That it's there! Ehm, my son he has an insulin pump now. I didn't want that. Never. I didn't want something on my body that doesn't belong there. ... [The remote control] you can place that away and it's gone! [laugh] you don't have to think about it. But this is, yeah, it's always there. You can't remove it.
- LD: So spinal cord stimulation, you don't consider it as part of you?
- MB: Oh no! No! Ehm, it's a big help for me. But it's still an instrument, and ehm [tears] I don't like it that he [her husband] can feel it. Yeah. At first you make jokes about it but at some point the fun stops.
- HMB: No, but, for me it's easier to see it as a part of her because without it she doesn't function that well. That's maybe easier as a partner to get over it than the person itself.

. . .

- IH: Because for you [Mrs. Bloemen], it's more like an annoying piece of...
- MB: Yes, an annoying thing that's sometimes in the way.
- IH: It's functional, but it's also in the way.
- HMB: Yeah, the only time I see it is when we're in bed, to put it bluntly.
- MB: Yes, yes, I know that. But with clothing, you do take it into account too. And then, you want to be sure that others don't see it.
- HMB: But if you wear a skirt or tight pants, you don't see it.
- MB: Yes, but you have to assume that that's the case.

Visually, haptically and affectively, Mrs. Bloemen cannot relate to or identify with SCS. The pulse

generator is what causes her the most distress. As she indeed added, "[m]y thing here [the pulse generator in her back] because you could ehm you could see it, you could feel it. ... I've had a hard time with that [tears]. I can see it for myself [tears] in the mirror. I can't wear all my clothes because I don't want anyone to see it [tears]". As she can see and touch the pulse generator under her skin, she cannot identify with and incorporate the neuromodulation technology. It remains a tool or an instrument; it is not (a) part of her body. Nevertheless, as the interview extract manifests, Mrs. Bloemen's rejection of, even revulsion at, spinal cord stimulation as it crystallises in the pulse generator cannot be apprehended by only considering the interactions between the somatechnology and her body. Or rather, even though intimate, these interactions do not stop at the boundaries of her skin but involve other bodies. The fact that one's corporeality is always (Merleau-Ponty 1962) is made intercorporeality intimate knowledge somatechnologies.

For Mrs. Bloemen, it is not so much the ability of her loved ones to identify with the implanted technology that is at stake as her "incorporation" of their bodies - their gaze, their touch, their chronic disease, and implanted technologies. Mrs. Bloemen's husband for example does not have difficulty accepting and even valuing spinal cord stimulation. For him, insofar as it enables his wife to "function," i.e. to have a world and be in the world, it is "a necessary evil, just like [his] glasses" (quoted in interview with Mrs. Bloemen). However, similar to her own neuromodulation device encapsulating her son's body with its insulin pump, her relation to her transformed body includes the projection of her husband's gaze, touch and relation to her somatechnologically-changed body. Further away, but with similar intensity, the gaze of others permeates Mrs. Bloemen's relationship with SCS. While all bodies are both seeing and seen, Mrs. Bloemen's distress over the visibility of implanted device(s) for others and her preoccupation with clothing reinstate the specular dimension of the female body, female bodies being more subjected (than men's) to others' gaze (Bartky 1997; Bordo 1997). Bodies with (soma-) technologies are not situated outside of (cultural and societal) power relations. The latter matter for one's - here Mrs. Bloemen's - ability to relate to one's somatechnology and to have it become (a) part of one's body.

While incorporating spinal cord stimulation is a highly relational process that brings to the fore one's intercorporeal dimension, it is also intrinsically linked to putative humanness. Who and what counts as human not only informs the extent to which the neuromodulation device can be incorporated but also how people can live with it. Mrs. Bloemen's suffering over the possibility for others to see the implanted pulse generator (which informs her inability to incorporate the neuromodulation technology) cannot be understood without considering how for her being

human is intrinsically linked to (white heteronormative) femininity. Having internalized the gaze (to use the Foucauldian terminology), her ambiguous yet intimate relation with SCS threatens her humanness. The presence of the pulse generator under her skin, implanted yet touchable and visible, "is in the way" of properly *doing* (white heteronormative) femininity, which entails achieving smooth bodily contours. "A woman's skin must be soft, supple, hairless and smooth; ideally, it should betray no sign of wear, experience, age, or deep thought," as Sandra Lee Bartky observes (1997, 137). The implanted neuromodulation technology obstructs the (re-)enactment of gender norms (in Mrs. Bloemen's case, femininity).

