MANOEUVRES IN THE DARK

Re-creating (new) stories about sexuality and the body within/by women with a spinal cord injury

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FACULTY OF PSYCHOLOGY
AND EDUCATIONAL SCIENCES

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Touched by lines

PREFACE

Welcome to my PhD dissertation created through and around my research about embodiment and intimate relationships as experienced by women with spinal cord injury; all women who had to suddenly live with a body different from what they had become used to, a body with altered (or disappeared) sensations, altered looks, and altered ways of moving. The following words provide glimpses of balancing acts between living with bodies that function "differently from before" and desiring and experiencing intimate connection and pleasure through those bodies. I searched for answers to the question: "how do they experience being a woman with sexual desires living in and with a body affected by SCI?". This journey did not only provide me with some (partial) answers, but it especially triggered more questions affecting not only their lives but the lives of all of us living with the chronic condition of being sexual in a world where intimate pleasure is highly yet often invisibly normed and regulated. How do we go about normality and embodiment? When do we feel free? What does a body mean to the person living in/with/through it and what does it mean for their close and broader environment? How does a body become a list of deficits or "too something", or a source of pleasure, exploration, and creation?

The past five years have been, for me, marked with connection, disconnection, and reconnection with the work I was doing. Questions about whether my participants were getting anything out of our time spent together, questions about the value of my thoughts for them and other women and basically anybody living with a body, questions about whether my project was meeting the expectations of fundamental research, etc. popped up whenever I had temporarily become unaware of the small ripples of movement brought about by insights of myself, my participants, my colleagues, and anyone else we encountered and who listened to our stories or watched us move or sensed our touch. Alongside ground-breaking, the project re-grounded me and those involved in our bodies and our desires, moving beyond the realms of conditioning and extending the scope of our imaginative manoeuvrability: the space we feel to have to move and experience intimate pleasure (intimacy as entailing touch, love, affection, privacy, bodies, care and being close), spaces created by ourselves yet always in intra-action with the materiality and discursive practices we are exposed to in our lives.

Initially my research focused on the interplay between the sexual well-being of women with spinal cord injury and their experiences of communication (and more often, non-communication; Tepper, 2000a) with intimate others as well as in more public contexts about sexuality. This focus was based on the assumption that discursive practices were key to creating contexts where desire and sexual pleasure could either thrive or be doomed to die in the darkest corners of despair and taboo. Quite quickly, however, I started getting that that is not what my dissertation and my participants' narratives were mainly about. Upon introducing this focus during the intake interviews, one participant fired back that "communication will not bring my orgasms back", and another doubted how communication could ease her nerve pain that was often triggered by touch. Communication had been given too much a central position for exploratory research about the women's lived experiences of sexuality.

The women did talk about othering or distancing communication, in the accounts about acquaintances asking about "whether sex is still possible" or healthcare professionals asking "why you should want to have a longer catheter at night because you can't move by yourself anyway", or the silence between partners after expressing the desire to be more intimate again and experiment. All these accounts were signalling the discomfort, uncertainty, or ignorance when thinking about sex and (people with) bodies deviating from the (unachievable) norms for a socially appropriate and satisfying sex life (read: norms of able-bodiedness, able-mindedness, heterosexuality, femininity and masculinity, youth, independence, etc.). And they did talk about inviting communication, with partners lightening up instances of otherwise shameful events with humour, and friends emphasising they had not lost themselves in the accidents that suddenly disrupted their normalities.

But the focus on communication did not cover enough of what was driving the sharing of the stories about lived experiences of sexuality. It was about something much more fundamental that needs to be in balance to "be sexually well": our embodiment—i.e., how we experience our bodies—and how we have given meaning to intimacy and pleasure with and through our bodies. So that is what I started to explore. This dissertation documents (partly) how I became increasingly intrigued by how bodies matter and come to matter, not by resorting to measuring reflexes, blood pressure, genital sensation, lubrication, and orgasm-ability (which produces tremendously valuable science too), but by diving right into opportunities to encounter our bodies differently: through talking, through adorning the body outside the comfortzone, through photoshoots and -graphs, and even through dance.

Many circling movements later, I sometimes feel that my PhD is not about sexuality, or not deep enough. But in fact, it might have gone deeper. Sexuality is a construction that is difficult to express in words, and which contains a myriad of components that get assigned different meanings and values by every single one of us. The words of my participants, including my own in the mainly autoethnographic chapters (and anywhere else in this dissertation, as I am always present as the author), are only the tip of a volcano we can see through a wildly growing jungle. Where women described the bodily impact of their spinal cord injury on sexuality and intimate pleasure—the not sensing of touch and the not experiencing of (the) orgasms (they knew before their injury) and the not being able to spontaneously move and hug and carress anymore—I now describe, based on my understanding of their understanding of their lived experiences, the psychological space to manoeuvre that they perceive and experience to have. Sexual wellbeing comes forth from the interplay between those physical and psychological spaces to manoeuvre that we experience in our own body.

I hope to have, in my very own way, done justice to the stories and the trust that the women featuring in my research gave me. I am truly grateful for all the connections, desire, pleasure and pain, blockages, challenges and openings that surfaced in our encounters. There is much more to tell beyond the chapters in this dissertation, but it is a carefully constructed beginning.

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My process of coming to understand more about moving in the world in a body has been a relational process. The many people I encountered and shared paths with during my personal/professional journey are uncountable, their presence stretches far beyond the confines of the categories I list below, and I do not even remember all their names, but I want to thank everyone who was part of this process of becoming.

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Inge
October 2014 - September 2019, Ghent and Leuven, in between and beyond

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Chapter One

General Introduction

I only know myself in that domain. How I feel intimately, and what is left of sexuality . . . I have never… he doesn't know 100% how I, what I actually experience. He probably thinks it is much more than it is for me . . . some things are somewhat an illusion for him . . . I don't want to pull that in a dangerous zone, by talking about that topic… It is not about not daring to. I would dare to. But the fear to say what I can really sense, my deepest inner me… There is the possibility that it worsens my-our sexual relationship. What is the value of disclosing? . . . Sex… I love doing it for him because I love him… I guess many women do it much more for their partners than for themselves . . . It is good the way it is, I leave that box closed.

(research participant)

Sexuality—i.e., sexuality seen as a normal and not intrinsically sinful or unhealthy part of life—has increasingly become an accepted and important research topic since the 1950s. Sexual health has even become an "integral component of the right to the enjoyment of the highest attainable standard of health" (WAS, 2008, p. 2), with sexual health being more than the absence of disease (Hull, 2008), sexuality being a "core element of self-becoming" (Shildrick, 2004, p. 1), and fulfilling sexual activity and intimacy working as antidotes to both physical and emotional pain (Tepper, 2000a) and as fundamental means of connection with oneself and others (Moore, Jesse, & Darvish Yahya, 2017; Shakespeare, 2000). Nevertheless, sexual feelings, sexual thoughts, bodily sensations reside in the dark, and problems in this domain are often covered by shame and anxiety for rejection. These protecting layers risk thickening when living with disabilities which can make a fulfilling sex life less self-explanatory (Gianotten, Meihuizen-de Regt, van Son-Schoones, 2008). Strikingly, given the importance of sexuality for quality of life (WHO, 2013) as well as the curious gaze projected on people with "extra-ordinary" bodies in an ostensibly predominantly able-bodied Western society (Garland-Thomson, 1997; 2009), sexuality among women with spinal cord injury (SCI) has received scant attention, especially beyond the confines of deficit frames in research, education, and healthcare practices.

This dissertation criticises and cracks the ear-numbing “conspiracy of silence”, i.e., the unspoken rule not to talk about sexuality when it concerns people exceeding a particular age limit or health status, that lives in hospital corridors and beyond (Enzlin, 2008), or rather the conspiracy of denial, as Kafer (2003) draws on the numerous sex-related questions that people with paralysis in particular receive about the scope of their sensations and functions to state that their sexuality is “denied loudly and repeatedly, not silently” (p. 85). This is done by uncovering some of the cherished pleasures, swallowed desires, hidden barriers and explored sensations of women with SCI alongside the practices (performed by themselves and their environment) which foster cherishing, swallowing, hiding and exploring.

The first step, however, is to offer my apologies, as I cannot talk about my research and its history without problematising talking about my research participants. Throughout my PhD, I have grappled with the question how to avoid confining the women (including myself) on whose stories this dissertation was based to the bodily markers abundant in research about “sexuality and disability”. Only when these words have seeped in, I will briefly present some insights of previously-trodden paths of research about sexuality and living with SCI. Without essentialising the participants who contributed to this research as “women with spinal cord injury” or catapult them into the category of “people with (physical) disabilities” (see Ellingson, 2017, on problematising the body), the presence of the body that functions differently (from before the injury and from what is deemed “normal”) as well as sexuality and disability’s history of invisibility must be recognised. Further down the road, I will introduce you to the theoretical contexts (including sexual script theory and Disability Studies) that inspired my research. This will be followed by the Slow methodologies I used (Ulmer, 2017) as well as the research questions that will help us to stay focused during the read of the subsequent chapters.

Apologies

Thé woman does not exist, neither does thé body affected by SCI nor thé woman living with SCI. Rather the woman with SCI is created, enacted every time SCI is discussed or treated (Mol, 2002). Experiences of the body and intimacy are constantly shaped in encounters with oneself and with others, enacted every time the body is touched, seen, smelt, reflected upon, portrayed as pleasure-providing or not, remaining multiple. I need to state it, because I, too, plead guilty in talking about my research participants and using the words "women with SCI" as first identifiers, labelling them for the sake of narrowing down research questions and composing and describing research "samples". I plead guilty for letting binary-creating, quantifying gazes lead my search for participants at first, only allowing women with traumatic spinal cord injury (and without any other medical label, as these could be "confounding variables") and aiming to find a quantitative balance between women with paraplegia and women with tetraplegia (assuming there would be a difference in their sexual experiences based on the 'severity' of the injury, following studies reporting on the high priority to regain sexual functioning for people with paraplegia, and to a lesser extent for those with tetraplegia; Anderson, 2004; Anderson, Borisoff, Johnson, Stiens, & Elliott, 2007).

It has been, and still is, a delicate act of negotiation between acknowledging the varying impact of chronic illnesses or injuries on (experiences of) sexuality, and thus bringing to the fore research that narrows down its focus to people with specific 'conditions of the body', yet not *other* my research participants and their experiences and create a distance between them, us and you but instead see every human being constantly shifting positions on a continuum ranging from able-bodied to near-dead. Each chronic illness or injury can impact differently on an individual's physical and psychosocial ability to engage in the expression of sexuality as well as the perception of their sexuality by others due to a range of factors including class, gender, age, sexual orientation, origin of impairment (congenital, acquired, gradually as part of ageing process) (Di Giulio, 2003; Shakespeare, 2000), and their medical labels do not necessarily serve as master "narrative arcs" to understand their experiences of being in the world as a sexual being (Gallop, 2019, p.9). I am wary of subscribing to the "grand binary narrative" of people being either able-bodied or disabled/ill and their experiences of life as dominated by their physiological "condition" (Grosz, 1994).

I am grateful to be able to look back at my encounters with my participants with the feeling that labels became irrelevant from the moment we started conversing and engaged in emergent listening practices (Davies, 2014), characterised by "a radical break … from usual ways of making sense of difference" leading us to a space "through which the not-yet-known might open up" (Davies, 2016, p.73).

And here I am. Writing the general introduction to my doctoral dissertation. Seeing the need to sketch the academic context in which my research was born, yet cautious (and in tremendous awe) of what words can do. On my office wall, bell hooks reminds me to remain conscious of how I listen and what I write (hooks, 1990, p. 43):

> [There is] no need to hear your voice, when I can talk about you better than you can speak about yourself...Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own. Re-writing you, I write myself anew. I am still author, authority. I am still [the] colonizer, the speaking subject, and you are now at the center of my talk.

Both the concise literature review and the crafted selections from the women's personal narratives you will read serve as a "window on the social" (Thomas, 1999, p.75), not to be understood as the highway to these women's or anyone's psyches or a template of "what it means to live with spinal cord injury" that can be blindly applied to all women with spinal cord injury, but as a means to enhance our knowledge of how constructions of sexuality and the body work and affect everyone. I invite you to read this dissertation not as a dissertation about some distant "other" or about a specific group of people, but as a text concerning human beings and human rights and "a potential site for collective reimagining" (Kafer, 2013, p. 9).

Necessities

Whilst pleading for thinking and acting beyond binaries in human embodiment, however, it is necessary to acknowledge the history-continuing-into-the-present of neglect of sexuality when covering disability and of disability when covering sexuality in research, healthcare, media, and education. The history of sexuality reveals an evolution with numerous cycles of repression and liberation (Foucault, 1978; 1997). Traditionally, the sexual lives of people whose bodies are most clearly not positioned at the perfectly able-bodied end of the human embodiment continuum in particular have been actively disregarded or stigmatised (Tepper, 2000a; Kafer, 2003), with their disabled form portrayed as undesirable in terms of "physical, cultural and social capital" (Hughes, Russell, & Patterson, 2005; Houston, 2019) and their sexuality as inherently bizarre and exotic, hyper (i.e., uncontrollable sexuality which is potentially dangerous for themselves or others; Waxman Fiduccia, 1999), or non-existent (i.e., lacking desire for sexual intimacy; Asch & Fine, 1988; Shakespeare, Gillespie-Sells, & Davies, 1997). Half a century ago, the dominant social approach to deviation from the norms of human embodiment was segregation and institutionalisation (Braddock & Parish, 2001; Kline, 2001). Traces of such histories and herstories affect many practices today, abnormalising and challenging the sexual development and expression of people who do not "fit" in the current portrayal and highly normalised view of sexuality as the rightful domain of the youthful, masculine, heterosexual, white, able-minded and able-bodied in society (Garland-Thomson, 2011; Tepper, 2000a). Not seldom, they are "viewed under a paternalistic prism and considered as child-like and in need of protection, totally void or unworthy of sexual drives and as a result their sexuality is a taboo issue" (Sakellariou, 2006, p. 104)

In both media and sexual education, there is the absence of role models who (visibly or known) deviate from the norm of able-bodiedness (Hughes, Russell,

& Paterson, 2005; Van Ertvelde, 2019), theorised to affect people's views of their abilities to be a sexual partner (Esmail, Darry, Walter, & Knupp, 2010). Education focuses on sexually transmittable diseases, anti-conception, and performance using templates of sex with fully reproductive organs and standard bodies rather than intimacy, relationships, desire, pleasure, and diversity (van Lunsen, Brauer, & Laan, 2013). Mainstream media is the one institution that has not ignored sexual pleasure, but has, in its exploitation for gain, targeted a market that excludes people who have been traditionally marginalised in society (Tepper, 2000a).

In healthcare, there is still a misconception that SCI diminishes the need for sexual, physical and emotional intimacy (Atkins, 2002). This reflected in the low priority that professionals assign to sexual issues, together with and due to their discomfort with the topic, in the lack of knowledge about sexual functioning, in the adherence to strictly (Western) medical and technical models of sexuality (Dyer & das Nair, 2012; McColl, Aiken, McColl, Sakakibara, & Smith, 2012); in the lack of physical access regulations (e.g., women with disabilities receive less frequently pap smears than temporarily able-bodied women partly because of the inaccessibility of many gynaecologists' practices and examination tables; Tilley, 1996), etc.—all resulting in a lack of support beyond what is known to be possible or impossible or potentially possible on the templates created per physiological condition despite their ideal position to support psychosexual health through counselling and education. Whereas many professionals in the 1970s endorsed the view that "the less said to cord injured patients regarding sexual functioning, the better; and that repressive mechanisms should be allowed to take their course in stifling thoughts and preoccupations about sexuality" (Hohmann, 1972, p. 55), sexuality is now a standard topic in Flemish rehabilitation hospitals, but often only in the form of one group presentation by a physician about what technically is/might (not) be possible (anymore) and a conversation with the in-house psychological counsellor, maybe a moment where experts by experience come and give peer advice on a voluntary basis, and it is questionable whether everyone is reached (enough).

Research on sexuality and people living with disabilities began to emerge after World War II, focusing on the sexual rehabilitation of injured men. With the rising of the Disability Rights Movement in the 1970s research started to address the psychosocial aspects of living with disabilities. It took another two decades for voices such as Anne Finger's (1992) on sexuality as "often the source of our deepest oppression… the source of our deepest pain" (p. 9) and Barbara Faye Waxman's (1991) questioning "Why hasn't our movement politicized our sexual oppression as we do transportation and attendant services?" (p. 85) to be put on the disability activism agenda. Other feminist authors within Disability Studies—with an intersectional lens, incorporating social categories such as disability, gender, race, sexual orientation, and processes such as sexism and misogyny—have challenged the marginalisation of the sexual politics of disability by writing about their own lived experiences of impairment, disability as a phenomenon (referring to the interplay between the biological 'impairments', the sociocultural context, and lived experiences; Van Hove, Schippers, De Schauwer, & Cardol, 2016) and their multiple identities (Crow, 1996; Morris, 1989; Panzarino, 1994; Thomas, 1999; Wendell, 1996).

This PhD aims to contribute to the stream of research and activism countering deficit-approaches (De Schauwer et al., 2017, Mona et al., 2009) and advocating for sexual citizenship (Shakespeare, Gillespie-Sells, & Davies, 1997, p. 206) and intimate citizenship, broadly defined as "*the control (or not)* over one's body, feelings, relationships; *access (or not)* to representations, relationships, public spaces, etc.; and *socially grounded choices (or not)* about identities, gender experiences, erotic experiences" (italics in original; Plummer, 2003, p. 14; see Liddiard, 2018; Shildrick, 2013).

Setting the Scene for Sexuality with Spinal Cord Injury

International incidence data suggest that every year between 250 000 and 500 000 people acquire a spinal cord injury worldwide of whom at least twice as many men as women (WHO, 2013, p.17-20). Spinal cord injuries can be traumatic (following traffic accidents, falls, sports injuries, violence, etc.; this is the kind of

SCI acquired by the women you will read about this dissertation) or non-traumatic, usually involving an underlying pathology (such as infectious diseases, tumours) or congenital problems. From a medical point of view, spinal cord injury is a complex condition involving complete or incomplete damage of one or more levels of the spinal cord and/or the nerve roots in the spinal canal affecting the connection between the brain and parts of the body. Depending on the (in)completeness and the level of the lesion (the higher up the spinal cord, the more extensive the scope of affected body functioning), spinal cord injury can result in loss of motor control (i.e., the ability to control body movements) or sensory control (i.e., the ability to sense touch, temperature, pain, etc.), as well as loss of the autonomic regulation of the body (including breathing, heart rate, blood pressure, temperature control, bowel and bladder control, lubrication, orgasms, etc.) (WHO, 2013). ‘Paraplegia’ refers to a lesion on thoracic level with paralysis of the legs, whereas ‘tetraplegia’ refers to the paralysis of both arms and legs and a bigger compartment of the torso (Kiekens & Post, 2008). From a social and psychological point of view, the acquirement of a spinal cord injury suddenly disrupts one’s normality; personally and within a society characterised by the normalisation of bodies as well as the normalisation of sex (Foucault, 1997).

Many people—and men more frequently than women—with SCI report sexuality-related problems (Kiekens & Post, 2008, p. 222; Post, van Dijk, van Asbeck, & Schrijvers, 1998). In comparison with people without SCI, they report to have sex less frequently and to be less satisfied with their sex lives (Beckwith & Yau, 2013; Reitz, Tobe, Knapp, & Schurch, 2004). This is in line with research that shows that in (married) couples where one person has a chronic disease or injury sexual problems are frequently reported (Enzlin & Pazmany, 2008). Women with spinal cord injury (SCI) have been found to report the same sexual desires and needs as temporarily able-bodied women, but a significantly lower body image, sexual self-esteem, and sexual satisfaction (Moin, Duvdevany, & Mazor, 2009), as well as lower levels of activity, desire, and arousal (Kreuter, Siösteen, & Biering-Sørensen, 2008). A few studies report on the sexual recovery process after SCI, involving acceptance of the changed body, feeling attractive again, finding a new clothing style, gaining confidence to communicate about their body, exploration through information-seeking about sex (Beckwith & Yau, 2013), and having sex, with the first experiences post-SCI being an indicator for subsequent sexual interactions (Komisaruk, Richards, Tepper, & Whipple, 1997).

The "technically" sexual body with SCI

Most research about the sexual lives of women with SCI starts from a medicalised, performance-based view on sexuality, examining the impact of physical deficits on sexual functioning rather than sexual well-being and focusing on the "technical" aspects of sexual functioning rather than lived experiences and the relational context in which sexuality takes place (Kiekens & Post, 2008, p.221). This body of literature focuses on barriers women with SCI might encounter during their sexual lives due to spasticity, lubrication problems (depending on the level of the SCI), lack of bladder or bowel control, absence of genital sensation, medication affecting arousal, risks of autonomic dysreflexia, difficulties in moving into certain positions, etc. (Sipski, 2007; Stoffel, Van der Aa, Wittmann, Yande, & Elliott, 2018; WHO, 2013). Uncertainty remains when it comes to orgasm-ability, or rather, the experiences that have been labelled as orgasms in Western medicine (even less is known about how neurological damage interacts with the energy pathways leading to full body orgasms known in Eastern practices such as tantra; Moore, Jesse, & Darvish, 2017; Stubbs, 2000; Tepper, 2000b). The ability to experience these orgasms with a SCI regardless of the level of the injury is theoretically impossible (Kiekens & Post, 2008, p. 225), although a significant number of people with SCI report to still experience orgasms (more women than men, and on average half of the women with SCI; Sipski, Alexander, & Rosen, 1995; Sipski, Alexander, & Rosen, 2001; Sipski, 2007). It has also been found that after a SCI new erogenous zones can develop, often in the region between the "normal" and the "disturbed" sensibility zones and sometimes elsewhere (ears, neckline, …) (Kiekens & Post, 2008, p. 224).

Remarkably, sexual disorders in people with some types of chronic disease or injury are supposed to be a given, which marginalises or pathologises their sexual experiences. Until May 2013, the DSM-IV even listed SCI as a condition that physiologically results in sexual dysfunctions, thereby making healthcare providers fixate on and fixate their clients as bodies with neurological damage and making them less inclined to think about sexual difficulties and pleasure from a more holistic perspective.

The lived sexual body: Sexual scripts and dis/ableism

This PhD is built on the premise that the experiences of living with a neurologically blocked sexual body as described above are largely coloured by context. Moreover, this sociocultural context may be more inhibiting than physical impairment (Sakellariou, 2006). Sexuality is a multi-dimensional aspect of life, involving psychological and lived experiential aspects, physiological and biological aspects, within a social and cultural context (Enzlin, 2008). As described in sexual script theory that considers the "complex relation between intrapsychic experience, interpersonal relationships and the intersubjective cultural surround" (Simon & Gagnon, 2003, p. 491), "it is the historical situation of the body that gives the body its sexual (as well as other) meanings" (p. 492). The meaning of the body and sexuality is produced over the course of one's life through personal experiences and through the collective imaginary. To get a feeling of the vibes through which the disabled body specifically (and thus also sexual expression and pleasure with such a kind of body) is given meaning—alongside the body beautiful, patriarchy (referring to the social hierarchy through which men hold social and sexual privileges) and the deep-rooted ideas of sexuality as universal, spontaneous, self-explanatory, etc. that affect anyone on the continuum of human embodiment (Gagnon & Parker, 1995), we turn to the social relational model of disability where Thomas defines disability as "a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being" (1999, p. 60) and thus as a consequence of social injustice rather than a problem located in the body.