Although it would be tempting to construe the neuromodulation technology's interference with femininity and its performance as a welcome disruption and transgression of gender norms (thereby revealing how gender is always an – arbitrary and violent, always unattainable – artifice), in Mrs. Bloemen's case it is lived as a failure to "be" fully human. Furthermore, her distress over the visibility of her neuromodulation technology (and pulse generator especially) is intertwined with the injunction to pass as able-bodied in order to be (seen) as fully human. Humanness, or rather the recognition thereof which entails civil invisibility (as opposed to stigma), is granted to unmarked, i.e. putatively normal and abled, bodies (Garland-Thomson 1997; 2011). To a certain extent, Mrs. Bloemen's malaise over her somatechnologically-transformed body is imputable to the "compulsory able-bodiedness" that governs our societies, as Robert McRuer (2006) named it. For Mrs. Bloemen, the invisibility of her implanted devices is closely connected to the invisibility of her own body. Even though her body is no longer present to herself as a hindering absent absence (it no longer dys-appears), she experiences it as having become highly present to others: with spinal cord stimulation, especially the neurostimulator, it/she is marked and stands out as differently-abled. She becomes disabled. Yet, enacting femininity is intertwined - or intersects with enacting an able and healthy body. Like (white heteronormative) femininity, health and ablebodiedness are unachievable (if only because they are only temporary conditions) yet potent positions against which humanness is measured.

Interestingly, age/ing seems to ease conceiving the somatechnology as (a) part of one's body. To a certain extent, age/ing naturalizes living with somatechnology. As Mrs. Baten (61) told me, when she talks to friends about her neuromodulation technology, she

make[s] jokes about it, I'm very relaxed about it because my back is broken, my eyes, I just had iris detachment, I've got rheumatism, I've got all kinds of stuff. I'm losing my hair, I've got implants in my mouth. The only thing missing is a wooden leg! [laughs].

Mrs. Baten, who is experiencing ageing and its effects, considers SCS to be (a) part of her. In fact, it might be insofar as she is becoming (an) elderly and views the neuromodulation technology as a normal or ordinary part of the ageing process that she is able to identify with it. Age/ing renders intimacy and identification with spinal cord stimulation un-, or at least less, problematic. To a certain extent, somatechnologies produce ageing, and even elderly bodies. Mrs. Bloemen's rejection of the neuromodulation is quite comprehensible in this frame: she is after all only 45 years old with two children (16 and 20) still living at home. Ageing and its effects are usually not (expected to be) experienced as intensely yet. In contrast to Mrs. Bloemen, and similarly to Mrs. Baten, Mr. van Houten who is very happy with the neuromodulation technology compares it to its much more troublesome knee and tooth implants while referring to it as "his pacemaker for the legs," thereby normalizinging it for himself and others. Age/ing seems to ease one's acceptance of and identification with spinal cord stimulation – its incorporation; it matters for one's ability to live in an intimate relation with somatechnology.

Conclusion

Living with spinal cord stimulation (SCS) is an intricate matter. To apprehend it, an account of the intimate relations between bodies and such a technology is necessary. Insofar as they tend to be bound by the temporality and configurations of use, STS and philosophy of technology's frameworks (e.g. technical mediation and script) foreground only particular types of human-technology relations that do not exhaust what happens between bodily humans and implanted technologies. Implanted technologies are somatechnologies. With them, it is first and foremost bodies that are reconfigured, thereby profoundly affecting one's being in the world, for oneself and for — but also with — others. Thus, the ways in which the technology transforms bodies, and inversely, the ways in which bodies affect the latter must be accounted for. While it must attend to materiality and agency, such an account cannot stop either at the visible physical borders of the skin and the technological artefact. The embeddedness of bodies with SCS in networks of relation matters for the liveability of the implanted technology.

Implantation does not amount to the technology's disappearance. Rather its disappearance or transparency is a bodily process. While the technology becomes progressively embodied through a playful groping process in which gestures are central, it profoundly changes the way the body is present for oneself (it eu-appears), which entails becoming attentive to and intimate with one's bodily materiality. Through the elicitation of novel sensations, the remaking of gestures and postures, and the realization of the body-in-pain concurrently to the body-in-

paraesthesia, bodies are transformed with somatechnologies. Empowering, this bodily transformation is experienced as a re-worlding.

While embodiment of spinal cord stimulation is necessary to live with the technology, it is not sufficient to live well with it: the technology must be incorporated. Incorporation – i.e. apprehending the neuromodulation device as (a) part of one's body – is not an individual event that takes place between oneself and the technology. In their intimate relations, bodies and SCS are entangled with human and nonhuman loved ones, whether they are one's spouse, children, grandchildren, friends, or the dog with which one goes for a walk everyday. The latter are pivotal for one's ability to identify visually, haptically and affectively with one's technologically transformed body and incorporate SCS. The intimate relations between bodies and the somatechnology also involve other technological devices, whether it is one's car or whether it is the insulin pump of one's son, one's own knee and tooth implants or organ transplants. In this respect, the presence and action of screening, imaging, and detection technologies in hospitals, airports or shops are also part of what it means to be living with spinal cord stimulation, and with which the density of "the texture of [the] 'technosphere' within which we undertake our daily affairs" is vividly experienced (Ihde 1979, 7). Furthermore, within specific historico-cultural contexts – e.g. the Netherlands in 2011-2013 – they are also entangled with apparatuses of bodily production, such as compulsory able-bodiedness, gender norms, and age/ing. Dominant norms are instrumental in one's ability to incorporate the neuromodulation technology. Be(com)ing cyborg is a vital and material entanglement wherein bodies with spinal cord stimulation are also always intertwined with what matters as (putatively proper) humanness. It is an articulation of what it means to be human.

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Notes

¹ Haraway (1991) is more concerned with the (epistemological) intimacy of bodies and technoscience than with the (lived) intimacy of bodies and technological artefacts. It is biology, its changing discourses, its intervention at the level of "life itself," and the implications for what it means to be human that have been investigated (e.g. Åsberg 2009; Haraway 1997; Rose 2007).

² Empirical philosophy (Mol 2002) weaves philosophical reflection with empirical material generally gathered by means of ethnographic methods. It resonates with philosophy of technology's "empirical turn" to which this article is also indebted and where attention is given to technological artefacts rather than to a transcendental notion of Technology and its conditions of possibility (Verbeek 2005).

³ Clinically, while acute pain is a healthy and useful warning signal (it indicates that something is wrong with one's body), when it is chronic, pain has no warning function anymore: it becomes the problem. Intractable chronic pain severely impairs people's lives as it has a negative influence on almost all aspects of life: on one's physical abilities, sleep, social life, mental health and wellbeing – on one's world (Jackson 1994; Scarry 1985).

⁴ SCS is originally based on the gate control theory elaborated by Ronald Melzack and Patrick Wall (published in 1965 in *Science*). It postulates (electrical) inhibition of pain by non-painful stimuli (Rossi

2003, 10). However, as Cecile De Vos argues, while the gate control theory constitutes the first framework for understanding how SCS works, it remains "an oversimplication of the complex mechanisms that occur in the spinal cord and brain" (2013, 11).

- ⁵ Stimulation frequency influences the perceived paraesthesia. Frequencies below 30Hz induce distinct tingling sensations (described as many tiny prickles or tickles), whereas stimulation with higher frequencies is experienced as a smoother sensation. New stimulation paradigms (frequencies of 500Hz and above) are believed not to cause any paraesthesia and to achieve good results (De Ridder et al. 2010; De Vos 2013).
- ⁶ Were Don Ihde (1990) concerned with the ways technological artefacts mediate the relation between someone and his/her body, rather than with human-world relations (of which material bodies tend to be absent), such an instance of technical mediation could constitute a hermeneutical relation. This relation points to the world being perceived by means of an artefact, the latter providing an interpretation of the world that needs to be interpreted.
- ⁷ The body's absent absence does not amount to its "mere" presence, but rather to dys-appearance. Dys-appearance is negatively connoted: the body is experienced or present to oneself as a something bad, ill, or alien. Presence does not have such connotation. Conversely, as I will discuss later, with spinal cord stimulation, the body can be experienced or present to oneself as something good, well and even pleasurable, such as when swimming and enjoying the strength of one's arms or the sensation of the water on one's skin: the body then eu-appears (see Zeiler 2010). For able bodies, most of the time, the body is experienced or present to oneself as an absence presence: it disappears. Unnoticeable, it is me.
- ⁸ The concept of incorporation has mainly been used to differentiate between usable or handleable tools and intimate technologies, especially prostheses. Incorporation has been linked to body ownership (De Preester 2011), but implanted technologies have been left unexplored as if implantation amounts to both straightforward embodiment and incorporation. Others have showed that incorporation is an active and relational process of identification with one's changed body (Slatman 2012; Slatman and Widdershoven 2010; Sobchack 2010). These approaches particularly resonate with how SCS becomes (conceived as) part of one's body.

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