Ableism and disablism are used intermittently in the literature to refer to these practices of injustice, where disablism is “the exclusion of people with impairments” and ableism “the system by which standards of human anatomy and capability are made as key indicators of human worth” (Liddiard & Goodley, 2016, p. 152). To capture the duality of these processes, I will use the term dis/ableism hereafter (Liddiard, 2014a). Operating on both the public and the personal level, the structural dimension of dis/ableism acknowledges barriers affecting what people can *do* (e.g., inaccessible spaces to get to know potential sex partners, financial cost of assistance/medicine/etc. making social outings or frequent sex too expensive, inappropriate personal assistance, lack of employment), whereas the psycho-emotional dimension of dis/ableism entails barriers affecting what people can *be* (e.g., harder for people to beam with self-confidence and thus sex appeal in a neoliberal society that systematically devalues and excludes people without “able” bodies, routine objectification and voyeurism) (Reeve, 2002; 2004; 2014; Shakespeare, 2000; Thomas, 1999). Psycho-emotional dis/ableism is relational (Liddiard, 2014b), embodied through “hostility or pitying stares, dismissive rejection, infantilisation, patronising attitudes, altruism, help and care on the part of non-disabled people” (Goodley, 2010, p. 96), which “frequently results in disabled people being made to feel worthless, useless, of lesser value, unattractive, a burden” (Thomas, 2006, p. 182).

Myths celebrating dominant able-bodied corporeal standards such as “people with disabilities lack sex drives”, “disabled people are dependent and child-like and, thus, need to be protected and not exposed to sex”, “disabled people should stay with and marry their own kind”, “women with impairments are less affected sexually than men because of their more passive sexual role”, and “if able-bodied people find people with disabilities desirable, they settle for less” continue to permeate interaction in every layer of society (Olkin, 1999; Brodwin & Frederick, 2010). Thereby they detrimentally affect the public, interactional, and private sexual scripts (i.e., social and cultural guidelines that embed sexual feelings and behaviours in certain meanings, and by doing so define sexuality, prescribe what is appropriate and what is not, and who has the right to be sexual, and what pleasure can be; Dune & Shuttleworth, 2009; Gagnon & Simon, 1973) on which one's sexuality is based and ultimately foster stigmatisation, sexual marginalisation, and social isolation (Duna, 2013; Kimmel, 2007).

Although social beliefs and attitudes are slowly changing for the better, impairment still easily overshadows all the other features of a person as anomalies—distortions of known physical and social rules—tend to unsettle or trigger curiosity (see Murphy, 1990, on the spread phenomenon colouring most interactions between temporarily able-bodied people and 'others'). Disability easily becomes "the inescapable social label", which "may lead to disabled people being unilaterally excluded from the sexual arena" (Sakellariou, 2006, p. 102), given that sex is seen as a privilege of the non-disabled who embody the Western values of independence, beauty, and marketability (Ryan, Bajorek, Beaman, & Anas, 2005, p. 121; Tepper, 2000a). Oppressive and excluding ideas such as those listed above influence how people are talked about (or not) and engaged with (or not). Being acculturated with and internalising these ideas—referred to as "internalised oppression" in social psychology, occurring when "individuals in a marginalised group in society internalise the prejudices held by the dominant group" (Reeve, 2004, p. 91)—people may come to believe that although they want to be sexual, they cannot be or are not entitled to be sexual (Sakellariou, 2006). In short, as the body and associated sexual scripts are modified throughout the life course, disability comes to restrict individuals' space to freely express themselves sexually (Jackson & Scott, 2010).

Psycho-social-cultural factors affecting sexuality as those discussed above are slowly finding their way into healthcare research (Kreuter, Siösteen, & Biering-Sørensen, 2008). This includes research on components of disturbed intimacy due to "indirect secondary effects" after SCI (i.e. effects not stemming directly from the neurological damage), covering decreased libido; lowered self-esteem; coping problems due to ongoing comparison with able-bodiedness as a reference and distancing from the own body exacerbated by the loss of sensitivity under the lesion; aversion from the own body due to significant changes in body appearance such as thin and white legs (van der Spiegel, 1998); the need of support from others in daily activities such as eating, bathing, toilet;

participation problems due to accessibility of social spaces; the balance in relationships between being each other's lovers and being caregiver-careasker (Post, Bloemen, & de Witte, 2005). A recent study on the "intimate spaces" of the lives of people with non-traumatic spinal cord damage (SCD; associated with a chronic condition, in contrast to traumatic SCI) considers sexuality and pleasure to be shaped by embodied changes and suggests that, although the severity of the injury significantly affects participation in and satisfaction from sexual activities, the effects of "social constructs regarding sexuality, disability, gender and aging are more profound", with rigid adherence to norms by the people with the SCD themselves and others inhibiting their sexual pleasure whereas "flexible norms served to enhance sexual satisfaction" (Seddon, Warren, & New, 2017, p. 2).

Research Quest(ions) into the Search for Sexual Expression and Pleasure

Notwithstanding the importance of studies on neurological functioning, the research trend described in the section on "the 'technically' sexual body" offers and reinforces medicalised and performance-oriented views of sexuality. This fosters healthcare practices that ultimately run out of options in (re-exploring) sexual expression and pleasure (Tepper, 2000a), once rehabilitation and medical interventions have reached their limits in fixing and modifying the body. The research trend about "the lived sexual body"—mainly fuelled by disability and social justice studies—urges us to attend to the disabling impact of social/cultural/environmental factors on sexual identity formation and possibilities for sexual expression, yet in doing so risks to neglect the reality of living with physical limitations and discomfort and hence lead to reverse essentialist approaches renouncing that impairments may affect sexuality (Kool, 2010; Linton, 1998; Sakellariou, 2006; Snyder & Mitchell, 2001; Thomas, 2006). It also risks to erase the agency of people with impairments. As Shakespeare (2000) warned in his introduction of a social model of disabled sexuality, "[t]here is a great temptation, within disability politics, to play the game of who is most oppressed, and to speak from the victim position, but there are costs to that game" (p. 162). Therefore, research that voices the idea of people with impairments being "victims of an oppressive society" on top of being "victims of their malfunctioning bodies", should also "show the ways in which people resist disabling barriers … people can and do overcome discrimination and prejudice" (idem). Research that voices the lived sexual experiences and desires of women with SCI and positions them at the intersection of matter and normative discourses (about gender, sex, bodily pleasure, disability, etc.) remains scarce (Kafer, 2003). This absence—especially in the context of a growing focus on sexual pleasure in sex research—is unacceptable as this ever-growing minority is likely to encounter many barriers in experiencing their body as a source of pleasure.

The current research project entails an in-depth exploration of the lived experiences of being a woman with sexual desires living in and with a body with SCI. Hereby we focus on their own perspective, yet consider the interdependence with the people around them, the discourses they are exposed to, as well as the materiality of their lives. Aware that research about people dealing with disability is often written as if things happen *to* them (featuring notions of broken bodies, discrimination, taboo, etc.) and as if they are merely undergoing normalising semiotic, material, and social "flows" (Deleuze & Guattari, 1987, p. 22), special attention is paid to how they intra-act with these flows and play an active role in the assemblages of their sexual lives. Two research questions, which are addressed in all subsequent chapters to varying degrees, were helpful to stay focused:

> (1) How do women perceive their sexual experiences and well-being, i.e., their lived experience of their bodies and intimate relationships in the past, present, and future, to have changed after acquiring SCI?
>
> (2) How are their views affected by material-discursive practices around sex and bodies enacted by the women themselves and their environment?

Two research lines contribute to getting insights about women with SCI's meaning-making and embodied experiences of searching for intimate pleasure and connection, and on a broader level the material-discursive practices at work in order to contribute to knowledge about what creates blockages and openings in the search for sexual expression and pleasure. One research line delves into the life 'herstories' of nine women with SCI, focusing on their subjective experiences of romantic relationships and sexuality as well as their SCI-changed body (mainly Chapters Three & Five). Another research line is autoethnographic, and offers an embodied insider/researcher's perspective (woven through the four following chapters, but most explicitly present in Chapters Two & Four).

The research focus is on the subjective experiences of the body and sexuality, rather than on sexual functioning (cf. physiological processes possibly affecting lubrication, orgasms, muscle relaxation, sensation, etc.). Sexuality is seen as more than sex in its most widely known form as a mobile and sensory performance affected by physical ability. It is seen as the way people experience themselves and others as sexual beings, "encompass[ing] sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction", "experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships", and entailing the needs for expressing affection and feeling accepted, valued, and attractive (WHO, 2006, p. 5). Sexuality "can include all of these dimensions, [but] not all of them are always experienced or expressed" (idem). Hence, we have left it to the participants to define sexuality, cautious of (de-)prioritising aspects of interacting with their body and other people that might (not) be relevant for them (Shakespeare, 2000, p. 164; Shakespeare, 2006, p. 168).

We research and write on the waves of the postmodern shift in Disability Studies from approaching disability as an individual deficit to disability as a dynamic outcome of intra-actions between the materiality of one's body and of one's lifeworld intertwining with meaning-making of one's self, intimate others (romantic partners, sex partners, friends, family, specific healthcare providers, etc.) and more public, invisible others (discourses permeating and spread by media, education, healthcare policy, academia, etc.) (Shakespeare & Watson, 2001; Watson, 2002; Stroman, 2003). People manoeuvre within relational *assemblages*, and it is in these ever-shifting constellations that disability comes into existence. Disability is a "quintessential post-modern concept, because it is so complex, so variable, so contingent and so situated. It sits at the intersection of biology and society and of agency and structure. Disability cannot be reduced to a singular identity: it is a multiplicity, a plurality" (Gabel & Peters, 2004, p. 588). Furthermore, bodies are seen as "neither whole nor broken, disabled nor able-bodied, but simply in a process of becoming" in "a model in which corporeality is no longer to be thought in terms of given and integral entities, but only as engaged in ever dynamic and innovatory linkages" (Shildrick, 2009, p. 159). Accordingly, able-bodiedness is "not an immanent feature of 'the body' (as if it could be decoupled from its environment) but is a dynamic index of architectural, economic, industrial, biomedical, discursive, material, informational, affective, political, and sociocultural assemblages" (St. Pierre, 2015, p. 340).

Reaching also beyond the legacy of Disability Studies, we are inspired by material feminism which emerged from the work of Karen Barad (2007) amongst other feminist theorists and scientists. Whereas the use of new materialist work as metaphors outside the realms of post-humanism might not be appreciated by hardcore new materialists, which I do when I phenomenologically explore the lived experiences of human beings, they have opened up my thinking about experiences of the body as *intra-acting* with material-discursive practices and I feel compelled to say so. Once you have been introduced to a lens, you cannot leave it behind, and when you go back to your research materials, you will see differently. Intra-action (Barad, 2007), as explained in "The intra-active production of normativity and difference" (De Schauwer, Van de Putte, Blockmans, & Davies, 2018) signals "the conceptual movement away from separate entities engaging with each other (interaction), toward the unfolding process of becoming in relation to others, where each one is capable of affecting and being affected by the other (intra-action)" (p. 609). The new materialist stream of theorising provided me (and Vagle's (2014) post-intentional phenomenology, cf. infra) with conceptual language that "expands the idea of social construction of reality toward a material-discursive understanding of phenomena and matter" (Garland-Thomson, 2011, p. 592). The emphasis is on interactive dynamism—what Barad calls ''intra-active becoming'' (2007, p. 146)—, which "understands the fundamental units of being not as words and things or subjects and objects, but as dynamic phenomena produced through entangled and shifting forms of agency inherent in all materiality" (Garland-Thomson, 2011, p. 592).

When listening to participants' stories and reading the products I have crafted, we turn our attention to "world-making involved in material-discursive becoming" (Garland-Thomson, 2011, p.592). The use of "becoming" in disability research fuels the "move away from tightly defined identity categories that distinguish unequivocally between disabled and non-disabled bodies, and underscores a radical intersubjectivity and fluidity" (Simpson & Matthews, 2012, p. 142). We are interested in "the question of becoming", which is "not which subject to become but how to escape the forces of subjectification that block flows of desire and re-inscribe the subject" (Goodley, 2007; in Fritsch, 2010, p. 7). That is, I am sincerely interested in the lived experiences of the women I have had the honour to connect with *and* I am interested in world-making-in-becoming, i.e., the semiotic, material and social flows that constantly affect their desires and how they can imagine to and can experience their body as sources of pleasure and intimacy.

The value of research focusing on material-discursive practices affecting the lived experience of the body in Disability Studies is in its contribution to exploring ways to talk about whatever-kind-of-bodies and build bridges. As Alaimo and Hekman phrase it (2008, p. 4), "[f]ocusing exclusively on representations, ideology, and discourse excludes lived experience, corporeal practice, and biological substance from consideration. It makes it nearly impossible for feminism to engage with medicine or science in innovative, productive, or affirmative ways".

Participants

Search for voices

I spread information letters (in print and online) with the invitation to contact me via phone or e-mail through: (1) the healthcare team I worked with at the UZ Leuven rehabilitation centre (see Chapter Two), (2) my gatekeeper (a psychologist) at UZ Ghent, (3) managers and spokespersons of organisations working for or with women with SCI such as Project U/TURN, REVA2015 (information exposition for people living with disabilities), Persephone, and Vlaams Agentschap voor Personen met een Handicap (VAPH, Flemish agency for people with disabilities). In these letters, I announced that I was looking for women with SCI who were 18 or older, fluent in Dutch/Flemish, had spent at least half of their lives in Belgium, and who wanted to take part in individual or group interviews at a time and location of their choice, with the explicit statement that their current relationship status and their sexual history were not important in order to be eligible for participation. Eleven women with SCI responded to this call. One of them e-mailed me to say she considered herself too old to take part (she was in her 70s, and unfortunately did not respond to my reply that her story was valuable too), and one only spoke French (which made it impossible for me to conduct in-depth interviews myself). Another four women responded to the calls of some of other volunteers (snowball sampling).

Connection interviews

In total, I conducted 13 connection interviews (7 at the volunteer's own house, 4 in a public space, 1 at my house, 1 over the phone). During these interviews, I answered the women's questions (about the aims of the study, the time investment, participant requirements), collected demographic information in the flow of the conversation (i.e., age, sexual orientation, current relationship status, religion, level of SCI, etc.), and discussed the informed consent form. Most women started sharing personal stories relevant for my PhD as soon as I had mentioned the topic, which showed their readiness and/or need to talk about sexuality and relationships. The first two times I asked them to keep this information for the in-depth interview, but I regretted this afterwards because spontaneously disclosed information by association or by being in the flow of informal conversation is invaluable for qualitative researchers. Hence, the next time this type of spontaneous disclosure happened, I quickly asked for permission to record it and followed the participant's pace. One woman found the intake interview "a heavy start, much heavier than expected" and decided not to continue her participation. My memories of her, however, would many times pop up during my research journey, activating my ethical radar that considered the power of asking questions and opening up pathways of thinking never explored before, the history of voyeurism when it comes to studying disability, and my appearance as the "confident, stunning woman" this research participant had not expected. Two other women unfortunately felt compelled not to take part due to health problems and the corresponding decrease in time they could invest, and another one never replied to any phone calls or e-mails after the intake interview.

Demographics

The ten women (including myself) whose stories are woven through the dissertation lived spread out over Flanders and all spoke Flemish as their first language. All are heterosexual (although this was not a requirement). At the time of the interviews, seven were married and had children (either before or after the injury); one was in a relationship at the time of the first interview in June 2015 and gave birth to her first child shortly after the final data gathering encounter two years later; one was single and had never had a sexual or romantic relationship; one (or the only one of whom it is known) had varying relationship statuses throughout the project. Their age at the time of the connection interviews ranged from 22 to 57, and the time they had lived with SCI ranged from 1.5 to 34 years. Eight acquired their injury due to an accident, two due to medical complications (epidural injection, cancer).

Seven participants are paraplegic (SCI-p), of whom four use a manual wheelchair and live without basic healthcare assistance; one has SCI-p but can walk short distances and lives without basic healthcare assistance; two have SCI-p but do not have enough arm power to use a manual wheelchair outside the house or to easily do transfers without assistance and need some basic healthcare assistance (such as toilet, washing, and usually getting dressed to speed up this process). Three are fully tetraplegic (SCI-t), alternate between using a manual and an electric wheelchair, and need daily assistance with both healthcare and some other day activities (such as toilet, washing, getting dressed, cooking, transport, etc.). For most, retained sensory function corresponds to retained mobility function.

Please find below an overview of basic demographic information of the participants (birth year, onset and level of SCI, relationship status at the time of their participation). If their stories served as the major, explicit foundations of a chapter, it is indicated between brackets. I consciously do not give more details (about exact lesion level, number of children) for reasons of confidentiality and irrelevance for understanding the findings of my research. On a critical note, what is written in the boxes below does not tell us much about the participants and life. Participant 10, for instance, is paraplegic and in medical reports she has two lesion levels connected with a hyphen, and she is currently in a committed relationship, but was in a committed relationship at the beginning of the research and in the middle, all of which only partly overlapped with the periods of gathering research materials and writing papers, and she engaged in not-quite-committed relationships in between.

Participant	Birth	SCI	Relationship status
1 (Ch. 5)	1973	2008 - tetra	Married, mother (before SCI)
2 (Ch. 5)	1984	2013 - para	Committed relationship with man with SCI, mother (after SCI)
3 (Ch. 5)	1977	2002 - tetra	Married, mother (after SCI)
4 (Ch. 5)	1960	2013 - para	Second marriage (together since 2000), mother (before SCI), grandmother

5	1958	1983 - para	Married, mother
6	1961	2002 - para	Married, mother
7	1961	2007 - para	Third marriage (after SCI), mother (before SCI)
8	1955	2010 - para	Married, mother (before SCI), grandmother
9 (Ch. 3)	1993	2007 - tetra	Single
10 (Ch. 2 & 4)	1988	1991 - para	Committed relationship

We met on the following days for connection interviews (C.I.), follow-up individual interviews (I.1 & with some participants I.2), connection interviews for the next stage of the research (C.E.: connection for ethnography), the two ethnographic parts (E.1: shopping; E.2: make-up/photoshoot), the joint interviews with a friend (Joint) and the focus group discussion with the four participants who took part in the ethnographic exploration (FGD):

	C.I.	**I.1**	**I.2**	**C.E.**	**E.1**	**E.2**	**Joint**	**FGD**
1	4/09/15	06/07/15		23/11/16	11/02/17	18/02/17	9/03/17	18/03/17
2	13/04/15	10/06/15	12/07/16	24/11/16	15/02/17	18/02/17	22/02/17	18/03/17
3	23/04/15	2/06/15	7/06/16	14/11/16	14/02/17	24/02/17	3/03/17	18/03/17
4	14/04/15	10/08/15	11/07/16	31/10/16	5/12/16	24/02/17	9/03/17	18/03/17
5	13/05/15	13/08/15						
6	15/04/15	18/06/15						
7	25/04/15	11/08/15						
8	9/06/15							
9	23/10/15	27/11/15	16/6/16					

Caveat: Although Chapter Three focuses only on one of the research participants, Chapter Five focuses on four others, and Chapters Two and Four have been labelled as autoethnographic, all encounters and stories shared throughout my research trajectory by all research participants (and colleagues, friends, (ex-)lovers, etc. as my PhD did not evolve in a bubble) have contributed to our developing insights.

CHAPTER ONE

Methodology: Gathering the Story Building Blocks and Crafting the Stories

Methodology of wandering and becoming with

We have aimed to be guided by “an ontology of becoming(s) rather than being” throughout data gathering, analysis, and presentation of the research, in the tracks of Deleuze and Guattari (1987) who believed that “the task of philosophy in our times is not to know who we are, but rather what, at last, we are in the process of becoming” (Braidotti, 2010, p. 5-6). It is in the process of doing and living my research that my research took shape and became, contrary to what the formulation of ‘the’ research questions ahead of the chapters with research insights might suggest. Mazzei puts it as follows (2016, p. 159):

> Instead of beginning with questions, which, according to Whitehead, prompt answers that foreclose thought, researchers might begin with those things that present problems in the sense that they take hold and would not let go, that which Barthes (1980/2010) described as acting with a force that wounds.

I would add that my dissertation is the result of a journey revisiting over and over again those fragments in my participants and my own becoming-in-the-world which acted with a force that not only wounded but also healed. The research was driven by wandering with “wonder”, “simultaneously Out There in the world and inside the body. . . distributed across the boundary between person and world” (MacLure, 2013, p. 181). Gathering ‘data’ from the encounters with my research participants and from my own life as it was happening as well as interpreting these data were overlapping and cyclical, characterised by re-turning again and again to those moments that ached as they signalled extinguished or hidden desires or being lost in the darkness of uncertainty or social injustice and those moments that witnessed openings to manoeuvre, to act, to create.

It has become a lyrical, "messy" qualitative research project (Denzin, 1997), playing with the feature of qualitative inquiry as a wonderful "craft" in service to "generating deep understanding, unpacking meanings, revealing social processes, and, above all, illuminating human experience", highly valuing "sensory knowledge and experience, multiple meanings, and subjectivity in the research process" (Leavy, 2016, p. 21). I embraced Leavy's validation of literary experimentation as a social research practice and experimented wildly with poetry, a fictional monologue, dance and photography, as I believe that "imagination and metaphor are needed in order to portray lives sensitively" (2016, p. 23) as well as to trigger readers to think beyond the lives of 'others'.

(Auto)Ethnography—culture writing—was chosen as method of knowledge making. In its engagement with "the specific and localised lifeworlds or discursive spaces and material conditions of a small number of people" (Goodley, 2004, p. 59), ethnography is inherently open to what unfolds during the "immersion within, and investigation of a culture or social world" where the ethnographer tries "to make sense of public and private, overt and elusive cultural meanings" based on collected narratives, fieldnotes of observations, and thorough reflection (p. 56). My contact with participants did not entail 'just' interviews; it involved meeting people at their homes, using their bathrooms, sharing lunch, conversing on the pavement on our way to shops or back, participating in body-centred activities, etc. Ethnography's central strength is its "potential to reveal the unanticipated loose ends and discontinuities of everyday life ((that)) are critical to a deeper understanding of social complexity" (Seymour, 2007, p. 1189). The product, in "thick descriptions" (Geertz, 1973) elaborated with moving with the data and at its best in the shape of storytelling, offers "partial and situated renderings of particular social realities" which bridges "people's individual biographies (micro-level experiences and situations) and the larger (macro-level) sociohistorical contexts that shape their experiences and in which their lives play out" (Leavy, 2016, p. 30).

In response to Leavy's question "how does one write culture?" (2016, p.30), I have followed the growing wave of "ethnography as a deeply personal research experience" (Van Maanen, 1988; paraphrased in Leavy, 2016, p. 30) and moved constantly on the continuum from ethnography (as far as research can ever be not about the researcher who decides what to select and how to write) to autoethnography (where the researcher reflexively writes the self into and through the ethnographic) (Denzin, 1997; 2015, p. 125). I describe this movement as a constant zigzagging between participants' stories and my own experiences, discovering movement in my own ongoing exploration journey towards feeling free to be intimate and present in/connected with my body, and going back to my participants with that insight, with a different angle of listening and daring to probe further questions about how they move. Whereas I have chosen to present the papers making up my doctoral dissertation in the order they took on their final form and were submitted (and accepted) for publication, the events they were based on and the processes of analysing and writing were often overlapping and inevitably affecting each other.

For the more explicitly autoethnographic research line, I was inspired by Ellis' resonant, evocative, emotional, narrative essays that embed the personal in the social (2009), Spry's more performative oeuvre about the self and the other, questioning who the "I" refers to (2016), Wyatt's lyrical and deeply personal accounts about his counselling practices (2018), as well as Davies' work with memories in her collective biography workshops driven by her view that (Davies, Masschelein, & Roach, 2018, p. 266; see also De Schauwer, Van de Putte, Blockmans, & Davies, 2018; De Schauwer et al., 2017):

> Our embodied memories are not worked with to tell "who we really are," or in an orgy of narcissistic pleasure, but as material that takes us inside the aspect of the human condition that we are interested in exploring.

In the autoethnographic work I present to you, "[t]he 'I' has no story of its own that is not also the story of a relation" (Butler, 2005, p.8). The I is a "negotiation of … subjectivities in meaning making" (Spry, 2011, p. 503), and this meaning-making comes forth from my encounters with, amongst others, my research participants. When I write about "my body", there is actually "no story of my body, only the daily, momentary mediations between experience, senses, memory, desire, understanding—mediations between my body and beyond" (Smyth, 1998, p. 19). Autoethnography "requires that we observe ourselves observing, that we interrogate what we think and believe, and that we challenge our own assumptions, asking over and over if we have penetrated as many layers of our own defences, fears, and insecurities as our project requires" (Ellis, 2015, p. 10). It is a method that is as reflective and as deep qualitative inquiry can go (especially into lived experience), revealing "hidden features of the present as well of the past" (Denzin, 2015, p. 126). The goal is "to self-consciously problematize a definitive sense of self and others, pursuing instead a richer understanding of the fragmented, temporally and contextually shifting nature of selves and relationships" (Anderson & Glass-Coffin, 2015, p. 73).

Speaking of relationships, I invite you as the reader, with the words of Bochner and Ellis (1998), to:

> compare their own worlds with those of the people they meet on the pages of these stories… ((and to)) bring the written product of social research closer to the richness and complexity of lived experience… ((in an)) attempt to bridge the gaps between author and reader, between fact and truth, between cool reason and hot passion, between the personal and the collective, and between the drama of social life and the legitimized modes for representing it. (p. 7)

Encounters with the white coat (Chapter Two)

I started my research project by doing fieldwork at the rehabilitation centre of the Leuven University Hospital (13/01-13/02/2015), where I assisted the healthcare team in sports therapy, counselling, basic caretaking and had informal conversations with the residents about struggles and optimism in rehab. I saw the internship as a way to gauge the place of sexuality in rehab as well as an introduction to the environment where women with SCI spend the first year after their injury and learn to deal with their changed body and hence an important context for understanding their lived experiences (Vagle, 2014, p. 122). I should have known in advance that "'being there' in the ethnographic field is a fuzzy process, fluid, with the emphases on process, participation, and ongoing 'becomings' of embodied and emplaced body-selves, including those of the researchers" (Ellingson, 2017, p. 81), but I only found out by rolling with it and finding participatory observation (them) turning into observing participation (us), becoming a "vulnerable observer" (Behar, 1996).

By immersing myself in this context where I was surrounded by people with "broken" bodies (Shildrick & Price, 1996) and by travelling with them, I did not only learn about the doubts and fears and joys that arise during those first months of learning to live with a changed body, but I also learnt quite a lot about implicit attitudes held towards different bodies by myself. It was the foundation for an autoethnographic chapter on how I saw myself, being a female researcher with spinal cord injury, in relation to my research, my research participants, women with spinal cord injury, normativity and difference (see Chapter Two).

Furthermore, I came to see the value of "peer as method" yet also the relational ethics that come with it (after Tillmann-Healy's friendship as method, 2003), when I noticed that my body and my being, alongside my body being a point of interest and discussion itself, facilitated establishing trustful relationships with participants that made them feel comfortable to talk about their own bodies (Ellingson, 2017; Turner & Norwood, 2013). Stories came without me asking for them. I simply welcomed them whilst wandering with people, and this wandering continued throughout my PhD trajectory.

Clicks and flowing desires (Chapters Three & Five): Working with other women with SCI

Data gathering

I continued with the playful and organic flow I had come to know during my work at the rehabilitation centre. I organised three data gathering rounds between April 2015 and March 2017, aiming to explore participants' meaning-making of key events and concerns when it comes to sexuality and living in and with their changed/changing body and, especially in the second data gathering round, their "imaginative manoeuvrability"—a concept that I developed over the course of my PhD and which will be elaborated on in more detail in the discussion chapter. I have chosen the word "data gathering", as it conveys the relaxed openness of the encounters I experienced with my participants as well as the feeling that Vagle describes as "as though we could just as easily be taken up by the data than doing the taking" (2014, p. 73).

The first data gathering round involved in-depth individual life story interviews with ten women with traumatic spinal cord injury (two or three times each, 45-90 minutes) and explored the meaning of sexuality throughout their life and how these meanings came to be in relation to their environment. The employed interview style can best be described as "convergent interviewing", beginning with an open-ended way of conversation to maximise participants' input (Goodley, 2004, p. 85), and "InterViewing" on this journey shared by interviewer and interviewee (Kvale, 1996). An interview guide was nevertheless designed in case of silences of not knowing how to start or to continue, based on a combination of the narrative interview method developed by sociologist Fritz Schütze (see Riemann & Schütze, 1987) and the episodic interview designed by psychologist and sociologist Uwe Flick (2007). I usually started the research-focused part of the encounter from one main question: "Could you please tell me your life story with a focus on your development of relationships and sexuality?". Furthermore, aiming to help the participants find a tangible and for them relevant point of reference, I invited the interviewees after the connection interviews to tell their story—if they felt comfortable with this way of working—by bringing one or more object(s) that marked for them "an important stage or moment in their relational or sexual development" such as a picture, clothes, letters, quotes, etc. In this way, I aimed to give the interviewee the freedom to start from the episode she believed to be most important in the development of her sexuality and relationships (which is not necessarily concurrent with the onset of SCI) as well as something more concrete than a main and potentially too general question to start from. Three interviewees brought along an object (for one the only pair of red heels she had kept after her injury, for another pictures of daughters in which she recognised herself, and for another a diary when she was 12). The other interviewees either forgot or had a hard time finding an object by the time the interview took place, or spontaneously found a starting point during the intake interview on which they expanded in the following interview. Throughout these interviews, I checked my own interpretations. Also, after the interviewee had finished talking about a (sub)topic, I presented perspectives of other participants on similar experiences and invited the interviewee to respond in order to check connections of similarity, opposition, and nuance with other cases, thereby—as an interesting side-effect—creating focus group discussions within individual interviews. In all interviews, the injury was the cut-off point between a past of satisfying sexual experiences and a present dominated by a changed, psychological and physical labour-consuming body impacting on sexuality. The interviewees meandered around how they saw and lived with their bodies, but seldom talked about recent experiences of bodily pleasure.

This led to a second data gathering round with four of the participants, aiming to go deeper into embodiment as the changed and changing body was a recurring thread in the first round of encounters and to create a context for re-encountering their body. Together with the participants, a stylist who was also a trained pedagogue, and a master student sexology, I sought for a way to explore embodiment just enough out of the participants' comfort zone to come to insights about how free they felt in their bodies. Ideas such as shopping for lingerie or a naked photoshoot were soon considered to be too challenging, so we settled for a photoshoot with clothes that triggered for them a persona they wanted to explore, but which they would otherwise leave in the clothing racks. Whereas this approach might be criticised for its normative load (cf. body beautiful perpetuated in media), the presence of the body (as shape of appearance, tool for movement, vehicle for sensations, etc.) as a recurring topic in the previous data gathering round suggested that the desire in people to conform to the very norms that are questioned in this research cannot be neglected, and could offer an entry to self-reflection. Encounters were arranged as 'on-the-road' conversations during these body-focused activities with a self-chosen friend ("a person with whom you feel you can discuss your body and desires"; all participants chose a female friend) including:

> (1) A search for clothes and accessories just outside their comfort zone in a public space with a female friend, female stylist Yasmin Janssens, female sexology student Maaike Boonstra, and myself;
> (2) A professional make-up session by the same stylist and her female assistant, and a subsequent professional photoshoot in a studio aiming at dynamic pictures with a female photographer Cheyenne Dekeyser;
>
> (3) Follow-up joint interviews (conducted by the sexology student and myself) with the woman with SCI and her friend who had been invited to take up the role as 'mirror' and help the participant reflect about the whole process behind learning to live a fulfilling life again with a changed body.

The joint interview entailed a discussion of the photographs and the whole make-over experience. This was followed by showing participants on pieces of paper a selection of what they had said during the activities (e.g., "Participant in the mirror of the changing room: I am not used to seeing this person", "I feel feminine again", "Participant: Is it obvious that my fingers do not open? Photographer: They look relaxed") and three main themes/questions: "How do I see myself as a person, as a woman, sexually?", "change and process", "How do/would I like myself?". The whole data gathering round led organically towards discussing embodiment of difference, embodiment of femininity, struggles in maintaining ownership of their body, and how both SCI and body work had changed their relationship with their bodies and their perceived possibilities to achieve sexual pleasure and intimacy. Interestingly, the “make-over” was reported as triggering movement towards more self-awareness and self-exploration with change situated in the change of focus, simply by “doing totally different things for yourself” or “for once, not being occupied with the injury” (participants’ quotes).

The third encounter round was a focus group discussion with the four women with SCI about the preliminary findings of an inductive thematic, phenomenological analysis of all the stories (i.e., of all ten participants) that had been shared throughout the doctoral research, including sexuality as a journey, SCI as life changing, disownment of the body and the chastity belt as a metaphor for feeling blocked. An unanticipated side-effect of this group discussion was the spontaneous exchange of knowhow to increase each other’s independence (involving information about catheterisation via the belly, day catheters, encouragement to voice their desires to their partners, etc.). This highlighted the need for more contact with experts by experience not only during but also after rehabilitation.

All conversations and ethnographic field trips were audio-recorded and transcribed *verbatim* by the first author in the first data gathering round and by a student working on her master’s dissertation in sexology in the second and third data gathering rounds. Initially, we planned to film the shopping and photoshoot activities to record how the participants moved in the space and responded to the triggers they were offered, but the presence of our recording equipment (i.e., go-pros) made the shopkeepers so nervous that the atmosphere became less relaxing for the participants. In the analysis stage, rich transcripts were read, commented on, and analysed by the same student as well as by my two supervisors to ensure the quality of the research (Yardley, 2000).

Data analysis

All data were analysed phenomenologically to make sense of how the participants experienced be(com)ing a woman with sexual desires living in and with a body affected by SCI. Phenomenology acted as an agent to ground my inquiry in the life worlds of the women I have worked with, concerned as it is with lived experience and experience understood as "a lived process, an unfurling of perspectives and meanings, which are unique to the person's embodied and situated relationship to the world" (Smith, Flowers, & Larkin, 2009, p. 21). The term 'phenomena' in this dissertation refers to "the ways in which we find ourselves being in relation to the world through our day-to-day living … The verb find is not meant to signal an archaeological excavation of meaning, but a careful, reflexive, contemplative examination of how it is to BE in the world" (capitals in original; Vagle, 2014, p. 19). This research is infused in glimpses of being and becoming that touch upon different ways of be(com)ing in relation to the world, depending on the angle you take (loss, connection, resistance, etc.).

All data from the first data gathering round were first analysed by drawing on a quite new yet fairly traditional way of analysing: *interpretative phenomenological analysis* (IPA) (Smith, Flowers, & Larkin, 2009). It was first established in 1996 in health psychology and is now commonly used in other domains, popular for subject areas such as physical condition/illness experiences and psychological distress: (Smith, 2011). It is phenomenological in its commitment to study "what the experience of being human is like, in all of its various aspects, but especially in terms of the things which matter to us, and which constitute our lived world" (Smith, Flowers, & Larkin, 2009, p. 11). Given its suitability for exploratory research with small sample sizes and its detailed analytic focus on "personal lived experience, the meaning of experience to participants and how participants make sense of that experience" (Smith, 2011, p. 9), it was considered a good analytical framework for a paper focusing on the interviewed women's sense-making of their sexuality while living with SCI. It drew our attention to things that mattered to the participants—"key objects of concern such as relationships, processes, places, events, values and principles" (Smith, 2011, p. 83)—and the meaning that these things had for them—"what those relationships, processes, places, etc. are like for the participant" (idem). Important is the recognition that using an interpretive analytical method (such as interpretative phenomenology) involves "engaging in a *double hermeneutic*, whereby the researcher is trying to make sense of the participant trying to make sense of what is happening to them" (italics in original; Smith, 2011, p. 10). A good interpretative phenomenological paper investigates a specific topic in depth, offers a transparent, coherent and plausible analysis, with supporting extracts and interpretations for each theme, and engages the reader (Smith, 2011, p. 17). Drawing from Smith, Flowers, and Larkin (2009), my initial notes focussed on claims/concerns/understandings on an explicit level (descriptive), language use (paralinguistic), and my own reflections and my supervisors' reflections as researchers (conceptual). These helped to identify (grounded and conceptual) themes which were connected per case and across cases. We opted to write out the analysis of the stories of one participant in detail to give the floor to the complexity of the processes of (self-) desexualisation and naturalisation of truths of the body (see Chapter Three).

In the analysis of the second and third data gathering rounds, we set out to further dig into the potential scope for manoeuvres that research participants (including myself) experienced and could imagine to have when it comes to experiencing their body as a source of pleasure (see Chapter Five). To get this exploration of "imaginative manoeuvrability" off the ground, we were inspired by *post-intentional phenomenology* (PIP; Vagle, 2014) which draws on Merleau-Ponty's notion of embodiment, while at the same time expanding it to include gendered and cultured embodiments and invites experimenting with new materialist concepts. PIP still seeks to interpret lived experiences, but explicitly endorses "a post-structural commitment such as seeing knowledge as partial, situated, endlessly deferred, and circulating through relations", which is a "sort of 'loosening up'" that "would allow for a more nuanced reading of lived experience" (Vagle, 2014, p. 106-107). Post-intentional phenomenology embraces "innovative ways to conceptualize things as fluid, shape-shifting assemblages continually on the move in interacting with the world, rather than perceiving them as stable essences" (Vagle & Hofsess 2014, p.1). Chasing the “lines of flight” (Deleuze & Guattari, 1980/1987) that phenomena can/might take, the goal is not to “determine the essential structure a phenomenon ‘has’”, but “to see what the phenomenon might become” (Vagle & Hofsess, 2016, p. 334 & 338). Chapter Five is one of the most explicit results of my journey to present researched knowledge as fragmented, based on the detailed analysis of the four richest stories, with the stories of the other participants as satellites.

In practice, both analysis rounds were initially quite similar: we worked per participant, read their transcripts as a whole first to feel the spirit in which the stories were told with only marking “Aha?!”-passages, then commented line by line, then looked for themes, then moved on to the next participant’s transcripts to do the whole process all over again; listing quotes from all participants under recurrent themes; and going through the whole analysis with concepts from theories of subjection, resistance, and becoming (Butler, 1997; Deleuze & Guattari, 1987; Shildrick, 2004; Shildrick & Price, 1996) (i.e., “plugging in” theory; Jackson & Mazzei, 2012; see all chapters for more details on which concepts). Different was what I allowed myself to see and work with. Post-intentional phenomenology opened my eyes to the materiality of one’s lifeworld and inspired to use more creative ways of writing to bring to the fore the complexity of lived experiences and partiality of knowledge. The fact that academic insights and products are meticulously crafted by its writers was out in the open, in contrast to more traditional reports (such as Chapter Three) that have become habitual and so “natural, and real that we’ve forgotten they’re fictions” (St. Pierre, 2011, p. 623; see also Geertz, 1994). Experimenting with post-intentional phenomenology served as a lever to carefully unsettle and turn tradition (Ulmer, 2019).

Retouching and revisiting the strangers within (Chapter Four)

Unsettling tradition is what I certainly did when I reflected and wrote about my embodied experiences with dance at the time of the second data gathering round, when my participants were invited into body-focused activities. While I was using my body in dancing, i.e., in ways I was not used to but which I deeply wished to explore, I found myself deeply in relation with the stories of my participants. I was feeling embodiedly "the ongoing, mutual, co-constitution of mind and matter" (Alaimo & Hekman, 2008, p. 5). My sensations, emotions, thoughts, and the brain concussion that were triggered in the context of dance triggered me to re-search their and my stories in ways that my participants had never shared in words, and certainly affected the analysis of their stories as presented in Chapter Five. I decided to craft an autoethnographic paper about the shifting assemblages I found myself in whilst growing in my dancing moves, because I believe dance is one of the contexts besides sexual intimacy where the body takes up a central place and I wanted to experiment with making knowledge from the combination of theoretical concepts and empirical data.

Chapter Four analyses embodiment with my body as "the research site" (Seymour, 2007, p. 1192). It explores my lived experience of my moving body through "touchpoints", i.e., encounters through touch, and simultaneously sparks methodological questions about what (working with) matter can tell us that language cannot or does not completely tell (here: about becoming or the feeling of being a sensual, sexual woman free to move smoothly in and with her body), and how (working with) matter can transform living in, with and through a body; not a body in isolation, but a body in relation. The paper tackles autonomy, agency, and freedom, with the 'auto' in autoethnography, more than in the autoethnographic paper about the white coat, as an 'I' that does not envision human beings as fully autonomous individuals and self-contained beings, but comes into being in connection.

Crystallization

And so, time has come to present the four chapters that trace my research activities on the middle ground to the more interpretivist position on the continuum of methodology (cf. Ellis & Ellingson, 2000; Ellis, 2004; Ellingson, 2009, p. 7-9; who describe how there is no a science/art dichotomy, but a continuum ranging from positivism with scientific research that claims objectivity to radical interpretivism that sees scholarship as art). Whereas this introduction has been written in quite a recognisable format for academic scholars, you will find me to be "the scholar" that sociologist Richardson (2000) describes in her classic essay "Writing: A method of inquiry":

> The scholar draws freely on his or her productions from literary, artistic, and scientific genres, often breaking the boundaries of each of those as well. In these productions, the scholar might have different "takes" on the same topic, what I think of as a postmodernist deconstruction of triangulation. . . . I propose that the central image for "validity" for postmodern texts is not the triangle—a rigid, fixed, two-dimensional object. Rather, the central imaginary is the crystal, which combines symmetry and substance with an infinite variety of shapes, substances, transmutations, multidimensionalities, and angles of approach. . . . Crystallization provides us with a deepened, complex, thoroughly partial, understanding of the topic. Paradoxically, we know more and doubt what we know. Ingeniously, we know there is always more to know. (p. 934)

You will find me "crystallizing": experimenting with different forms of analysis and multiple genres of representation, aiming to "[build] a rich and openly partial account of a phenomenon that problematizes its own construction, highlights researchers' vulnerabilities and positionality, makes claims about socially constructed meanings, and reveals the indeterminacy of knowledge claims even as it makes them" (Ellingson, 2009, p. 4).

Chapter Outline

In Chapter Two, *Encounters with the white coat: Confessions of a sexuality and disability researcher in a wheelchair in becoming*, I will take you down my revisited memory lane as a researcher in a Flemish rehabilitation hospital: a context where I was surrounded by people with supposedly "broken" bodies and in which implicit attitudes held by myself and others towards bodily difference became revealed. It is an (auto)ethnographic portrait of a vulnerable observer, discovering a research practice of playfulness and wandering with participants as peers in humanity, which continued throughout further data gathering encounters.

Chapter Three, *"So I made this click not to look at a guy that way ever again": About desexualisation, disownment, yet also rethinking possibilities of a young woman('s body)*, offers an exploratory phenomenological analysis of one participant's story. It shows how a body and the person living in/with it can become desexualised and voiceless, yet also how manoeuvrability can be expanded. The themes that most clearly illustrate the dynamic and intra-active nature of this participant's self-(de)sexualisation, i.e., abnormalisation and disownment of the body, alongside the naturalisation and persistence of normativities in social encounters that feed into one's positioning of one's self as a(n) (a)sexual being and one's perceptions of what is possible when it comes to experiencing sexual pleasure and intimacy, can also be found in the interviews with the other participants. In short, it is a paper about the persistence of normativities, the need for obvious alternatives, and the fragility of imagination.

In Chapter Four, *Retouching and revisiting the strangers within: An exploration journey on the waves of meaning and matter in dance*, I disentangle how the phenomenon of me being a woman feeling free to express herself intimately was developing and unmade and re-made through the intra- action of matter, movement, and the meanings I had come to give to my body and encounters. This autoethnographic paper explores the value of research data based on working with the body on top of and alongside the value of language in the search for knowledge about bodily relationships.

Chapter Five, *Flowing desires underneath the chastity belt: Sexual re-exploration journeys of women with changed bodies*, will submerge the reader intimately in a bath of desires and questions told and untold. It explores participants' desire for sexual pleasure within their wider search for the intimate (re)exploration of their changed and vulnerable bodies and digs into the potential scope for manoeuvres they experience to have in this journey of rehab(il)itation of their own body. It aims to rethink how their bodies and material-discursive practices around sexuality, touch and (health)care as well as the women's 'own' meaning-giving of sexual pleasure and their body may (not) contribute to bodily pleasure and frame their seeking and experience of sexual pleasure. Its writing style deliberately aims to trigger thoughts and feelings rather than to conclude my final PhD study with a sterile list of themes to make it nearly impossible for the reader to leave these pages unaffectedly.

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Chapter Two

Encounters with the White Coat

Confessions of a Sexuality and Disability Researcher in a Wheelchair in Becoming

This chapter is based on:

Blockmans, I. G. E. (2019). Encounters with the white coat: Confessions of a sexuality and disability researcher in a wheelchair in becoming. *Qualitative Inquiry, 25*(2), 170–179. https://doi.org/10.1177/1077800417750181

Abstract

In this autoethnographic essay, I will deconstruct my own being and becoming of a female researcher with a spinal cord injury (SCI) in the first half of my doctoral research on the sexual well-being of women with SCI, more specifically in the aftermath of a 1-month internship at a rehabilitation hospital where I assisted the healthcare team and had informal conversations with residents. Following Barad's plead for diffractive methodologies, I aim to track interference patterns of the range of relationalities—imagined or mobilised by myself or by others—that I embraced or shied away from during my fieldwork based on field notes and memory in order to discover from them the constant process of my own becoming-in-the-world with a "broken body".

Key words: autoethnography, diffraction, disability, humanising research, nomadism, rhizome

Introduction

What better place to start a story of being and becoming the person I am in my research but here and now? When it comes to explaining personal and even professional development, there are no clear beginnings and endings. Dates of the start of my PhD, of my internship in a rehabilitation centre, of specific interviews I conducted with participants… pieces of paper that provide proof of trainings I completed… they claim to pinpoint milestones in my young career, but they do not tell you or me much about how I became and am and am becoming a female researcher with a spinal cord injury doing research on the sexual well-being of women with spinal cord injury. So rather than sharing my academic resume with you, I will take you down my memory lane. On the way, we will pause at certain viewing points, describing encounters which might seem clearly defined in space and time, but are not, as I am re-experiencing and writing about them now, experienced them back then with the backpack I had at the time (the contents of which have been reassembled over time). I simply hope to provide you some insight into the interference patterns of the range of relationalities, i.e., conditions of being in encounters, that I embraced or shied away from during the first three years of my doctoral research—relationalities mobilised by the intra-action between myself and others,[1] as well as objects such as wheelchairs and white coats and the range of meanings they can trigger, and memories and undoubtedly other players that I am unaware of at this point in time: all mutually affecting and transforming each other (Barad, 2007; De Schauwer, Van de Putte, Blockmans, & Davies, 2018). I will draw on my research diary, excerpts from my field notes and living memories in order to discover from them the constant process of my own becoming-in-the-world with a "broken body" (Shildrick & Price, 1996), a process in which "identity and any sense of a contained or static sense of embodiment is constantly confronted and displaced" (Fritsch, 2010, p. 7).

Let's start with my body. My body that can make me feel feminine. Or disabled. Contained by labels. Or "broken" indeed. *Is it broken? For whom? When? And how does it relate to me? And to others? And why "or"? Do femininity and disability not get along well?* At present, at this very moment of writing these sentences – *a morning in winter, longing to see my date again tomorrow, at the threshold of starting preparations for a wheelchair dance competition (one of those things that popped up on my path and attracted my sensual self that has only just started to discover life), feeling good about the transformation I have noticed in some of my research participants towards becoming whole again, and just finished a personal development coaching course where I consciously decided to let go of all the negative energy I had collected after other people's reactions to my body in my past, the gaze* – I feel complete. Fairly complete, that is. I feel complete in my brokenness. I do not deny that I wish I had had a body through which I could sense every single touch. And a body that was reliable. But it is what it is. I have learnt to be a friend to my body. *And I said to my body softly… I want to be your friend… It took a long breath and replied: I have been waiting all my life for this (Nayyirah Waheed).* Enemies is not what we were before. Rather, we were existing alongside each other. *Although I am not sure how I would feel if*

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[1] Intra-action, coined by Barad (2007), does not refer to the interaction between separately existing entities, but focuses on the continuous mutual constitution and emergence of these entities.

my date had not been strong enough to carry me and did not have shoulders broader than mine... At my darkest moments, however, —*and sometimes I do go there still, even though I have come a long way*—I feel that I cannot be one with my body because of that lack of control, because it forces me to explain how it works (or rather, not works) before I can be purely intimate with someone whereas sometimes I simply do not feel like talking and more like doing, and because my body seems to belong—if it even belongs—to someone else, to the whole world, in fact, with an opinion about what bodies should look like and how they should function.

"Actually, I want to move away from disability as far as possible", are the words that I have lately heard myself pronounce quite often in response to people's questions about my ambitions after my doctoral research. I already grew tired of people I had never met before asking me about why I was in a wheelchair and approaching me either as a baby or a granny, offering blankets for my legs in summer when all my friends were wearing shorts, a long long time ago. Now I am growing wary of the omnipresence of the word "disability" in my professional life. Disability Studies, wellbeing of women with a disability, rehabilitation of people with disabilities, etc. I have grown allergic to the (I know!) inherently human tendency to categorise, to stuckness. I have seen some people frown at that response, worried that I am struggling with my identity and denying that disability is part of my life. But I believe I am taking becoming friends with my body in all its beauty and its deficits to self-love at its deepest, where disability is not made to matter anymore.

When I started my doctoral research, I believed that that transformation was already complete. Even more, my transformation was complete, and I set out to help others transform in the sense of getting unstuck. Four months down the road, however, that turned out to be a story I had made myself believe. True transformation would come from around an unexpected corner.

CHAPTER TWO

First Days in the Field

The hospital where I completed a 1-month internship had one floor that was specialised in the rehabilitation of adults who had recently acquired spinal cord injury or limb amputations, and whose physical condition had been evaluated as stable enough to start rehabilitation by intensive care staff (usually after a couple of weeks). Most people stayed in rehab between six and twelve months, depending on the accessibility of their homes and on their remaining potential to make significant progress (read: reduce the impact of lasting damage to their bodies on their functioning in everyday life). Some residents had acquired their injury years before, but came in for rehab after injury-related surgery or for additional ambulant therapy. Every resident was supervised by a multi-disciplinary team of physicians, nurses, physiotherapists, sports therapists, occupational therapists, and a psychological counsellor. None of the healthcare professionals themselves had visible physical impairments, which made me, introduced as temporary member of the team, quite an exception.

I did not really have a job description. I had asked the head physician and her team to grant me freedom to follow my instinct and join residents and professionals alike whenever it seemed relevant. I was granted that freedom from day one, but I was also given two rules to obey. For starters, I was not allowed to conduct formal interviews with “patients” and I was certainly not allowed to initiate conversations about sexuality and relationships. *(My research topic)*. I recalled words published over four decades ago and referring to a time even more decades before, when some professionals felt that “the less said to cord injured patients regarding sexual functioning, the better; and that repressive mechanisms should be allowed to take their course in stifling thoughts and preoccupations about sexuality” (Hohmann, 1972, p. 55). Was it really 2015? I did not understand, or I refused to understand the physician when she elaborated that those topics were likely to be too fresh for the residents, as if she feared that they were not able to decide for themselves whether they were ready for these topics. It seemed unfair to me. I was frustrated. I had become so familiar with concepts such as self-agency and agential cuts and the fact that the autonomy and freedom of choice of people with disabilities are very often neglected or ignored. Rather than delving deeper into what this first rule might tell us about the place of sexual wellbeing in rehab, however, I wish – *with resistance, though, because I feel ashamed for what will come* – to focus on the second rule, as that one struck me even more deeply. Its impact did not only involve my doing. The second condition affected my being.

I was asked to go and pick up my white coat in the office, to make it clear straightaway for the residents that I myself was not in rehab. I perceived it as an attempt to create a distance, to avoid that the residents would recognise me as one of them and thus would share more of their innermost feelings with me than they would with any other, "normal" healthcare professional. I felt sick. The coat triggered memories of being observed myself by people in white coats (e.g., when I was walking in braces for the first time as a 6-year-old surrounded by excited medical professionals and parents of other paralysed children who all considered this to be a major achievement in the history of the rehab centre whereas I felt like a rusty robot deprived of the freedom of my quickly spinning wheels, or when yet another physiotherapy intern watched my physio work on my body and subsequently repeated the action without announcement for the sake of his own learning rather than for my benefit) and of moments in which my knowledge and experiences of my body were questioned or neglected by people in uniforms (e.g., when a government doctor came to check whether I really needed the tools I had listed for reimbursement, when a team of physicians pushed me to continue swallowing medication against spasticity and even recommended surgery despite the fact that I could easily live with it, when I asked a law doctor co-responsible for one of the many medical examinations following my car accident whether there was a section in the damage claim report for sexual experiences and the only answer I got was a short "you should learn to be satisfied with your high score on esthetical damage"). I definitely did not want to embody the "other" (here: experts by education) who had frequently made me feel as an object of study and surveillance. I did not want to frame the residents in ways that already felt pre-defined by the white coat and see them as either an exotic, fascinating species or creatures whose lives where to be evaluated by others.

Despite the reluctance that I felt deeply, I stuck by the rules out of respect and sympathy for the staff who gave me access to their world. I joined the healthcare team for lunch and assisted them with therapy (e.g., giving writing exercises, finding new ways to cook safely, washing residents—which seemed to be treated as less intimate or intrusive than sex talks), which invited them to talk freely about their jobs and the progress that residents were (or were not) making. Respecting the dress code, however, was both an emotional and physical struggle:

> Fieldnotes - Day 2 - My first working day
>
> Bah. The coat is way too long and constantly gets stuck in my wheels, so hardly practical. Even worse, the coat is way too big for me, so hardly flattering. I really felt fat today. I felt unattractive as well. Bye bye confidence. I wanted to show the residents that it is possible to be both a wheelchair user and attractive, but yeah, that intention—goal?—was derailed. My effort to look well was an altruistic attempt to bring a positive vibe, but I guess it was also self-driven… I knew that my presence as the only white coat bearer in a wheelchair would not go unnoticed. I still remember the staring when I was catapulted out of my wheelchair on entering the gala event three months ago, and that was not exactly the kind of red carpet entrance I had wished for…

And here is the moment that I need to come out. Out of the closet and clean. In the first draft of this chapter, my reflections on my field notes about my encounters with the white coat revolved around how I saw myself as a woman who saw her efforts to look “good” according to a set of norms (here: not overweight and self-composed at all times) disappear beneath layers of uncomfortable coat fabric, as a potential role model in relation to the residents, as a wannabe-peer who was worried that the white coat would create a distancing power-imbalance toward the residents that could close down connection, and as an ethnographic researcher who saw her power to observe how the residents interacted with their broken bodies and their caregivers/therapists diminish as well as the ease to participate herself. The white coat underscored for me unequal power relations in research, made me look like the all-knowing healthcare professional – *I was never introduced as such, but the presence of "doctor" in "doctoral research" and "psychology" in my education as a linguist and social psychologist conveyed that impression* —, whereas I wanted to interact with the residents on the same level and without barriers that could close down communication[2] — *after all, I had been arguing in all my conference presentations and scholarship applications that I felt that I as a person with a spinal cord injury could "make a difference exactly because I can draw upon my own lived experience as someone who cannot walk nor feel sand tickling my toes etc. to spot gaps in research perspectives, gain people's trust to disclose, and disseminate the results of disability research in a convincing, authentic way."* Whereas all of these reflections are true – *I definitely was convinced of their complete truth back then* – , they also functioned as a cover-up story. My story was that I was aware of my play with marks and normality, of how I used or wished to use my whole palette of identity layers in conscious response of my encounters with the people I met in the field. My story was that I was tolerant of disability, of people with disabilities, and of myself.

The truth is that at that point I still needed to feel less disabled than other people with disabilities. I was allergic to being reduced to what the gaze of others pinpoints as my main identifier. When I first put on the white coat, it made my stomach turn, but I simultaneously enjoyed the status it brought along. I enjoyed – *and needed?* – being perceived as the professional and the support giver, not being treated as the patient for once, not being the care asker, not being perceived as the dependent one. For the purpose of my research, it was important to get close to all the people I met at the rehabilitation centre and especially the residents as my research questions focused on the lived experience of women with spinal cord injury, but I could not resist being thankful for the

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[2] I admit I was guilty of reducing (doctors in) white coats to their white coats and the distancing, paternalistic, medicalising discourse they often represent.

forged external difference between me and the residents. At times, I even regretted not having the white coat, as I believed it would have saved me from being reprimanded by a greying man for speeding when I was making my way back to the rehab wing after lunch: "30kms an hour is the maximum speed here, young lady!" … although my youth might have prevailed over my doctor's coat in the man's judgement about the appropriateness of his joke.[3] The white coat was granting me favours. Most of all, however, I enjoyed the forged similarity between me and the healthcare professionals. As none of the staff members themselves had visible physical impairments, I was quite an exception. One day, I had lunch with the team in the hospital cafeteria, and the day after the head nurse told me that a staff member of another unit had inquired: "You seem to have a new member on the team?" I had stood out and was recognised by the healthcare professionals of other units much more quickly than other new members would have been spotted… A previously walled world of glitter and glamour had opened its gates.

Peers, Aren't We All?

The first big crack in my own wall came after two weeks of intense field work. Interestingly, in my first draft of this chapter, I had decided not to include the fieldnote extract below, waving it away as "less important to show my growth as a researcher". Now, after my acknowledgement of my own transformation

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[3] At times after the end of my internship, I would long for the white coat as a dis-identifier of me as primarily being a wheelchair user. Half a year later, for example, I was to meet a potential research participant in a (different) Belgian hospital. My mission that day was to find the right location in the maze of streets, alleyways, and grey building blocks. I had parked my car at the rehabilitation wing. According to the road map of the hospital site, the building I needed was only a couple of blocks away. Signs on street corners led me to a promising path around the corner of the rehab wing… promising if it hadn't been blocked by construction works, that is. So I asked a passer-by, who happened to be a nurse, where building X was. Rather than answering my question, however, she first asked her own question: "Don't you want to go back to the rehabilitation wing?" It took me a couple of minutes to reassure her that I was intentionally moving away from the rehab wing, and that I was definitely searching for building X. Upon seeing my wheelchair, the nurse assumed that I was a patient. This assumption was grounded so deeply that she even doubted that I was asking her for directions to the correct venue. It did not occur to her that it was possible to encounter a person in a wheelchair in her medical working environment who was not in the hospital for personal health reasons.

that was set about by the people that I was to transform, I cannot but confess it is the most important extract. Three residents I had been playing sports with, Thomas, John, and Luke, were smoking outside.[4] I was about to go home, but I felt drawn to join them for a chat before leaving. I liked them for their honesty, their engagement, and even—switching off my radar for tracing remnants of sexism—for how they welcomed me each day with "well, good morning, flower". Shortly after, three other male residents joined us. Despite the huge gender imbalance, it did not feel like a men's gathering where I was excluded. Above all, they were—*we were? My field notes say "they", carrying traces of my ongoing resistance and dissociation at the time*— "peers, aren't we all", as two of the residents called it. One moment I was gasping for air because it dawned upon me that I was included; I was perceived as a peer. *"Of course you were peers, you had just been playing sports together," my supervisor, a basketball player, commented after reading my second draft… back to reality: not making disability to matter is still quite a challenge for me.* The next moment I became aware of my stomach, heavily loaded with rocks, when I noticed Luke's surprised expression upon my confession why I was not quite looking forward to go and swim in my new home city, worried about my environment's opinions... I felt busted, a traitor to their trust, ashamed.

> Fieldnotes - Day 10 - The residents' pep talk. I am not weak… It's just… I have my own style.
>
> Thanks to the sports therapist's swimming lessons yesterday, I can now swim in such a way that my neck does not get overused, but my bum looks like a hippopotamus' nose popping up above the water's surface… "Such a typical disabled's stroke," my voice says, before I realise that this is exactly an example of the stereotyping, humiliating logic I am trying to get out of the world through my PhD and in all other aspects of my life.
> Luke is quicker in responding than I am: "Well, I hadn't seen that one

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[4] All names used in this paper are pseudonyms, except for the author's name.

> coming from you. Isn't this what you are fighting, this imaging?!"
>
> I explain that I don't wish to lose my current "status" in Ghent by exposing my different way of swimming. Please let me continue saying I am a well-experienced swimmer. (which I am). But don't look at me, appearing weak and swimming like my grandfather who only started with swimming lessons at age 65. My grandfather is my hero, but my brothers and I can simply not hold our laughter when he is exploring his water skills.
>
> Luke refuses to let go of me. "Madam psychologist, aren't you still you? Let people watch. Ultimately it is content rather than packaging that matters, and that is not something you should worry about. You have been given the green light for your doctoral research, with a fancy scholarship, isn't that something that you have achieved? That wheelchair didn't have to do anything with it, now did it? I am also still the same, people simply look more." The other men join Luke. "Yes, isn't it the content that counts?" John adds: "Everything step by step, you know. Give it some time. Now I am learning to walk with short leg prostheses with feet backwards, and once I can do that, I get longer prostheses like Luke's, and I start the learning process again. It is not up to others to judge. You are your only measure. For others, it is not difficult to walk 500m, for me it is. If I can walk 100m, really slowly, I am proud of myself, because that is an achievement."

I remember feeling slightly uncomfortable. All this wisdom for life was well-intended, and I wished to internalise the conviction that I was great and my own and only measure, but I felt threatened as well. I felt my positions as social psychologist and researcher being challenged, undermined. Luke sensed it: "Being a psychologist doesn't mean you shouldn't be showing your weaknesses. And besides, you are not weak. Remember what the sports therapist said, you have your own style, but you moved quickly. Isn't that good?"[5] I had only just

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[5] Luke and the other residents already picked up what I would only fully acknowledge and resolve over a year later, when I was preparing a lecture for healthcare students by

started to get closer to accepting and even welcoming the men under the smoker's roof, participants in my ethnographic fieldwork, as peers, and I was already receiving counselling from them. Even more, I was getting a beat up for letting my self-worth depend on the result of my comparison of myself with others (able-bodied, or "more" or "less" disabled). Being open for unexpected encounters whilst doing research was teaching me humility.

My discomfort mainly arose from being explicitly included in a peer group (the membership of which I had considered as mainly unfavourable before)… and from a sense of belonging bubbling up from deep-down in my chest, an answer to a longing for belonging I had previously only allowed myself to feel if I could control my position in some sort of hierarchy of disabilities. And there I was, receiving peer support from people who had only just acquired their injury—*I still grumble every time my great-aunt comes in head-over-heels to tell me about the heroic deeds of yet another famous person with a disability who popped up in the media, thinking "has she forgotten that I was first?" even though I always shrink whenever she does put me on the pedestal of The Inspirational Disabled. I have not been able to catch the trigger of this automatic response yet, but a spinal cord injury, or the loss of a limb in the case of my newly-found peers, is something you acquire, and the longer you have lived with it, the higher your status in the value hierarchies of knowledge and lived experience.* Whereas I had started my internship imagining I might provide some first-hand lived experience knowledge to residents, they acted as *my* peer counsellors instead.

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reading my notes from a conference presentation I gave not long after my internship at the rehabilitation centre… notes that told the story (again) of me having a satisfying romantic relationship *(I was going to show them that sex and disability were not mutually exclusive players in a relationship)* ... which did not match with the reality of our break-up, fuelled by what I described as "a lack of passion" … an incongruence which led me to re-visit the long-term relationship I had had … ultimately leading to my recognition, acknowledgement, and subsequent public confession of how deeply I had internalised an ableist view towards my body. I, the person who was going to spread the message that women should love themselves because they are worth it, had been doubting that my "own style" should suffice for finding a romantic partner. I had made myself believe I should find satisfaction in my relationship and consider myself lucky that I had found a handsome, good-hearted man who accepted my body the way it was and moved, even if I was not feeling fully complete and happy in our relationship. The irony.

It was quite a significant moment, as I had always been reluctant to engage in peer contact, out of fear to get entrapped in the box of “the disabled”. Especially when close to me another person was present who might trigger the label (making this social category more salient). I was afraid that others would then easily assume we are clinging together and ostensibly conforming to a segregationist ideology as if disabled individuals feel most comfortable amidst “their own kind”. (*And honestly, I still am fighting that drawback reflex when I am in the company of people who are visibly not able-bodied and temporarily able-bodied people I do not know well).* When Luke referred to the group of people chatting outside—including me—as “peers”, I felt vulnerable in the sense of “weak” at first, associating the word with self-help groups and associating self-help groups with suffering and -coping difficulties and associating suffering and coping difficulties with weakness.[6] However, it is exactly this moment that has made me comfortable promoting “peer contact” with exactly those words. The residents made me feel and fully realise the value of contact with people living with similarly broken bodies. Being open for unexpected encounters whilst doing research was teaching me the beauty of vulnerability.

Turning a Border into Unpredictable Lines of Connection and Encounter

When I let go of the distance mobilised by the coat and by my own internalised hierarchies with the rational, independent, able-bodied subject in the top position, and with it also left my make-up and hair styling and the ambition to be a perfect rolling model of possibility and imagination, space was created for embracing common humanity with the residents to a point where the white coat was not made to matter (engaging in work-outs together, exchanging life experiences related or unrelated to disability over dinner, etc.).

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[6] Note that the Dutch word for “peers” is “lotgenoten”, a word that often triggers associations with suffering and illness, connotations which are visible in English translations: “fellow-sufferers”, “fellow-patients”.

The white coat was not a barrier anymore. On the contrary, through my encounters with both residents and staff, it became a lifting bridge that gave access to whichever world I wished to enter. The white coat facilitated blending in with the healthcare team and becoming familiar with their optimism and their challenges of juggling with time and dealing with their often limited power in preparing residents for everyday life outside the rehabilitation walls. Quite unexpectedly, the white coat also gave me fast lane access to the heart of my research topic. The residents that I was having coffee with and whom I was teaching wheelchair skills all wanted to know why I was wearing a doctor's coat—they had never ever seen a healthcare professional in a wheelchair before. I challenged the status quo of "able-bodied" healthcare professionals vs. patients with disabilities. So I told them, honestly, that I was doing my PhD on sexuality and spinal cord injury, and that I wanted to feel what it is like to be in rehab and go through that first period of readjusting to your body because I did not remember. Trying to keep my promise not to ask them about their sexual wellbeing, I talked about my favourite colour of compression stockings and my trips abroad. But my PhD topic and my first go at personal disclosure was all they needed to start talking about sexuality and relationships, about their pleasures, fears and painful encounters, about tips and tricks to be a parent, and so on. I did not initiate a single conversation about sexuality. Stories came spontaneously from all sides: men, women, all generations, with wheelchairs or without limbs. They appreciated me as a person, treated me as one of them, and accepted me as a researcher.

Yet, the concerns voiced during brainstorms with my supervisors and healthcare staff about which role(s) to take up during my internship (undercover resident, researcher, psychological counsellor, peer support worker, linguist, etc.) did not entirely prove unnecessary. Letting go of feeling different from the residents, I gradually came to more fully understand the challenges, both emotionally and ethically, of opening up to and delving into participants' life stories. I shared the joy of residents who had returned from their first weekend back home and reported with a head-over-heels smile that they had been able to hug intimately with their partner without transfer problems and without pain, that their pets were not afraid of their wheelchair, that their houses were already partly adjusted to their new needs, etc. But I also breathed in the pain of not being able to hug (grand)children, of the prospect of aging more quickly in shoulder joints and its effects on independent transfers and self-care, of the decision not to tell partners that orgasms had become a question mark. My connection with the residents (and the people I interviewed after my exploratory fieldwork), based on identifiability and empathy in both fun and deeply painful moments, enabled me to get closer and deeper into their lived experience than I could have ever wished for as a qualitative researcher, but also rendered me a "vulnerable observer" (Behar, 1996). I needed every inch of my energy and capacity to put my emotional responses in perspective and tone down my fears, especially the anxieties that I had not overcome yet by collecting counterevidence in my personal life. During those moments of vulnerability, my white coat—or rather, the professional persona that I associated it with—protected me.

Letting go of feeling different from the residents also drew the residents closer to me, which brings in a huge responsibility to monitor relational ethics. At times, I felt like a traitor towards the residents. To start, I was expecting them—be it with great kindness and respect—to give me access to "their" territory, reasoning we shared this territory. I had even dared to state in my funding application: "I feel I can make a difference exactly because I can draw upon my own lived experience". Yet, when we got close to feeling like peers under the smoking shelter (despite the fact that I do not smoke), during wheelchair hockey competitions, etc., I was ambivalent, longing to belong and to celebrate connection, yet also feeling resistance to accept peer status and feeling not quite similar enough. I felt I was betraying their openness to connect. I was struggling not to join any club, fighting "the uneasy, often self-destroying tension between appearance and identity" (Samuels, 2003, p. 233), and they did not know. Also, I had not forgotten that I was at the rehab centre primarily as a researcher, and I could not guarantee that the people I was interacting with remembered that as well. I did not audio-record a single conversation, and did not analyse their personal stories, but *I was observing* the atmosphere at the rehab wing and *they were sharing* their personal stories with me spontaneously. I did not want to see or use the people who confided in me as a one-way data collection bank. With a mixture of feelings of contempt and disgust, I feared that my travelling at the rehab centre would fit Nietzsche and Deleuze's cruel image of the nomad who opposes his/her own code of conduct and takes whatever (s)he can get wherever (s)he is, nomads who spread and go to different places in order to own a domain (De Kesel, 2006), rather than wander about to be surprised what comes on their path.

Of course, I was not such a nomad. I became a nomad, balancing between being a researcher and a person-thinking-about-job-possibilities-in-healthcare and a woman and a person with SCI and "simply me"—or completely me?—but prioritising recognition and embracement of common humanity. The beauty of allowing connection with participants is the gift of stories that arise in the natural flow of conversation. The issues of my PhD project "emerge[d] organically, in the ebb and flow of everyday life" (Tillmann-Healy, 2003, p. 735). A grandmother's worries about not being able to caress her grandchildren in her arms anymore, a young boy's conviction that he would never be able to please a girl and a young man's struggles to find alternative ways for making love to his wife, healthcare professionals' worries about residents who did not make eye contact, an older woman's recollection of a visit to a sexologist who could only give "I am sorry, but I can't help you" as advice when she and her husband approached the expert with the question of how to get around their physical problems, a middle-aged woman's relief of having dared to get (successfully) pregnant 20 years before despite her physician's warnings and an adoption centre's message "Are you sure you want to proceed? If two healthy people turn up, they will be given priority", the most outgoing woman's tears after having been left in her own stool for two hours and not being given the clothes she had chosen—that last bit of autonomy snatched away in front of her face, … These glimpses of lived experience were not brought to the surface in interviews, but mostly popped up during my observations in the physiotherapy hall, in the kitchen while trying (in vain) to bake pancakes in a curved frying pan or while chopping carrots for spaghetti, when we were sweating together at the hospital gym, during a race on wheels in the city or on the escalator (in a shop that actually prohibited anything or anyone on wheels to use the moving staircase), over coffee and dinner, and when residents were chatting in their rooms in-between therapies and invited me to "just pop in" and look at the drawings from their (grand)children while they continued gossiping about fellow-residents and staff. As a traveller, I meandered freely around their territory in space and time, conversing with them in the original senses of the Latin word "conversation" as living, moving and turning about together (see Kvale, 1996, on the interviewer as a traveller).

And perhaps the most beautiful outcome of allowing connection with participants was the emergence of energy to not just listen to stories but also act upon them, the enlightenment of a fire to fight for human rights and social justice—the ultimate goal, for me (and most postmodernist researchers, I assume), to conduct research. Allowing connection, I even became angry for the first time in my life (as far as I can remember). I was angry about how sometimes pain and struggles were left unattended by staff knuckling under the tight time frame in which they needed to fit in all the washing and toileting and feeding and disinfecting. My anger expanded when I was confronted with how some people who were working hard to get their lives back on track took the weight of the consequences of a failing system on their shoulders:

> Fieldnotes - Day 17
>
> Julia kept repeating "I am not used to this" through her tears… as if that explained to her and even justified why she felt so miserable. And I cried with her, although my tears were not visible. Because it hurt me deeply to feel that this woman felt bad about feeling miserable. And because I know that my own dependence on others and lack of control over my body still hurts after a quarter of a century. I would be lying if I said "it's something you get used to". No. It is that kind of pain you learn to ignore with the exception of a few cracks when it becomes too much. It is the kind of pain you do not consciously acknowledge every single second of every single day, because that would leave no energy

> for living. But I could not tell her. Instead, I asked whether it had happened before, and we discussed how we could try to prevent these issues from happening again.

In the end, my anger made me even more passionate about my research and making a difference.

Fieldwork Method in Hindsight: Diffractive Tripping

My stay at the rehab centre was not set up as an autoethnographical study. It was to be an introduction to one of the contexts I would be studying indirectly when interviewing women with SCI about their sexual and relational development and readjustment in general as well as related communication experiences in particular. However, being introduced by the head physician to the staff as a social psychologist and intern, and clearly being a woman in a wheelchair to every person I encountered, my presence at the centre quickly started to lead a life of its own. I immersed myself in the rehabilitation culture, participatory observation became observing participation, and ‘studying “them”’ became ‘studying “us”’ (Tillmann-Healy, 2003, p. 735). After Corbette’s description of ethnography, my preparatory internship turned out to be “an immersion within the deep culture of a social group that attempts to find hidden treasures and submerged dangers” (1998; paraphrased in Goodley, Lawthom, Clough, & Moore, 2004, p. 56-7). I departed the familiar academic environment inhabited by rather distant observers of the “deep culture” of life with disability and suddenly arrived and tried to find my way at a destination where the culture of living with spinal cord injury is ‘at its deepest’ in many ways (due to the high visibility and prevalence of people with medical problems and due to the acuteness of the injuries in the rehabilitation centre). Little did I realise that I would be entering the eye of my own storm of becoming with a broken body, with ocean waves and water flows under the surface converging from all directions.

During formal one-to-one interviews with women with SCI, I tend to feel quite "normal" and "unmarked". In these private encounters, my wheelchair (and the spinal cord injury that necessitates the use of this mobility tool) are not markers of disability but "merely" identifiers which unintentionally act as keys to barrier-free conversations. In the rehabilitation centre, however, I experienced that which went unmarked suddenly as marked and judged: SCI became a medical condition to be cured as much as possible for healthcare professionals, a disability to be pitied or supervised for visitors, and the signifier of "peerness" that drew residents to me—and possibly myself to them—and that scared but was also valued by healthcare professionals. Their white coat, in turn, was not simply a garment that I found ugly and unhandy, but became a rule to be obeyed, a position to resist, an object blocking my wheels, a distance to fear and to embrace, membership to desire, a key to unlock gates, even a bridge. By immersing myself in this deep culture, a "playful research" practice unfolded in which implicit attitudes held by myself and others towards broken or different bodies became revealed (see MacLure, 2003; Anderson & Braud, 2011, on playful research).

To loop back to me moving around in the field as a nomad and to me entering the eye of my own storm of becoming with a broken body, with ocean waves converging from all directions, I label my becoming of a sexuality and disability researcher as a diffractive trip accelerated by my rhizomatic immersion in a place and time where the broken body is omnipresent. My choice for "diffractive tripping" is based on Barad's (2007, 2008) plead for diffractive methodologies (see below), on my love for travelling, and on what one of my participants said during an interview, namely that her sex life with SCI had considerably improved after she had started smoking weed again, as the drug made her much more sensitive for and receptive of or towards every single touch and movement of her partner and herself, whereas without it, she feels less connection with her body, and thus also with herself and her surroundings. My stand is that when you work with people, including yourself, and you study them, you need to be open for everything, you need to see and hear everything and be conscious of what you feel… and to touch upon the illegal nature of weed, sometimes the most unexpected yet eye-opening findings come when you do not follow the path laid out by certain research paradigms.

Studying the tension between the immersion of oneself as a researcher (and person) in a culture and simultaneously maintaining a nomadic research identity, I came to visualise myself (after visiting the floating islands between Peru and Bolivia) as sometimes hopping from one floating island to another, sometimes drifting towards, sometimes being smashed onto the shores of an island that was yet to be discovered, and then spending some quality time on all these different floating islands to get to know the feel of the place. One floating island would be the island of the people in rehab, another one would be the island of the healthcare staff, another one would be the island of the visitors, another one would be the meeting venue for all the women of the Culture of Floating Islands, etc. Mapping these floating islands and zooming out, you can see how the islands are all connected, sometimes with bridges, sometimes with weeds that grow under water, sometimes with rocks, and with water flows driven by temperature, wind, and tidal forces, yet also always moving and without one fixed central island.

Now imagine these water flows that drove me from island to island, causing both forceful and gentle waves pushing against the shores, to be the lines that make up a rhizome. As Deleuze and Guattari described, “The rhizome is made only of lines: lines of segmentarity and stratification as its dimensions, and the line of flight or deterritorialization as the maximum dimension after which the multiplicity undergoes metamorphosis, changes in nature” (1987, p. 21). Being driven by these lines and sometimes finding the strength to jump on another line, me and my white coat got different meanings. For instance, lines of stratification drove me to the island of health experts when I was wearing the white coat, or, when I was not wearing my coat, to the island of people with disabilities where I was spotted by an inhabitant of the island of visitors watching others through a pair of binoculars. Sometimes reverse currents or lines of flights drove me to the island for women, or even made me splash above the surface so I could get a temporary glimpse of how all the islands were connected.

It was diffractive analysis that helped me to lay bare the water flows that drove me from one island to another, to dissect the nature of these flows, and to discover what it is exactly that I kept from all my travels. In physics, diffraction refers to various phenomena which occur/manifest "in the apparent bending of waves around small obstacles and the spreading out of waves past small openings".[7] Diffractive analysis, then, pleaded for by Barad (2007, 2008) and Haraway (1997), can be described as "a wave-like motion that takes into account that thinking, seeing and knowing are never done in isolation but are always affected by different forces coming together" (Lenz Taguchi & Palmer, 2013, p. 676). Its purpose is "to disrupt linear and fixed causalities, and to work toward ''more promising interference patterns'' (van der Tuin, 2011, p. 26). To study the interference of the waves in my storm of becoming, I kept revisiting both my fieldnotes and my previous drafts while writing, and I kept questioning my meaning-giving of the white coat, my interactions with the healthcare staff and the people in rehab in the hospital, and also after my fieldwork my encounters with research participants (the women with SCI that I interviewed), with colleagues, the words that I used whenever I talked about my research experiences, etc. so the relationship between signifier and signified never sedimented, and I never took the truth of my words for granted.

During my fieldwork, I kept my notes in a diary, tracking my observations of myself, residents, healthcare staff, and visitors, as well as my reflections about what I felt and why. The first draft of this paper, which I began writing about half a year after the fieldwork, started with a first selection of fieldnotes to portray my evolution as a sexuality and disability researcher. Between the end of my fieldwork and my first draft, I had an internal dialogue about wishing to talk about how experiences of the body and sexuality had its place in the rehabilitation centre but struggling with ethics and about wishing to show the

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[7] http://hyperphysics.phy-astr.gsu.edu/hbase/phyopt/diffracon.html

emergent multiplicity of disability from an insider's perspective but struggling with some kind of resistance that I was not able to pinpoint at the time. The second draft of the paper was driven by a critical revisiting and revision of all my fieldnotes and the first draft. Between the beginning of the first draft and the beginning of the second draft, more than a year passed and I completed two personal development and coaching courses where I was forced to peel of all my layers of protection and justification stories and then acknowledge and embrace what was left.

Whereas not everyone has the luxury of taking the time to let the analysis and writing ripen and go consciously into a personal breakdown storm and subsequent breakthrough, I definitely recommend to constantly ask yourself how much story it is that you are writing, ask yourself what is left, and then to not erase those stories but work with them, as they give us insight into the fluidity of identity and the emergent multiplicities we all are. When I argue for letting go of feeling different in research, I argue for getting off your island, for letting go of the fear to follow the water flows, because then you can start exploring all these islands and connecting the dots in the rhizome. The beauty of visiting all these islands and taking a ride on these different streams of water and even moving tectonic plates is that you will never be the same again, and that new normalities will enfold. From all these islands and water streams you'll take some treasures with you, seeds with which you can grow either flowers or weeds, sand which can be white silica sand you can use to clean your nuggets[8] or sand which will keep itching until you have given it your full attention.

Speaking of itchy sand, one might wonder what truth is left in my words about how I have moved away from disability (p. 5), given my current engagement with disability—epitomised by this paper's title and my ongoing work with the life stories shared by women with SCI. How can we talk about the fluidity of life without confining it in words? Throughout my interactions with my participants

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[8] As in: small roughly shaped pieces of gold, or something that a person has said or written that is very true or very wise (http://dictionary.cambridge.org/dictionary/english/nugget).

and their stories, I am cautious of binary thinking such as ability/disability, broken/complete, observation/participation, researcher/researched. I do not see my participants as disabled. They are women. I ask them about their “life stories with focus on sexuality and relationships”, not disability. When they report disablement or identify themselves as disabled, I ask for context. When I analyse their stories and write-up my interpretations, I approach their lived experiences as multi-layered and ever-shifting. When their words signal stuckness, I play with the definition of research, ask questions that could open up imagination and set up ethnographic fieldwork studies that can trigger change. And whenever disablement occurs, I will call it by its name, until there is no need anymore.

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Chapter Three

"So I Made this Click not to Look at a Guy that Way Ever Again"

About Desexualisation, Disownment, yet also Rethinking Possibilities of a Young Woman('s Body)

This chapter is based on:

Blockmans, I., Van Hove, G., & Enzlin, P. (2017). "So I made this click not to look at a guy that way ever again": About desexualisation, disownment, and rethinking the possibilities of a young woman('s body). *DiGeSt. Journal of Diversity and Gender Studies,* 4(2), 11-31. https://doi.org/10.11116/digest.4.2.1

Abstract

We tend to put people—others and ourselves—in boxes (such as social categories, professional conduct, research participant samples, braces) in our daily lives, especially when variation becomes associated with unruliness and triggers the reflex to manage/control/contain to prevent further deviation, which leaves little space for listening, creativity, externally and internally driven movement. This paper offers an exploratory interpretative phenomenological analysis of a young woman with a spinal cord injury's (SCI) becoming-in-the-world as a person with a physiologically "broken body" (Shildrick & Price, 1996) as a first basis for mapping the "psychic life" of normativities as manifested in her perspective towards her body and sexual/romantic relationships (Butler, 1997), i.e. the presence, persistence, and permeability of norms in her psyche influencing her sex- and body-related thoughts, feelings, motivations to act or not to act. How and why does she desexualise her body, yet also finds space to rethink the possibilities of living with her body? What can (her and her network's) processes of abnormalisation and disownment of her body tell us about (our) creation, treatment, and re-owning of unruly bodies? Sophia's story shows how a body and the person living in/with it can become something to be contained and managed physically (daily living assistance), medically (medication, check-ups), aesthetically (braces), socially ("no partner" and "no sex" click), and psychologically ("no attention to hands touching and moving my body" click) to such an extent that they become desexualised and voiceless, yet also, however fragile, the potential for acts of resistance and movement.

Key words: disability, disownment, embodiment, normalisation, phenomenology, sexuality

Introduction

Why I haven't read it yet? Well, purely practical, it's a paper booklet, so I'd need to ask someone to… ((laughs)) no thanks… plus purely time shortage, there's so many things I should do first…

(Sophia with limited hand function about sex-related information in paper booklet given by a healthcare professional in a rehabilitation centre)

My[9] youngest research participant's unquestioning matter-of-fact tone about the limited and inaccessible sexual information provision in a rehabilitation centre for people with spinal cord injury (SCI) (and other injuries) and her deprioritising of sexual exploration echoed in my mind when reading Shildrick's (2004, p.1) fierce argument that:

> What is at stake lies in the performativity of sexuality, not as a potentially pleasurable bonus, but as a core element of self-becoming that infuses all aspects of the materiality of living in the world . . . [T]o silence or strip sexuality of significance is to damage the very possibility of human becoming.

Whereas fulfilling sexual activity and intimacy have been acknowledged as a human right and vital for romantic relationships and one's well-being, fuelling feelings of belonging and connection, of acceptance of one's self and others (Shakespeare, 2000; Shildrick, 2013), there still is a "widespread western uneasiness in acknowledging or even recognising erotic desire . . . most clearly mobilised where the form of embodiment itself contests, either deliberatively or accidentally, the standards of normative corporeality" (Shildrick, 2004, p. 1). People who do not comply with these standards remain excluded from the "notion of sexual subjectivity" (Shildrick, 2004, p. 1). For instance, this becomes visible in the invisibility of people with disabilities living an active life in society

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[9] Whenever the first person is used, it refers to the first author.

alongside their hypervisibility as passive consumers and victims in popular imagination (Kuppers, 2001), the focus on performance rather than intimacy in media and sex education (Esmail, Darry, Walter, & Knupp, 2010), the low priority that healthcare professionals assign to sexual issues fuelled by their discomfort with the topic and lack of knowledge about sexual functioning with specific medical conditions (Dyer & das Nair, 2012), reference in healthcare manuals to "feminine" aspects of sexuality suffering less from SCI than "masculine" aspects—epitomising the approach of women with SCI as being less affected than men in both sexual functioning and experiencing sexuality (see Kiekens & Post, 2008, p. 227).

Sophia could be seen as one of the many women with SCI who, in comparison to temporarily able-bodied (TAB) women, tend to have a significantly lower body image, sexual self-esteem, and sexual satisfaction (Moin, Duvdevany, & Mazor, 2009), report declines in sexual desire and activity (Beckwith & Yau, 2013), and as one of the many people with disabilities 'overall' who tend to start later with dating and experiencing sexual relationships than their TAB peers (Miller, Chen, Glover-Graf, & Kranz, 2009).

The ostensible insignificance of sexuality in Sophia's life could be partly explained by a SCI-centring research trend that lists what is not physiologically functioning, focusing on barriers women with SCI might encounter during their sexual lives or childbirth due to limited mobility, spasticity, lack of bladder or bowel control, absence of genital sensation, and medication affecting arousal (Sipski, 2006), with low self-esteem, feelings of being unattractive, and bodily alienation fuelled by loss of sensation sporadically mentioned as secondary consequences of SCI that contribute to obstructed (search for?) intimacy (Kiekens & Post, 2008). Notwithstanding its importance and the recent inclusion of psychosocial factors to sexual experiences in healthcare research (Kreuter, Siösteen, & Biering-Sorensen, 2008; Seddon, Warren, & New, 2017), this research trend offers and reinforces medicalised, reproduction-oriented and/or performance-based views of sexuality of people with disabilities. This in turn results in healthcare practice that ultimately runs out of possibilities in (re-finding) sexual expression and pleasure (Tepper, 2000), once rehabilitation and medical interventions have reached their limits in fixing and modifying the body.

Another research trend provides explanations by listing oppressive forces in society affecting ways of feeling, thinking, acting towards people living with corporeal differences (Di Giulio, 2003; Liddiard & Slater, 2017; Shakespeare, Gillespie-Sells, & Davies, 1996). This research views disability as “a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being” (Thomas, 1999, p. 60) and thus as a consequence of social injustice rather than a problem located in the body, and sexuality as not purely originating from the body but sexual encounters as “a profoundly social act in its enactment and even more so in its antecedents and consequences” with the “historical situation of the body [giving] the body its sexual (as well as other) meanings” (Gagnon & Simon, 2005, p. 492). Myths celebrating dominant able-bodied corporeal standards such as “people with disabilities lack biological sex drives”, “women with impairments are less affected sexually than men because of their more passive sexual role”, and “if able-bodied people find people with disabilities desirable, they settle for less” continue to permeate interaction (Olkin, 1999; Brodwin & Frederick, 2010). Thereby they detrimentally affect the public, interactional, and private sexual scripts (i.e., social and cultural guidelines that embed sexual feelings and behaviours in certain meanings, and by doing so define sexuality, prescribe what is appropriate and what is not, and who has the right to be sexual) on which one’s sexuality is based and ultimately foster stigmatisation, sexual marginalisation, and social isolation (Duna, 2013; Jackson & Scott, 2010; Kimmel, 2007). This body of research urges us to attend to the destructive impact of social/cultural/environmental factors on sexual identity formation and activity of people with disabilities, yet in doing so neglects the reality of living with physical limitations and discomfort (Linton, 1998; Snyder & Mitchell, 2001; Kool, 2010). Moreover, it risks erasing the agency of people with disabilities, what Shakespeare (2000) refers to as the “costs to [playing] the game of who is most oppressed” (p. 162).

Whilst valuable and necessary, lists of physiological dysfunctions and normalising forces may stun people, but they do not move people. They tell us something about *what* happens to people (e.g., obstructed intimacy, sexual abstinence), much less about what it *means* to people and *how* it happens and is happening (e.g., the search for intimacy, desexualisation). The complexity of women's experiences of living with an impaired body remain largely unexplored (Rembis, 2010; Seddon, Warren, & New, 2017). To create possibilities for movement, we need holistic research focusing on processes rather than substance, seeing women and their bodies—normative and non-normative alike—as constantly in becoming (Shildrick, 2004), and embracing embodiment as "the claim that perception, thinking, feelings, and desires—that is, the way we behave, experience, and live with the world—are contextualised by our being *active agents* with this particular kind of body" (Taylor, 1995; paraphrased in Overton, 2008, p. 1). We need life stories about corporeal difference as they have the power to challenge how we understand and interact with human diversity (Garland-Thomson, 2011; Mintz, 2007), not in the least because they show the dynamics of experience by in-depth exploration, humanise "research subjects" by visualising their voice and making their experiences tangible, and thereby fuel connection between researched and reader, facilitating the transition from being stunned to movement. Accordingly, I have opted for a longitudinal case study of a woman with SCI, analysed phenomenologically to centre how she experiences her body and positions herself as an (a)sexual being whilst not losing sight of the body as the flesh in which we live in relation to the world. How and why does Sophia desexualise her body, yet also finds space to rethink the possibilities of living with her body?

Sophia's Story

Sophia is one of the participants of the first author's doctoral research (2014-2019) about women with SCI's lived experiences of sexuality by drawing on their stories of the past, their experiences of the present, as well as their perspectives towards the future. At the age of 14 she became tetraplegic due to a traffic accident, and needs her motorised wheelchair with proper support for her legs and her upper body as well as assistance from nurses, family, and friends for nearly all basic daily living activities such as going to the toilet, bathing, clothing, preparing food, and transfers into and from her wheelchair. Having spent three years in rehabilitation, she feels she has missed being a teenager. At the time of the interviews she is 23, living in a student flat, about to complete her university education in literature, and busy searching for a job and a house. She has many male and female friends, and sexuality is a topic that is common amongst her fellow students yet "confronting" for her as it is "difficult to talk about because you really are just a layperson in that field", as she has not had a long-term relationship or any sexual experiences yet.

Approaching Sophia's stories

I conducted three individual in-depth interviews in Oct 2015, Nov 2015, and June 2016 with a duration of 70, 90, and 80 minutes respectively. Sophia indicated she felt comfortable communicating openly with me, referring to me being a young woman with SCI as well.[10] The first two interviews were episodic (Flick, 2007), generating detailed narrative accounts, subjective definitions, associations, etc. The first two interviews revolved around one main question: "Could you please tell me your life story with a focus on your development of relationships and sexuality?" to explore Sophia's meaning-making of key events and concerns

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[10] The fact that we both currently live with SCI might have indeed facilitated for Sophia the process of talking about the body in all its leakiness, attributing to me a particular sensitivity to "uncivilised" or otherwise shame-provoking aspects of the body (Seymour, 2007, p. 1194). Her acknowledgement of us having common ground encouraged me to delve further into Sophia's experiences of her body in all its brokenness and potential. However, when considering the overall flow of the interview and the openness of Sophia, it should not be overlooked that we are also both women, heterosexual, of a similar age, literature-loving, etc. Also, she participated in another study of mine on disability-disclosure and topic avoidance in higher education (2011-2013). I am conducting my research with the knowledge that my participants and I have SCI in common, but even more so with the knowledge that every SCI impacts differently on one's mobility and sensory functions and on one's life course, and that every person with SCI deals differently with physiological dysfunctions and social oppression. Sophia cannot live without human assistance for basic hygiene and transfers out of her wheelchair, I can. She can feel her toes tingle, I cannot. She has not engaged in romantic and/or sexual relationships (yet), I have. Therefore, I do not see myself and Sophia as peers in disability, but rather as peers in humanity. I have elaborated on my becoming of a researcher of sexuality and SCI with SCI elsewhere (*International Congress of Qualitative Inquiry*, 2015; 2017; published in Blockmans, 2019).

when it comes to sexuality and living in and with her body, spurred on by questions of reflection and probing ("You said that… What did you mean?", "How did you feel?"). The second interview started from the discussion about the interviewee's teenage diaries which she chose in response to my question as researcher to bring along an "object" to the interview "that marked, for her, an important stage or moment in her sexual or relational development".[11] The third interview was semi-structured, enabling Sophia to complete her story while I checked my interpretations, connections and contradictions from the previous interviews. All interviews were transcribed verbatim.

I drew on Smith, Flowers, and Larkin's (2009) description of Interpretative Phenomenological Analysis (IPA) to make sense of how Sophia experienced her sexuality due to the technique's suitability for exploratory, often "explicitly process-oriented" research and its analytic focus on "people's experiences and/or understandings of particular phenomena" (here: being a young woman with sexual desires living in and with a body affected by SCI) as well as their perceptions in detail (p. 46). It fits within a relational embodiment approach which bridges the divide between inquiries of biological, phenomenological, sociocultural and environmental nature as it, whilst prioritising the role of individual beliefs and experiences of a phenomenon (approaching the participant and the wholeness of her experiences rather than discourse as unit of analysis), assumes that the body, the mind and the social world interact: people are both embodied and embedded within a wider assemblage. Initial notes focused on Sophia's sense-making on an explicit level (descriptive), language use (paralinguistic), and my reflections as a researcher (conceptual), guiding me in identifying what was essential to make sense of how Sophia has come to perceive and position herself as a(n) (a)sexual being. First, I will present the two themes which most clearly illustrate the dynamic and intra-active nature of her self-desexualisation, i.e., abnormalisation and disownment of the body. Next, I

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[11] The object was supposed to be the starting point for the first interview, but Sophia was so enthusiastic (spontaneously responding with personal anecdotes and opinions to my outline of the study and the informed consent form) that the intake interview became an in-depth interview in itself.

will zoom out and reflect on the naturalisation and persistence of normativities in social encounters which contributed to Sophia's desexualisation versus the movements she engaged in and which opened up potential for transformation.

Abnormalisation—Clicking away from the girl in the teenage diary and back again

Sophia brought her teenage diaries depicting her early pre-injury exploration of sexuality and marking a clear divide between her life before her accident and her life after. Recollections such as "Cedric looked at me", "I bumped into Simon by accident", "I have this feeling that I have a crush on Matt" are abundant. Fluttering from one crush to another, Sophia was aware that boys were attracted by her looks and she knew how to manipulate their attention. All the "drama" of crying boys that came along even became too much to handle: "I didn't want to be the popular girl anymore who…gets a lot of attention and functions as a kind of role model of everything… I wanted to disappear in the background". Today, however, the dairy that is full of "sentimental speech" for her reflects the popularity—and a source of self-definition—that she feels to have lost since, and due to, her injury, and which now seems unattainable for her: "Well , I have brought my diaries with all my sentimental speech from sixth grade onwards … because how I was…You know, I really used to be quite popular with…boys?"

She experienced her wheelchair and the swollenness of her body due to cortisone to have downgraded the attractiveness of her body, which she sees as the first main catalyst of annihilating her self-confidence, and as an explanation for being "catapulted" by her male peers from being "potential" to "one of the guys":

> I knew really well how to twist and turn before, and about the effect I had on guys. And then suddenly you end up in that wheelchair, and I gained 16 kilo's, and actually from that moment onwards I became tremendously insecure and I don't dare to think about boys in that sense anymore, don't even dare to look at them anymore, catapulted into the friend's zone and the "one of the guys" status where they talk

> with you about girls and you think "damn, in the past I was the one whom they… well, also talked about". Anyhow, I was potential back then and now not anymore.

The idea that her changed body ruins her chances on the dating market seemed and seems to be a given. Whereas she mentions her dependence on others for basic self-hygiene and struggles in a wheelchair-unfriendly architectural environment as add-ons ("stuff"), the consequences of her injury on the practicalities of daily life have significantly affected the way she feels about herself in relation to others (and the way she perceives others to feel in relation to her, see below):

> Your whole self-image is taken down and you go and cross yourself off, and ever since I have fooled myself… Because I was insecure. Thinking "a guy will never ever again…", you know, fall for you, and so I made this click for myself not to look at a guy that way ever again. Simply to spare myself the pain. To protect myself. Also, simply, purely because I cannot imagine a future of living together, of getting married, he would need to take care of me and stuff. Also I know, for example, going to the toilet and stuff is such a fuss, and I still find it something really embarrassing, and I cannot imagine lying in a two-person bed, how to deal with those toilet problems, and getting my clothes on, so that is also why I try not to look at guys because I don't know how things would go. And also, I do not want to oblige anyone to put up with me.

Sophia's meaning-making of the changes in appearance and functioning as desexualising in themselves and her perception of her male peers interacting differently with her have resulted into Sophia desexualising herself as a form of self-protective damage-control, avoiding situations that could confront her with the reality of her fear of having become undesirable. She has consciously made the "click", i.e., decision, of not thinking about and not looking at men as potential partners ever again and actively "crosses herself off" as potential (sexual) partner.

Becoming a burden: Where is the line that tells you what you can expect from people?

Stemming the flow of encounters with men, however, is more than a self-protection strategy. It is also a strategy to protect others from getting themselves involved in a burdensome future and/or a future full of socially embarrassing events. As the last sentence of the quote above demonstrates, Sophia sees herself (rather than the assistance she needs for practical matters) to have become the burden she does not want to impose on others. She connects her fear of being a burden to what she sees unfolding at home, where especially her mother is running out of energy to provide care:

> I still have this image in my head of the poor fellow that would need to take care of you … Where is the line that tells you what you can expect from people? On holidays my mother will always… she can dress me, but to what extent… I always try to arrange assistance now, simply because it's too heavy for one person . . . For a partner, in the end, it's so exhausting. After all, he has a life of his own that he needs to focus on. Because I know, my mother, she positions herself completely in function of me, I see that she loses her bearings and will come and measure my blood pressure every fifteen minutes . . . That's why I live here now, so she's a bit rid of me and she's forced to spend the time she has on herself… because I really value living a life of one's own, and it's so annoying that people need to plan their lives in function of me… Plus I think it'd be hard for a partner to indicate when he cannot cope anymore, when it becomes too much… stuff that is not told, but still present, can only result in a really heavy atmosphere at home.

Sophia understands her mother's struggling with stress, physical exhaustion, and leading a "life of her own" to be a direct consequence of her high need of assistance (disregarding her family members' own role in drawing resilience "lines" and communication ("stuff not told") to find a feasible balance in providing care vs. employing external caregivers). This feeds her impression that she is hard to live with as well as her fear that a partner would not be able or would not dare to draw the line in providing care. Being very concerned with the ideal of autonomously living a life of one's own and the corresponding undesirability of needing others rather than seeing interdependence as a natural feature of human connectivity, Sophia feels a burden and causing people in her close environment to be under constant threat of losing their own lives in enabling her to live. Whereas Sophia has decided to move out and arrange assistance to relieve her mother, she cannot draw a parallel line of flight in envisioning a balanced relationship with a partner.

Becoming an embarrassment: A cobweb of social scripts

As Sophia increasingly gets more attention from men at present, which she ascribes to her feeling "better in [her] own skin again" after losing weight, she cannot but imagine a future of embarrassment that she wants to spare not only herself, but also her partner. Throughout the interviews, Sophia frequently uses the word "embarrassing", usually when talking about hypothetical situations in which she and/or her imaginary date deviate from the rules scripted by ideal (i.e. flawless, smooth) date and sex scenarios and gender patterns. Her strict interpretations of these scripts (possibly because she has never had a relationship to provide 'counter-evidence') affect what she finds embarrassing and what she believes to be embarrassing for others.

> You notice you get somewhat more attention from boys and you start thinking about their potential, like "that one looks quite handsome" or "that one comes close to my type", but that's still a whole new experience for me. I find it hard to think further, as I still find it hard to push someone to put up with me or to imagine how it would go . . . even dating would be embarrassing . . . he'd need to put on my eating aid, and then we'd go and sit at a table and the table turns out to be one of those narrow tables so I don't fit between its legs, or I bump into

> something with my foot support, … to spare myself and to spare him those kind of things. Or if he'd kiss me, he'd need to put on my brakes first because I'd roll backwards and all those embarrassing things. ((laughs)) So I can only imagine really impractical events. That's why I always try not to think about it.

Rather than considering it a normal and potentially "hilarious" aspect of a "collective journey of getting to know each other" regardless of (dis)ability (as one of my other research participants described the scenario which, for her, had really taken place), Sophia imagines the search of workable ways to express physical affection to be unusual and therefore embarrassing and to be avoided. Her laughter about the "impractical events" does not reach far enough for her to escape from seeing herself as being different and moving differently as distressing for both herself and her potential partner. By saying she tries not to think about dating, she confirms that she does think about it but consciously decides not to see it as an option.

When imagining physical intimacy, Sophia envisions her disability to be an obstacle that would demand creative initiative of her partner, which suggests the internalisation of a dependent, even passive role for herself in interaction with others. Delving further into her idea that it is hard for a wheelchair user to get into a relationship, Sophia finds it harder for (heterosexual) women in wheelchairs as "girls tend to be more pitiful, will more easily approach a guy in a wheelchair if only out of…you know those girls who are simply goodhearted…" and she believes that deviations from date, sex, and gender scripts are more difficult to handle or to get away with for men. She reasons that men tend to get paralysed when "confronted" with the unknown (which she embodies), and need to act according to a socio-sexual script that is stricter and leaves less space for variety than women's—a script to which her body poses only threats:

> A woman will be more inclined to sit on a guy's lap than… I'd find it simply embarrassing if my guy would go and sit on my lap…and tough

> guys are more my type, which would make that even more difficult because they never do that . . . he would never roll around a park with that wheelchair . . . I think a woman will also take more initiative than a man who'd clumsily wonder what to do, which can only lead to embarrassing confrontati-well, embarrassing moments.

Movement towards (re)new(ed) potential?

Noticing men's attention, Sophia finds maintaining the mental switch in the "don't look at guys as potential partners" position increasingly difficult. She clearly longs for confirmation of her desirability (as in: her potential to attract) yet simultaneously struggles with denying her sexual desires and not thinking of others potentially desiring her. She is talking about the expansion of her group of friends:

> S: The downside is, in the beginning I knew, that one is gay, the other one has had a girlfriend for years plus his manners do not suffice to be eligible ((laughter)), well, to attract my interest. But now there's another guy, single and quite good-looking, and it's difficult for me to judge him as potential or not… I always wonder…
> I: But you have feelings for him?
> S: Not really, I just… actually I always wonder whether I'm eligible . . . I think we see each other as friends but that question remains, even if I don't have a crush on him, does he see me as potential? I don't need to be his type, but does he see me as a girl with whom he'd be able to start a relationship . . . Would they consider me… instead of their little sister or "yes but she's in a wheelchair so she is not an option", you know, that you're completely out of the running from the start…
> I: Actually you want to know whether your impairments, or extra needs, whether they…
> S: Play a role or change their image of me. And that's always my fear, because I want people to see me as Sophia.

As Sophia's confidence to dare and think about the suitability (rather than availability) of men as dating material is gradually growing, her concerns surface about how others look at her: Will the unruliness of her body overshadow who she wants to be? Throughout the interviews, especially when talking about encounters with new people or hypothetical dating situations, Sophia tends to see herself through the eyes of others, whom she anticipates to be put off by the abnormality that she feels to embody:

> The way I look now… is still one of the hardest things for me to accept. And it's also what I'm extremely afraid of in a relationship. Because I know that my body does not… look normal. I do my best to look normal… I diet, I wear my belly support, I even grow my hair. It really is quite an effort, but I know that if you see me lying on a bed, simply in my… well, in my underwear, that I, my feet are swollen, but they also, if I am not wearing my braces, go pointy, fall open and downwards, and that doesn't look normal at all. I know, I have no stomach muscles anymore, I don't have my chest muscles, it's all gone… I don't look anymore like, you know, someone, you can simply see an enormous contrast between a normal somebody, or even between me in my wheelchair and how I really am as, purely myself, without the belly support and stuff… I wouldn't want to showered in a chair or a bath because I cannot, I don't want to, I cannot behold my body, because I know it has changed so much and it makes me unhappy.

The whole act of desexualising her body and her encounters with others revolves around the fear that she can no longer be the Sophia who once embodied desirable femininity, even with props (e.g., tight belly support, long hair) that for her typify femininity. Whereas she "works on the norm" in other aspects of her life, explaining to her friends what her life is like to show she is not that different from them despite her corporeal differences (epitomised by the blog she wrote whilst in rehab to keep in touch with classmates, titled "Sophia, simply slightly different"), she sees "alignment with the norm" (Winance, 2007) as a prerequisite for access to sexual encounters, which underscores the strict sexual scripts she has internalised. Remarkably, she even indicates she would be denying reality if claiming her life has changed since her SCI, as if she has no other option than giving her SCI master status: "Relationships or… studying… it's just, on every level, it's different… I am not going to be weird about it, saying that it's not". Sex for "people with disabilities", and she identifies herself as having a disability, is different from "normal sex": "Here, in student housing, we do talk about normal sex, but not about people with disabilities . . . I join [my best friends] about common topics, such as periods, condoms, but applied to myself, gosh..."

Disownment of body and life through medicalisation

Sophia's positioning of undergoing rather than steering what happens surfaces even more when she talks about healthcare encounters, where her body is managed by the hands and eyes of medical professionals.

Self-disembodiment – About consciously-made mental clicks and ownership to be claimed

In intimate care, Sophia perceives a strong pressure to undergo whatever happens. Yet, she ascribes the discomfort she experiences not to some professionals' failure to respect her body ownership, but to her perception of the situation, her need to get used to the nurses' ways of washing her, her need to get used to people seeing her naked at any time, her need to get used to men washing her (including young men, which she finds harder to deal with as they could be potential). She reflected on a fight she had with female nurses after she had told them she felt uncomfortable being washed by a male intern at the age of fifteen - an issue that was "moved to the psychologist and then higher up and eventually I won":

> I want to, I dare to… if necessary, well, if necessary I will get over it, but I simply find it still difficult at the moment to get myself over it, and

> that is probably my-about myself, I will, I am aware that I will need to learn [to accept].

The learning is up to her, she feels. This learning has taken the form of trying to click herself away from intimate care situations by chatting during the sessions and put into perspective the loss of her ability to keep (the care for) her body and all the knowledge around it for herself. Once again, upon my question how care affects the ways she experiences her body, Sophia refers to a mental “click”:

> I remember when it started, in hospital, I was 14, and all of a sudden I needed to let men… wash me and dress me, and with all the tubes in my body… it was really painful, and ever since, I have… really made a mental click, you simply… switch off your brains.

However, her daily attempts to distance from her body ownership on top of physical discomfort are never completely successful:

> Show some respect for… well, anybody. They are washing you and then the door opens and then… well, somebody simply pops in unabashedly. Okay, she is a nurse too, but you are lying naked on your side when they are washing your back. Then you think: “oh, people, come on, can’t this wait?” . . . or they are talking loudly about whether or not you have been to the toilet, but you’re in a two-person bedroom and you know there is someone next to you. Those are all aspects that I often struggle with, because I’m like, “come on, we are human too, individuals” but on the other hand you know “yes, this is the hospital, everybody lies here for a reason”.

Strikingly, Sophia notices that female nurses “strictly” handle her body, much more than male nurses do. The adverb “strictly” seems to be an understatement as Sophia feels her wishes are disrespected, and could be seen as an instance of Sophia shying away from, minimising, or attempting to legitimise the way she is treated. She feels disrespected by the female nurses treating her as just a body rather than someone's (her) body. Female nurses strip off her clothes, leave her naked until they have washed her body completely, and only then give Sophia back her ownership, whereas male nurses "simply…show much more respect for a body", "never making a problem" out of her wishes:

> Nowadays I even prefer to be washed by a man rather than by a woman because they simply, well, they have much more respect for a body… For instance, when I ask "Could you please do my upper body first and then put on my bra already?" instead of, like some do, undress completely, wash in one go and only then put clothes on again, then a man would never make a problem out of it, he will always cover you up really well or anything or really do his best, whereas a woman can be much stricter.

Sophia experiences the ownership of her body as something to be claimed and to be granted, rather than a given right. Whereas temporarily able-bodied women are likely to feel equally uncomfortable with being stripped naked and others talking about private and taboo-topics such as their stool, Sophia experiences this daily, which is likely to increase the dehumanising/de-individualising impact of medical treatment on how she moves through life.

Internalised medicalisation and cracking mental clicks

For years Sophia has blindly trusted medical expertise, seeing accepting and putting things in perspective as the only options. Noticing the Little Black Dress Challenge (a 30-day diet and sports contest she participated in with her flatmates) poster on her wall, I asked her how she felt about dresses and skirts:

> S: I used to wear them, but with my white stockings and my braces it looked…stupid, stupid, and so bulky, so now I always wear trousers. Aren't you wearing braces?
> I: No…
> S: But your feet, don't they ever…? I don't know, why am I doing this

> actually?
> I: If you're wearing stable shoes up until here, your feet will stay where they are…
> ((I point at my boots))
> S: But they are not 90° now, your feet? Don't they need to be?
> I: I don't think so… As long as they are not in too sharp a corner
> . . .
> S: I don't dare to, I don't know why I…but I still have spasms, do you have that problem?
> I: Yes
> . . .
> S: I am scared… I don't know… matter of habit, probably…
> I: Give it a go, just like that.
> S: Yes actually I should.
> I: So you… also wear compression stockings?
> S: Yes, I could also…
> I: Choose a nice colour and…
> S: Exactly, then that's also possible, yes. Yes, because yours are crazy ((Sophia looks at my caramel-coloured stockings)) … but are they tight enough? Because I thought the pretty ones were not available in the strong version…
> I: This is the strongest version.

It is when Sophia stumbles upon differences instead of confirmation of habits she had taken for granted (here: the use of body management tools such as braces and compression stockings which are available in a whole range of colours and patterns yet only used and promoted in white in hospitals) that she starts questioning the medical gaze she has internalised and finds the confidence to resist and start rethinking the limits of her body.

Re-owning the body – Simply using common sense?

About half a year after I had acted unintentionally as a looking glass which disassembled Sophia's perception of what is good and necessary for herself, Sophia enthusiastically mentions that she "at least" has "already taken the step" to buy "a beautiful pair of sandals". However, although seemingly unaware, Sophia has not taken a minor step in body work, but a leap in imagination, which becomes clear when she expresses her frustration about (hence questioning of) her mother's focus on negative doctor's advice and frames her dad's gauging of the risks involved when not wearing braces as putting "things in perspective" and "simply using common sense":

> S: She's not quite agreeing. She's so anxious, "but sweetie, the pressure on the heels". She's so selective in what she remembers from what the doctor has told, it's horribly frustrating.
> I: But then there's your dad who…
> S: Puts things in perspective. He says, "if the rehabilitation physician says it's okay, it will be okay". Also simply using common sense. Also, I won't leave out my braces every day, it's just now and then, and if I manage, and if the pressure doesn't get too high and I don't get injuries or whatever in my feet or something else, it'll be alright.

Sophia still keeps in mind doctors' warnings which are repeated at home and make her hesitant to completely trust herself in what she is doing to her body, but her sense-making of what makes perfect sense has definitely changed.

When it comes to sex, however, Sophia retreats to clicking away any importance she might attach to this aspect of life. Whereas she has started to question the limited provision of information she has received from healthcare professionals, she rationalises the absence of sex-related information and downsizes its significance by explaining it as a logical consequence of a series of "coincidences", such as her age (whereas she was 17 when she left rehab—an age at which sexual exploration is not unusual) and a lack of SCI expertise. She does not even criticise the fact that she was given a stapled paper (old) black-and-white booklet (during a recent short-term stay at another rehab centre) whereas she needs a digital copy as she cannot flip the pages herself:

> I haven't flicked through it yet or they didn't go into it further, she simply passed by and asked "can this be of any use to you?" and I was like "ça va, hand it over" ((laughs)) but that was my only response. I guess it kind of shot by a bit because of… simply my age at the time, and the rehab centre was not specialised in spinal cord injury but aimed at children and youth. So they already barely knew how to handle my case at a normal level . . . So I guess because of all those coincidences.

Zooming Out

Sophia's framing of sexuality in her life as not practical, not a normal aspect of living with SCI, and not a priority is closely interwoven with her own and others' positioning of herself and her body. The first theme shows how she sees her body as not fit to be sexual anymore, her body which now deviates from the norms of desirability she once embodied and has, consequently, made it impossible for her to comply with the Western "sociocultural ideas of independence, beauty, and marketability" (Ryan, Bajorek, Beaman, & Anas, 2005, p. 121) that she has internalised and perceives as unnegotiable prerequisites for imagining a future of sexuality and partnership. Sophia's broken body and the abnormality in which it veils her—in her perception—overshadows what she desires, and steers much of her moves. The second theme shows how this abnormalisation of her body and subsequent devaluation of her body and herself as sexual happens alongside Sophia's extensive daily exposure to assistance which further gives the brokenness of her body "master status" (i.e., the most significant aspect of her life and primary identifier through which she gives meaning to her experiences; Allport, 1954) and through which she feels that her body is not hers to manage and to claim. The meanings that Sophia has come to attach to her body (abnormal and not hers) have not only affected how she feels about herself in relation to others but have also reinforced how she perceives others to feel in relation to her, ultimately leading her to actively change her ways of interacting with potential partners, by positioning herself in the outer world as someone who is not interested anymore in sexual/romantic encounters ("clicking away") and becoming passive in exploring her body and sexuality.

Naturalised truths of the body through the looking glass

Importantly, Sophia's deprioritising of her own body and sexuality and ultimately self-desexualisation (or is it first desexualisation and then self-deprioritising?) are not an authentic outing of her current sexual desires (which were not catapulted out of existence), but a strategy of dealing with what for her has become "naturalised as the truth of [her] body" (Shildrick & Price, 1996, p. 439). Throughout the analysis, Sophia's own meaning-making of herself as a(n) a/sexual being revolves strongly around how she perceives or imagines *other* people's meaning-making of her as someone with a body that looks and functions differently.

Already before acquiring her injury, Sophia was cultivating what Cooley (1902/1992) coined as her "looking glass self": seeing herself and the social world through the eyes of others (imagining how she appears to others and imagining the judgement of that appearance) and continuously adapting herself in function of what she thinks that other people think about her (developing her self on the basis of those imagined judgements), with the anticipation of non-conformity causing pain and discomfort. Nostalgically, she recalls the young teenage girl who enjoyed flirting, carefully attiring her body, and monitoring (the effects of) her moves.

Her accident catapulted her into a medical story where she lost control of her own story, physically through delivering her body to the care of other people's eyes and hands, but also psychologically by internalising the medical gaze on her body. She has come to see her body as deficient and something to be contained, evaluated, and protected by a board of medical experts rather than something to be made beautiful and to be explored for one's own pleasure.

Repeated exposure to medical advice, her compulsory dependence on others for basic daily survival, and repetition of complex mental work have deeply rooted a deficit-ideology, and have made it even harder for her manoeuvre away from and within the normalising systems (of healthcare, womanhood, sexuality, relationships, able-bodiedness) she finds herself surrounded by and has seeped into the positions she assigns herself in healthcare-unrelated encounters.

After years of rehabilitation, she has taken up her dreams again (studying, job, housing), but her thinking about sexuality and relationships lacks the sense of personal joy and desire she once experienced and is marked by her fears to deviate from what is normal. Her disability is an undesirable state of being in which she feels stuck. Rather than questioning and rewriting the scripts which for her imprint the well-defined image of a full-blown woman embodying sexuality, such as strict dating and sex scripts that prescribe a flawless process of getting to know each other, strict partnership scripts that draw the line of what you can expect from people when it comes to interdependence, and strict gender scrips that prescribe what behaviour can/not be expected and accepted from men and women, she tries to write herself out and distances herself from what is happening around her and from what is possible. She has "stripped sexuality of significance" and clicks herself into understanding sexuality as indeed "a potentially pleasurable bonus" which is unattainable for her (Shildrick, 2004, p. 1), simply a bonus. Years of desexualisation performed by herself and reinforced by an environment that failed in showing a horizon of possibilities (in the form of e.g. accessible medical information about sexual functioning with SCI, free market of mobility and healthcare aids, visibility of other women with similar bodies leading a sexually satisfying life, etc.) have led her to perceive learning about and experimenting with her body as unnecessary or impossible.

Re-imagining possibilities through the looking glass

Gradually Sophia becomes aware that she can take up ownership of her body and her life. Sophia is on a creative journey of rewriting her embodiment of unruliness: she has taken up management over her body by arranging assistance and living in student housing rather than with her family, by choosing clothes she likes rather than clothes that fit her braces (which she now sporadically dares not to wear), and she is taking up a more active position in encounters with men by making eye contact and thinking about their suitability rather than only availability. These acts of resistance and becoming are fragile, hesitant lines of flight exactly because chains of normative discourses keep coming back, already internalised as "the natural, configuring and restricting the doxa that counts as 'reality'" (Butler, 1997, p. 159) and externally reinforced in Sophia's environment (e.g., medical discourse re-enacted at home could easily click Sophia back into "broken body modus", hierarchical power play needed in hospital to get someone else to wash her, etc.).

Situated more broadly within Sophia's coming-of-age journey, in which she is slowly developing her competences to create and defend personal limits, with self-confidence related to appearance and performance (van der Doef, Meihuizen-de Regt, & Wiegerink, 2008) and moving towards a view about partnership not for self-validation but for the other's qualities (Enzlin, 2008), it is clearly important to encounter quite directly alternative ways of living with a broken body for widening one's horizon and sense of choice. Whereas I endeavour to be a peer in humanity rather than in disability exactly to counter the master status of disability in any 'personal' or professional encounter, Sophia, experiencing her SCI as having had a major impact on her life and making her too different from most people in her environment when it comes to bodily experiences, saw me as a looking glass in which she could recognise herself enough exactly because she knew I had a SCI to start questioning the naturalised boundaries of her body.

Breaking the boundaries

Clearly the ostensibly dominating disengagement from body and sexuality in Sophia's life is neither something that happened suddenly nor is fixed as could be inferred from analyses focusing on biographical disruption triggering what illness and disability literature describes as "adjustment to a new way of life"

(Yoshida, 1993). It is the result of a process of creating and breaking invisible boundaries that traces back to Sophia's history of becoming-in-the-world long before her accident as well as an ongoing performative process in which Sophia is not the only actor.

In "Breaking the Boundaries of the Broken Body", Shildrick and Price (1996) acknowledge "the experience of disability as an experience of a supposedly 'broken' body" (p. 432) yet simultaneously argue for a recognition of disability as a category with fluid boundaries, thereby creating the possibility to contest the "system of normativities which, although never inevitable, imposes . . . a powerful urge to behave in certain ways, to mark out the boundaries of the proper" (p. 438). The major challenge for all of us—regardless of abilities, profession, age, etc.—in breaking these boundaries lies in seeing them. Although the ideal image of what it is to be "fully human" is unattainable by anyone, our endeavours to embody ableist standards are so taken-for-granted and embedded in institutional practices that the normativities at work have become invisible. McRuer (2004, p. 52) visualises the outcome of this process as follows: "all the world may be an inaccessible stage that able-bodiedness has constructed for its own performance, but the performance has been so naturalized that the actors do not realize that they are working with costumes and props". This naturalised incorporation of ableism in our daily encounters incites what Kafer (2013, p. 4) calls the "ableist failure of imagination". We stop dreaming beyond the borders of what has been constructed as normal, universal, compulsory. However, by positioning disability as emerging from 'set[s] of practices and associations that can be critiqued, contested and transformed' (Kafer, 2013, p. 9), space is created for improvising on the main stage and living differently.

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Chapter Four

Retouching and Revisiting the Strangers Within

An Exploration Journey on the Waves of Meaning and Matter in Dance

This chapter is based on:

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Abstract

This paper explores what (working with) matter can tell us that language cannot or does not completely tell, about becoming a sensual, sexual woman free to move smoothly in and with her body. It explores how (working with) matter can transform living in, with and through a body, and how it affects and is affected. The text is centred around 'touchpoints', i.e., encounters through touch, as experienced by the first author as a dancer on wheels, and diffracted and narrated through poetry and images interwoven with theory. These encounters are seen as mo(ve)ments in a powerful agential assemblage that holds both danger and transformative possibilities, leading us to re-imagine freedom as a river of sparring intensities.

Key words: autoethnography, dance, becoming, agential assemblage, touch

Introduction

On a rainy winter night in 2016, I, the first author of this paper, opened my inbox and saw an invitation to participate in a television production of short documentaries about people with physical disabilities who have a dream that is difficult to realise because of their physical condition. I only took time to roll my eyes, before clicking it away. I wanted to dance, but no way was I going to contribute to 'boxing up' people like that—not others, and not myself. By the end of the following month, however, my independent search for dance instructors had yielded only a couple of dancers nearby, who could neither inspire me, nor inspire my friend who was aspiring to be my dance partner. My desire to explore how I could move my body—aesthetically, and fuelling connection with myself and with others—had become an important goal for self-care, going far beyond daily physiotherapy sessions and me-time bubble baths with rose petals and oil, scrub, and foam gels sparkling like diamonds…so I jumped. After an intake interview to check whether I was 'screenproof', a famous Belgian singer and television-presenter knocked on the door of my office, kneeled, and asked me for a dance.

Over a timespan of four months we created a choreography, developed our muscle-history, and won a bronze medal at an international wheelchair dance competition. We started from a story-outline I wrote about myself as a freed woman. I wanted to express a story in which everyone could recognise something of him or herself, a story of attraction and resistance, confidence and feeling small, within the search for love for one's self and the other. I started dancing the story that I considered the story of my life. And then I felt, not that the words of now being a liberated woman were untrue, but that I did not embody that liberation in each and every context or assemblage that I found myself in.

I came to know intimately that "feeling, desiring and experiencing are not singular characteristics or capacities of human consciousness. Matter feels, converses, suffers, desires, yearns and remembers" (Barad, 2012a, p. 59). Through working with the materiality of my body through dance, and through extending that work in the writing of this paper I extended my body's capacity for the freedom it discovered in the dance.

The dance project became an experiment of thinking about my body differently *and* using my body differently, where I increasingly moved my body on the waves of my own story, and through which I diffractively wove new materalist concepts in order to make sense of this new agential assemblage. My dance became a method of inviting and visualising "the ongoing, mutual, co-constitution of mind and matter" (Alaimo & Hekman, 2008, p. 5).

This paper aims to shed a light on what (working with) matter can tell us that language cannot or does not do alone. It works with the feeling of being a sensual, sexual woman, free to move smoothly in and with her body, and explores how (working with) matter can transform living in, with and through a body; not a body in isolation, but a body that affects and is affected. Recognising the dynamism of matter, and the agential contributions of all material forces (Barad, 2007), makes visible and breaks open boundaries, even with bodies that are 'broken' beyond repair according to the current state of medicine and rehabilitation.

In this exploration of imaginative manoeuvrability we ask what makes bodies 'ruffled' and 'ruffling' rather than broken. The metaphor of ruffled and ruffling bodies is a translation of Jacqueline Kool's "kreukelige lijven" (Kool, 2010a; 2010b). "Kreukelig" could also be translated as creased, wrinkled, crinkled, crumbled, crumpled, but 'ruffling' is interestingly associated with creating disorder or disarranging something, typically by running one's hands through it, i.e., through touching bodies.

In order to write this paper we selected words from the poetic reflection of the first author below that particularly resonated when thinking about touch, and we matched these with resonating visuals from the dance performance. These words and images resonated in turn with Barad's (2012b) thinking about the fluidity of matter:

> Being in touch with the infinite in/determinacy at the heart of matter, the abundance of nothingness, the infinitude of the void that is threaded in, through, and around all spacetimemattering opens up the possibility of hearing the murmurings, the muted cries, the speaking silence of justice-to-come. (p. 216)

With our resonating images and words we sought moments in the choreography that opened up the possibility of hearing/seeing/thinking the murmurings and muted cries of injustice. We worked with the video-recording of the dance, looking at how all touch differed and built, layer upon layer, ripple after ripple, the assemblage of dancing. As we immersed ourselves in that detailed work our ideas changed about the possibilities in researching the lives of women living their intimate lives with changed/changing bodies.

We invite the reader to watch the footage of the dance performance.[12] Together with that footage we worked with the lived experience of the dance project, with the initial story on which the dance was based, and with the poetic reflections in

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[12] The dance performance as broadcasted by VTM in Belgium can be found on https://youtu.be/S0DQtOoeLTE.

the lyrics of “Feeling Good” performed by Muse. Along the way we draw from the ‘touchpoints’, the encounters through touch. The footage itself is the material residue of the bodily expressions and practices, left out of the intra-active encounters during the process of creating, mastering, and performing the dance, and which generated new subject positions affecting both matter and meaning. Within the dance itself, the dance partners experienced many different, co-constitutive subject positions: we became—at least temporarily—the liberated and the oppressed, the one who looks and the one who is stared at, the one who redirects his/her gaze quickly, and the one who is ignored and kept small, the seducer, and the one worthy of being touched.

Sparring of Intensities

I breathe in deeply, deep is my smile, I am the light.	*Birds flying high*
My arm reaching for the sun trembles,	*You know how I feel*
my hands rejoice to *unglue* themselves from my lap.	
Suddenly my body grows small again,	
and tense. I stop breathing	*Sun in the sky*
the moment that	*You know how I feel*
very same liberated arm is grabbed, suffocated, *burnt*. I	
sense the embodiment of my darkest side. Am I	
enough? Can I do enough? The voice of my	
choreographer asking me for my most natural	
response. I turn my head and look away.	*Reeds*
Looking away becomes rolling away. Paralysis	*drifting on by*
becomes movement, and I slowly turn around.	*You know how I feel*
Reach out for recognition from the audience,	
the choreographer says. But I don’t. I forget.	*It's a*
Ready to dance with my	*new dawn,*
questions, the other’s questions.	
My chair gaining *speed*, my arms spreading	*it's*
like wings	*a new day,*

…and blocking.	
Danger. Trespassing.	
And I fall.	
And fall.	
Echoes from a friend who had spotted my dancing soul	*it's a new life for me*
What is needed for the dancer to break out, my friend?	
Falling	
Falling	
Brain concussion.	
Darkness	
My body is very present.	*and I am*
So are my thoughts.	
But my body is more stubborn.	
Born.	
Reborn. After five weeks of nothingness. Retraite.	
The light is blinding.	
Reaching unscripted limits.	*feeling good*
It is then, boosted by the smashing guitars,	*Fish in the sea,*
that my body feels	*you know how I feel*
like a	*River running free,*
river running free. I look the other in the face, and	*you know how I feel*
confront him with my anger, faster and faster, circling	
around it. I am my own engine.	
Anger that I didn't know I could experience. The floor	
not slippery but supporting my movement.	
Pushing him in a corner, me growing stronger, opening	*Blossom*
up.	*in the trees,*
Touch stopping me, but this time	*you know how I feel*
I do not give it time to leave *burn* marks	
on my body. My natural	
response is not to look away but to resist.	
And that action spins me around.	

Filled with love I invite him to come with me	*It's a new dawn,*
And I reach for freedom,	*it's a new day,*
Again.	*it's a new life for me*
	And I'm feeling good
But he refuses to let go of me.	*Dragonflies out in the sun*
He is heavy.	*You know what I mean,*
	don't you know?
The chair approaches, stops, and turns aggressively	*Butterflies are all having fun*
and threatening. My partner is rolling on the floor,	*You know what I mean*
keeping low, making me stronger.	
He gets up. Obstructs my view, makes everything	*Sleep in peace*
dark.	*When the day is done*
Mockingly gives me back my view. I gasp for breath.	
My body is taken and spun around	*And this old world*
one more time and then	*is a new world and a*
The beauty of the footwork, the wheelwork, and our	*bold world*
wings come together. I go. I spin	*for me*
	Stars when you shine,
I pause. My body pauses. I unleash my belt and with it	*you know how I feel*
my freedom.	*Scent of the pine,*
Darkness screams, it has lost its voice.	*you know how I feel*
I reach for	*Freedom is mine*
light	*and you know how I feel*
The *speed* of transformation makes	*It's a new dawn, it's*
it challenging to slow down	*a new day, it's*
Our bodies get	*a new life for me*
closer	*and*
My dress falls. His hands and my legs *entangled*. As	*I'm feeling good.*
powerful as water.	

Now pause with us to ponder some of the many enfolding encounters in the dance…

Unglue

My hands in my lap. Encapsulating my legs. My gaze out in the open. Forced, as I do not feel. Open. Deeply uncomfortable in this position. Is it because I want to dance, to move, to express my story of becoming a freely sensual woman so passionately? Is it because I feel pushed by a carer, straightjacketed and imprisoned in a moving box? Or does my discomfort arise from the strangeness of touching my legs outside the frame of daily routines and practicalities, not trying to pick them up for once to make them follow me? Sometimes I believe I have lost the parts of my body that I cannot sense. The loss of the body coming with "never feeling any new desires: they wither before they can be born" (de Beauvoir, 1965, p. 657; in Deutscher, 2001, p. 146). Meaning glued to material practices, matter glued to a "sticky web" of threads of discourses that "overlap and, twisting and turning, constrain and induce bodily movements and shapes, requiring significant force to break out of culturally determined norms and shaped by ongoing choices" (Rogers, 2003, p.2), with the kind of glue you are not aware of until you lick it, like the glue on old-fashioned stamps and its sticky power gets activated, leaving an unnatural taste on your tongue. But with enough water travelling with enough force, the glue gets unglued. Echoes of a partner travel through my body. Touch your body the way I touch it and feel for yourself. My hands in my lap. Tapping gently with my fingers *on my still legs, as if meeting them for the first time. Silently, exploring their pleasurably squeezable texture, sensing their warmth. Moving organically to my belly button where my energy wheel is stoking a fire.*

Barad speaks of touch as an "infinite finitude", in which "an infinity of others—other beings, other spaces, other times—are aroused" (2012b, p. 206). Her writing on touching revolves around the intra-active encounters with what/whom she calls "the stranger within" (p. 206). Self-touching as "touching oneself, or being touched by oneself", then, is "an encounter with the infinite alterity of the self" (p. 212-213). The unglueing woman cannot remember when exactly touching the parts of her body where nerves do not signal sensations and which, depending on the force of the touch (or simply chance), do or do not respond, stopped triggering the "uncanny sense of the otherness of the self" (p. 206), if it ever did. In daily care of herself and in intimate encounters with others, her legs barely exist—for her, that is. They often bother her when they start to tremble or do not follow what the rest of her body initiates. She covers them up in beautiful stockings and attractive boots. Her legs are always moved as a pair. They have been of tremendous value to intimate others to simply hold, to massage, to curve around their own bodies—enacted desires of them that in turn spark her desire, yet never reaching the point at which she feels connected with what an openly curious 7-year-old once called her "jelly legs". Often her legs are quickly classified as lifeless extensions of her body in contrast with her outspokenly developed upper body or her wheels. They are parts of her body that remain often unspoken, overlooked: her small legs, her tiny feet, her curling toes (and everything in between).

What happens if she accepts the invitation to meet the infinite alterity of the self? Unlike the "literal holding oneself at a distance in the sensation of contact" that Barad envisions (p. 206), she is more distant to her body when she does not touch, because then there is no sensation and her body remains a stranger. It is when she holds herself, that she comes close to, and gets in touch with, the lower half of her body. Unglue-ing from the strangers within, instead being drawn to it from a state of being present in the moment, meeting anew, breaking loose, exploring the “suppleness” of her legs (Irigaray & Burke, 1980, p. 70), not as lacking muscle tissue, but as an area of never-settling softness, unpredictable excitement, blending embraces…with the openness to see and feel “the warm face of the otherness of being” (Bergoffen, 1997, p. 203).

Burning Views

“Reach for the light,” the choreographer says. And so I start lifting one arm, the other one holding on to my knee so tightly that my fingers ruffle the fabric of my denim dress. The distance between my body and the floor is growing. I feel less grounded, away from the safe haven of my loops (my name for the pushrims of my wheels), my arms close to my body and my chair. The recorder glued on the inside of my corset must be driven crazy by my heart beat. Do I dare? Cameras are watching, following my every single move from a one to seven metre distance. I do. And soft is the meeting of my hand with my face. Hi, dear me. “Higher,” I hear. And so I look. The mirrors show a woman with arms blocked at shoulder level, fighting the attraction of her torso and the floor, struggling to lift the weight of the lightest handkerchief. The glass windows reflect my body, setting alight the marks on my body made over the years. My eyes, as organs of touch (Marks, 2000, p. 162), move over my body, re-awakening doubts and desires past

and present. Elbows positioned well into the medical danger zone, and I sense them sparking off messengers of inflammation to my shoulders. Shoulders, broad. Echoes of objections to my "desire for little weak shoulders". Arms, muscly. "I am not going to arm-wrestle with you." As if I wanted to. Nude chest. Nude! The choreographer firmly putting her hands on my shoulders from behind. Our eyes connecting in the mirror, telling me I'd better show that beautiful body of mine. Pausing. Gently guiding my hand to reach for the limelight, moving me. Re-touching me. Re-turning me towards my own body with new eyes.

The woman looking in the mirror did not like what she saw, but the reflection was not a stranger to her. She looked as small as she sometimes felt, and as invisible as she often wished to be, trying to escape from prying, objectifying gazes and the pitying questions fired by the mouths below those gazes: "What do you have?" "Since when are you…?" "Is it…definite?" "Are you sure I can't help you?" Her arms glued to her torso. Where was the crazy, out-going woman who had signed up for yet another exciting adventure in her life? Known to herself and many others as drawn to roll on and flirt with the edge of things, yet how limited was the space that she had now assigned for herself.

Like camera's inexorably recording everything in search for sensational yet also normalising images, she mechanically reviewed her body. Her eyes dropped down to her shoulders, never perceived by her own critical gaze as a part of her body that could possibly make her look sexy. Smaller shoulders were the ultimate shape of elegance, associating broad shoulders with masculinity and associating masculinity with anything but attractive for a woman to embody. So were her arms, their bumpy biceps triggering many invitations from men to…wrestle, as an intriguing competitor. So was her wide ribcase, the result of years of wheeling and swimming, a spacious home for her heart and lungs, but often ripping seams of cute cocktail dresses and breaking all laws of symmetry with 'the rest' of her body.

She also felt sorry, recognising that body as a set of tools. Treated as such: essential for survival, and thus to be protected. Protected, managed, contained.

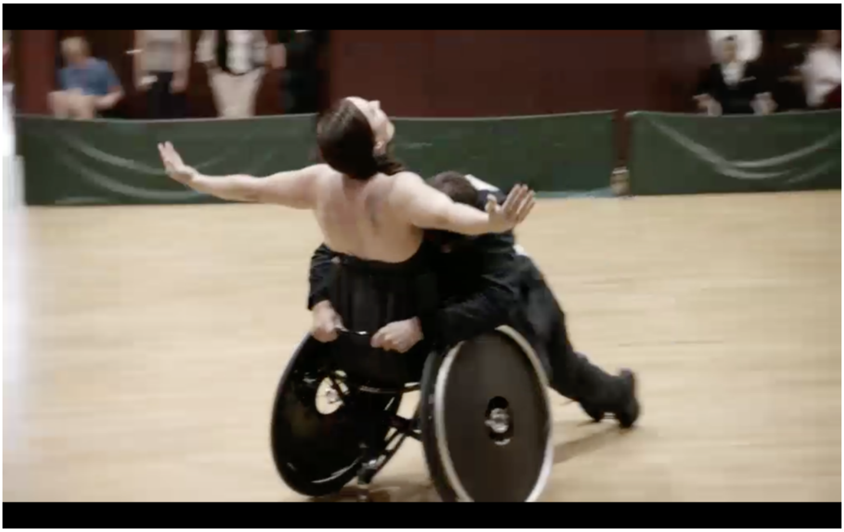
Burning were her arms strong enough to climb volcanoes but equally vulnerable to get inflamed when doctor's echoes to limit movements above shoulder level are disobeyed. Over the years, a medical eye had pierced its way through her skin so deeply in her muscles and joints that she had come to embody a medical damage-protection discourse. And with it, different ways of being in relation to her body had become more untouchable.

Her blocked body was a shocking instance of what could be the end of what Butler refers to as "a process of materialization that stabilizes over time to produce the effect of boundary, fixity and surface we call matter" (1993, p. 9). Her body seemed to have become a piece of "inscribed surface" after long-term repetitive exposure to and embeddedness in practices and discourses of femininity, sexual attraction, paternalism, … To follow Irigaray (in Irigaray & Burke, 1980, p. 76):

> If we don't invent a language, if we don't find our body's language, its gestures will be too few to accompany our story. When we become tired of the same ones, we'll keep our desires secret, unrealized. Asleep again, . . . we will be paralyzed. Deprived of our movements. Frozen, although we are made for endless change.

So she stretched herself and her space a bit more not only following every training session, but also every second within the safe walls of her home, and in a crazy carefree mood she even pulled a friend off her chair and swung her around in the middle of the street. In her tiny flat she turned on music, sounds of water drops, streams in the woods, crashing waves on the shore, because the voice of nature resonated more than anything else. She squeezed herself in the corner where she could access the only available full body mirror. Looking at her body she slowly lifted first her hands, her elbows following her fingers, sneakily dropping looks in the mirror to catch herself. She was critical. She adjusted the position of her fingers with changes as smooth as possible until she saw an aesthetically pleasing image… and then she closed her eyes to trust, and to being moved by the music. She left the tiny corner and claimed the whole space.

Speed



A ripple. Starting from her wheels, spinning from within and around her core, engaging her body, her folded dress and wheelchair in a flow, inseparable. Imagine the ripple expanding, encircling the woman and her partner, melting their shadows in interwoven movements. Like a girl giggling from deep inside, twirling and swirling for the first time, opening her arms, letting go of everything holding her back from trusting herself and the other, attached yet free. Their eyes touching, a connection where light and darkness meet. With a plunging neckline and experiencing the wind on her face, the woman she has become feels the sparks, amazed by the speed the two of them create together, excited about what else is possible. Both dance partners are embracing and showing their vulnerability, daring to be vulnerable; they are strongly connected in an invisible yet deeply sense-able encounter. His arms locked around her. Both using their bodies as one another's extensions, providing enough contra-power to stay balanced in the movements of attraction and rejection. The other's legs becoming her legs, her wheels becoming their wheels, his arms around her waist, propelling them into a new dawn. The other's touch. Caring. But not too caring. Careful. But not too careful. Gentle yet powerful. Protective, yet also searching protection. Finding peace on her belly's soft pillow. She spreads her wings and inhales. There is no end to the stream of oxygen re-awakening her body. Ever-

growing is the ripple, swelling into a powerful wave swallowing the cameras and blending the mirrors' myriad of images.

Wheels. Her wheels. Usually so natural an extension of her body which she barely notices, apart from those joyful moments when she catches their beautiful curves and spins in the reflection or in the trails left behind after splashing through pools of water. Not here. The choreographer's first aesthetic concern was how to make the wheelchair blend in by making it less present, covering it up with black spoke guards, so the metal framework would not distract the viewer from the presence of the woman, un-wheeling her "en-wheeled" being (Papadimitriou, 2008). In her daily lived experiences, the wheelchair is not an obstructive, untrustworthy piece of technology. From very early on it has functioned as her vehicle for freedom and encounters, giving and receiving opportunities to move, to head somewhere, to ride away, to break loose. In dancing, the turning and spinning and gaining speed is a way to let go without exactly knowing where the dancers will end up. Shimmering below the view and experience of speed, however, these movements require the woman to remain conscious of her wheels at all times and control her speed, stop in time, trust the other one to stop in time, precisely adjust the position of her hands and her point of gravity, …

The woman felt energy flowing through her body as never before, which created space for discourses of pleasure, desire and connection. She enjoyed the freedom of gathering the speed in ongoing movement, and experimenting with using her arms while she was in that flow. This perception of becoming is described by Hickey-Moody (2007, p. 15):

> The human body is an effect of its own movements and processes of connection . . . the body doesn't precede the flow of time through which it becomes . . . We do not begin as fixed subjects who then have to know a fixed world.

The encounter opened up possibilities she had never been able to imagine before. Gaining speed together and stretching her wings so wide, with confidence, opened up a radical fluidity for her in imagining the potential in using her body, her wheelchair, the connection with another human being… In the experience of being touched as an equal, and recognised as capable of being a full partner in speed, she embraced the beauty of increasingly intertwined bodies on wheels and on shoes—she broke through blockages that she had encountered for years, even not always fully aware of them.

Pushing the boundaries of her imagination about what was possible in working with matter was not without risks. When the wheelchair had become the vehicle for freedom and her dance partner brought the gift of speed, powerful enough to spin around on her own, the woman trustfully spread her arms ready to fly and… gravity took them down. She fell, because of the coming together of the speed of the spinning, the far-beyond-the-circle-of-the-chair reaching body, the fifth wheel behind set in standard safety mode, and the height of the dance chair, positioning her 20cm higher than she was used to in daily life—a distance so big she needed a belt designed in such a way that it protected her from losing her balance and tumbling over on the slippery shiny dance floor, yet holding open the option for her to release it herself when she felt the desire. The footage showed an impressive backward flip but the dancer mainly remembers the brain concussion. The construction of wheels and a metal frame was still a piece of technology not completely fall-proof. Exploring the potential of the material promised both danger and freedom.

Entangled

I am touching and I am touched. Both of us are toucher and touched. The touching neither comes purely from within me nor from within my dance partner. Rather, the touch originates in between us (MacLaren, 2014, p. 100), by virtue of our reciprocal fragility. No shadows are cast, my profile glued to his eyes, his eyes to my shoulder, my hand embracing his head, his hand embracing the tattoo of the swirling leaves and flowers to flourish and be lifted by the wind. "The sky isn't up there: it's between us" (Irigaray & Burke, 1980, p.76). I am drawn deeply into my body, although my boundaries have never felt more fluid, blending in with the world around me. Grounded in my body, my feet connected with the earth through my dress, my dance partner's body becoming my axle, enabling me to spin and play with gravity. My legs float and fly because they belong, their sail set, their veil dropped with the might of a waterfall.

The dance performance was an assemblage of two dancers both with their desires, anger, fears and hope moving through their bodies, embedded in wider material-discursive practices, yet not without power to fly. When two bodies touch, Barad writes: "There is a sensuality of the flesh, an exchange of warmth, a feeling of pressure, of presence, a proximity of otherness that brings the other nearly as close as oneself. Perhaps closer" (2012b, p. 206). The dance fuelled their bodies to become different from what they were before—differently viewed through the eyes of others and themselves, differently sensed, differently felt, differently moved. Chesters and Walsh (2005; in Fritsch, 2010, p. 7) have described becoming as a "process of symbiosis, the connection of heterogeneous elements into new assemblages with emergent properties." Touching makes limits of each body more tangible and fluid. Her waist, a rarely touched, barely explored area, nearly invisible, hidden within the frame of the carbon clothing protectors hovering over her loops. The shared body warmth throws the woman back to those precious, conscious hugs of a handful of friends—those who kneel to share and be at the same eye level and cover as much skin, pressure, closeness as possible.

The image of melting together reveals the beauty and power of an agential assemblage—just here and now for a short while—the force of the two bodies becoming more than the sum of two individual bodies in connection with the wheels, the dress, the wooden floor. "An assemblage is a contextual arrangement in which heterogeneous times, spaces, bodies and modes of operation are connected" (Hickey-Moody, 2007, endnote xxxiii). The woman and her dance partner in a close and intensive dance performance: both are able to transcend their limits. Both were not dancers, both needed to stretch the limits of their physical abilities, to fly off on several lines of flight that were opened in the encounter with the choreographer and the act of dancing together. Any notion of contained or fixed embodiment was constantly confronted and disrupted.

The woman learned to be in touch with her body by experiencing the energy of moving it, of seeing it as part of the assemblage she was forming with her dance partner, and eventually by consciously showing it, discarding her veto for a custom-made strapless dress after being gently pushed by the choreographer who was set to get her shoulders out and shine. The dress empowered her by accentuating the lines of her body and by showing the tattoo of the wind on her shoulder that had brought her closer to taking up ownership of her body (De Schauwer et al., 2017). It also expressed a femininity that rocks; a stylish, but sober feminine look very much in contrast with the carnivalesque masquerade of feathers and glitters worn by the dancers they were competing against. Soon the dress claimed its place as a storyline in the television episode that moved and united people. All involved, dancing or watching, were mesmerised by the extension of the woman's legs: would the fabric drop with the might of a waterfall, or would it stay wrapped up in its cocoon? All these vibrations triggered in the intra-active encounters with the dress challenged dismissive responses to how the "tyrannies of postmodern times are aesthetic" (Hughes & Patterson, 1997, p. 331). Matter holds beautifully transforming power, even if it comes in the form of a dress primarily designed for its aesthetic value.

River Running—Interwoven Thoughts

Is freedom 'mine'? Is freedom tangible? How can we talk about freedom if we see encounters as entangled? There might not be freedom, but there is light and darkness, running, interweaving, intertwined, searching. Being entangled in an agential assemblage is as much about being free as not being free. Becoming entangled is like a running river, a sparring of intensities. When I believed I knew my body, dance broke open matter and meaning and knowledge, and ran parallel with the flow of life as a constant dealing with moments that touch us and move us. Mo(ve)ments that force us forward unpredictably, like little rolling waves, first modest circles on the surface but gradually more powerfully assembling water, air, sand, fish, reeds, the occasional bird, butterfly and dragonfly while gaining its momentum, rippling, ruffling, and swirling everything around. Dance urged me to meet both the known and the unknown within, and I wonder in the flow of Irigaray (in Irigaray & Burke, 1980, p. 76-77):

> How can I say you, who are always other? How can I speak you, who remain in a flux that never congeals or solidifies? How can this current pass into words? It is multiple, devoid of "causes" and "meanings," simple qualities; yet it is not decomposable. These movements can't be described as the passage from a beginning to an end. These streams

> don't flow into one, definitive sea; these rivers have no permanent banks; this body, no fixed borders. This unceasing mobility, life.

Through dance I came to move like water; I moved like a water spirit. Water slowly changes whatever it meets on its path and its own being, its deep tracks only becoming visible after a long long time. Easily wiped dry when encountered in dribbles of sweat or drops of rain, but its power is not to be underestimated when it keeps welling up and re-visiting old places. I cannot run on my feet, but I can run like a river.

Importantly, I neither saw nor felt the mo(ve)ments happening consciously. I was mainly enjoying myself while investing a tremendous amount of time and energy in making the dance performance work. It is only through diffractively re-viewing, re-thinking, re-phrasing, re-moving (rather than 'decomposing') the project afterwards—by performing the choreography, discussing and selecting and re-discussing the photographs made during the trainings and screenshots from the television footage, weaving through the concepts of touch, becoming, and assemblage—that it became clear what the dance opened up. Thinking with and through materiality was invaluable in coming to articulate the mutually affecting and inter-weaving of ourselves with each other through our repetitive enactments during and long after the dance project. Our attempt to unravel the entanglement of meaning, memories, and the materiality of 'touchpoints' has given us a glimpse of understanding the workings of power in the dance project that ruffled bodies and challenged and opened our imaginative manoeuvrability in expressing and experiencing our intra-active sensuality. We have drawn from Barad (2003, p. 810):

> Crucial to understanding the workings of power is an understanding of the nature of power in the fullness of its materiality . . . to figure matter as merely an end product rather than an active factor in further materializations, is to cheat matter out of the fullness of its capacity.

Matter, she writes, "does not refer to a fixed substance; rather, *matter is substance in its intra-active becoming – not a thing, but a doing, a congealing of agency***.** *Matter is a stabilizing and destabilizing process of iterative intra-activity*" (italics in original; 2003, p. 822). In deeply intimate ways, matter has come to matter and has made itself felt as dynamic and transformative by paying attention to and experimenting with the body's very materiality alongside other "bits" of matter in its "unfathomable multitude" (Barad, 2012b, p. 214). Thinking with intra-active processes of becoming has enabled us to re-visit some of the material-discursive practices as they are working on us, but also touch upon how those very same practices that intend to keep us small and immobile can be reconstituted through the materiality of how we live our lives and the "powers of engagement" that we can choose to discover and share (MacLaren, 2014, p. 101).

We, "'[i]ndividuals' are infinitely indebted to all others, where indebtedness is about not a debt that follows or results from a transaction but, rather, a debt that is the condition of possibility of giving/receiving" (Barad, 2012b, p. 214). Even more than being indebted to 'the other' in ourselves and others, we carry the gift of connection. Having worked through this narrative about a woman feeling free to express herself intimately, being made and unmade and re-made through the intra-action of nature, culture, and technology, we see that we all have "response-ability" in the touchpoints of our lives (Barad, 2012b, p. 214):

> *In an important sense, in a breathtakingly intimate sense, touching, sensing, is what matter does, or rather, what matter is: matter is condensations of response-ability. Touching is a matter of response. Each of "us" is constituted in response-ability. Each of "us" is constituted as responsible for the other, as the other.* (italics in original; p. 215)

Epilogue

As soon as the dance project got media attention, both media-shapers and the public took ownership of the story, and our carefully crafted, emergent entanglement was torn apart. Stratified. Our lines of flight were captured, not only on camera, but by (ab)normalising lines of charity, heroism, ableism and disableism, shooting holes in our wings and the binary-breaking power of the intra-active encounters of matter, histories, and dreams of everyone involved in the prior assemblage. Our collective body work was framed as “my dream” and one of the five instances in which my dance partner was “a buddy” for people “overcoming hardships”. My dance partner was the good soul, the “man with the golden heart in the right spot”, praised and congratulated on social media for “how amazing that he was helping those people achieve their dreams”, “helping people conquer their physical impairments”.[13] I became one of “those people” in comments on facebook, or the “paralysed woman” in the newspapers, which used my face (but not my voice) in a more general article titled “Blind or homeless, and suddenly famous: Why ‘minorities’ these days spark off your television screen”, aiming to critically map out the current booming of “minority programmes” that (cl)aim to, alongside making “feel-good” television, “support” the “emancipation” of “groups that once were (more) invisible by giving them a voice and a face” (Van de Perre, 2018, p. 48).

I could continue feeling nauseous every time I am thus confronted with others’ framing of me in ways I cannot recognise. We could deem our quest quite futile, with little power to open up new ways of thought about bodies deviating from whatever norm. Futile our quest to answer “the question of becoming”, which is not about “which subject to become but how to escape the forces of subjectification that block flows of desire and re-inscribe the subject” (Goodley, 2007; in Fritsch, 2010, p.7). Or we can focus on the moment that ripples of movement were created, accept the temporality of (the transformative power of) that assemblage—its temporality strikingly exemplified by the media take-up, showing how easily people get stuck again in a particular way of thinking about the world, immobilising people and their bodies—but not forget the power it

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[13] Translations of Flemish comments on the dance trailer posted on the television company’s facebookpage.

holds, for the people directly involved then and now, and for many others who will explore their response-ability for breaking boundaries.

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Chapter Five

Flowing Desires Underneath the Chastity Belt

Sexual Re-exploration Journeys of Women with Changed Bodies

This chapter formed the basis of:
Blockmans, I. G. E., De Schauwer, E., Van Hove, G., & Enzlin, P. (submitted for final review). Flowing desires underneath the chastity belt: Sexual re-exploration journeys of women with changed bodies. In R. Shuttleworth & L. Mona (Eds.), *Routledge Handbook of Disability and Sexuality*.

Abstract

Approaching people and their experiences of sexual pleasure as continually in a state of becoming, we have aimed to allow for and explore these movements throughout data gathering, analysis, and presentation of a study on the sexual wellbeing of (four) women with traumatic (i.e., non-congenital) spinal cord injury. The data gathering methods—ranging from individual life story interviews over 'on-the-road' conversations during fieldwork to a focus group discussion—aimed to provide the participants with different routes to reflect on their subjective experience of the bodies in/with/through which they live and intimate relationships in the past, present, and future, sometimes resulting in a transformation of their sense of self and their bodily expression potential. The assembled glimpses of life were analysed by drawing on post-intentional phenomenology and plugging in the concepts of containment and sexual and intimate pleasure as becoming. Through a mix of autoethnography, fiction, and participants' words, the metaphor of a chastity belt is presented to capture how material-discursive practices around sexuality, touch and (health)care as well as the women's 'own' meaning-giving of sexual pleasure and their body challenge their imaginative manoeuvrability, i.e., imagination related to one's potential for sexual pleasure.

Introduction

I can go into a coffee shop and actually pick up the cup with my mouth and carry it to my table. But then that… that becomes almost more difficult because of the… just the normalizing standards of our movements, and the discomfort that that causes when I do things with body parts that aren't necessarily what we assume that they're there for. That seems to be even more hard for people to deal with . . . I would really try to make myself go out and just order a coffee by myself. And I would sit outside for hours beforehand in the park just trying to get up the nerve to do that.

(Sunaura Taylor)

On a walk in Astra Taylor's (2008) documentary *The examined life*, Judith Butler and Sunaura Taylor ponder "moving in social space, moving – all the movements you can do and which help you live, and which express you in various ways" (Butler). The quote above is Taylor's reply when Butler asks her, while she is moving in a power wheelchair with limited use of her arms and hands[14]: "Do you feel free to move in all the ways you want to move?" They discuss how normalised expectations of moving—and by extension, living and being—make it hard for people to feel free (in their being, living and moving/ in their movements/ to be, live and move?). They pose the question, not "what is the body?", but rather, for Deleuze "the properly ethical question . . . what can a body do?" (1990; in Guillaume & Hughes, 2011, p.1). To answer this question, they approach people and their bodies as "assemblages", which "in [their] multiplicity necessarily [act] on semiotic flows, material flows, and social flows simultaneously" (Deleuze & Guattari, 1987, p. 22).

Along these lines, we do not see the body as autonomous and the experience of the body as something static and possible to be captured in a template of "what it means to live with spinal cord injury" that can then be pasted on to other people with spinal cord injury. Rather, we see the body and the experience of the body as in constant connection and intra-action with other people, matter, and material-discursive practices. People continuously need to pay attention and significant force not to get caught up in the various "flows" or "threads of cultural discourses that overlap and, twisting and turning, constrain and induce bodily movements" and choose otherwise (Ellingson, 2017, p. 19).

We aim to write about the manoeuvring around picking up a cup of coffee with your mouth in function of the search for sexual pleasure when it is impossible to comply with "the norms of normate sex", which "draw boundaries between appropriate and inappropriate desires, behaviors, identities, and spaces" and

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[14] These words to describe features of Sunaura Taylor relevant to understand the context of the quote were taken from a statement written by Taylor herself for the Wynn Newhouse Awards: https://www.wnewhouseawards.com/sunaurataylor2.html (last accessed on 1 February 2019).

"effect a privatization of sex, regulating nonnormate sex or keeping it taboo and under wraps, through a vast array of state and cultural supports for normate sex" (Wilkerson, 2012, p. 187).

In our research, we have focused on the lived experiences of women with traumatic (i.e., non-congenital) spinal cord injury, who experienced a significant position shift on the scale ranging from "normate" to nonnormate, i.e., "extraordinary" (Garland-Thomson, 1997) and once walked into the coffee shop unnoticeably and picked up their coffee with their hands. Women with SCI still have the right for sexually intimate lives and they still desire it. The question is: how? Where are the knots and openings in these women's search for sexual pleasure?

Following Deleuze and Guattari's philosophy of becoming where bodies are assemblages that are constantly moving without fixation, we also wonder what opens up if we approach spinal cord injury, and by extension the experience of living with a body affected by SCI, not as a self-contained, static condition, but as a continuous coming together of actions (which also include non-actions) in a myriad of contexts? We therewith hope to contribute to research practices where participants speak without being finalised by embracing:

> an ontology of becoming(s) rather than being. Reality is viewed as a continual process of flux or differentiation even though this fact is usually masked by powerful and pervasive illusory discourses of fixity, stability, and identity that have characterized most of western philosophy and theory since at least the Enlightenment. This ontology of becoming(s) enables (even urges) us to see things differently—in terms of what they might become rather than as they currently are. (Martin & Kamberelis, 2013, p. 670)

Method

Data gathering // Encounters

Throughout data gathering, analysis, and presentation of a study on sexual wellbeing of women with traumatic spinal cord injury happening alongside autoethnographic trips of the first author, we have chosen to be guided by an ontology of becoming(s). After ethical approval, we organised three data gathering rounds between April 2015 and March 2017. The first round involved in-depth individual life story interviews with ten women with traumatic spinal cord injury (2 or 3 times each, 45-90 minutes) and explored the meaning of sexuality throughout their life and how these meanings came to be in relation to their environment, starting from one main question: "Could you please tell me your life story with a focus on your development of relationships and sexuality?". To foster the conversation participants were also asked to bring an "object that marked" for them "an important stage or moment in their relational or sexual development". In all interviews, the spinal cord injury was the turning point between a past of satisfying sexual experiences and a present dominated by a changed, psychological and physical labour-consuming body. The interviewees meandered around how they saw and lived with their bodies, but seldom talked about recent experiences of bodily pleasure. This led to a second data gathering round with four participants, aiming to create a context for re-encountering their body. Encounters were arranged as 'on-the-road' conversations during body-focused activities with a self-chosen friend ("a person with whom you feel you can discuss your body and desires") including searching for clothes/accessories just outside their comfort zone with a stylist, make-up session, and photoshoot aiming at dynamic pictures; and follow-up duo-interviews that led organically towards discussing embodiment of difference, embodiment of femininity, struggles in maintaining ownership of their body, and how both SCI and body work had changed their relationship with their bodies and their perceived possibilities to achieve intimacy and sexual pleasure. The third round of encounters was a group discussion with four women with SCI about the preliminary findings of an inductive thematic analysis of the stories they had shared throughout the doctoral research, including sexuality as a journey, SCI as life changing, disownment of the body and the chastity belt as a metaphor for feeling (sexually) blocked. All conversations were audio-recorded and transcribed by the first author and a student for her master's dissertation in sexology.

Data analysis // Working with encounters and concepts

For this chapter, we have chosen to focus on the four participants who participated in all three encounter rounds, although the stories of the other participants and the autoethnographic work of the first author were present as satellites, with stories overlapping and differing, contributing to our developing understandings. All participants were in a stable relationship and were mothers (one pregnant for the first time during Data Rounds 2 & 3) aged 30, 38, 42, 54 at the time of the life story interviews in 2015. Two were paraplegic and two tetraplegic. The four women's stories were re-analysed drawing on Vagle's (2014) post-intentional phenomenology to make sense of how they experienced being a woman with sexual desires living in and with a body affected by SCI, with the experience of the body and the social/cultural world seen in a mutually constitutive relationship. The theoretical incentive in post-intentional phenomenological research does not concern whether something is or is not, but how the perception of something (here: the perception of the body as source of/vehicle for sexual pleasure) is produced (in particular moments) and how this production connects with other productions, assumptions and meanings associated with the object of study (Vagle, 2015, p. 607).

The analytical process was cyclical, involving reading the transcripts (finishing a first round of analysis of one participant's stories before continuing to the next participant's transcripts), commenting in the margins (on descriptive, paralinguistic, conceptual levels) on what was meaningful to the participants and what might be framing their meaning-making. During that process, we were also constantly questioning whether we were relapsing into binary thinking (e.g., "X appears to have stopped searching for sexual pleasure", "X seems to feel voiceless vs. Y is expressing her desires”) in order to remain conscious of the ambivalence and shifts in the glimpses of lived experience that the participants shared with us. During this process, inspired by Jackson & Mazzei’s (2012) “plugging in” of concepts in data, we gradually started to focus on “containment” (Liddiard & Slater, 2017) as well as on sexual pleasure as “becoming” (Deleuze & Guattari, 1987). Our focus was not so much on what it ‘means’ for participants to live with a changed, uncontrollable, not fully sensitive body that was less mobile than before, but rather on how their experience of and imaginable potential for sexual pleasure “becomes-in-the-world-with-others” (Price & Shildrick, 2002).

In the final stage of the analytical process–which overlapped with the write-up stage of this chapter–, we took up Vagle’s invitation to “explode beyond tradition” (2014, p. 132) and used our summaries per participant, selected rich citations, and our notes as building blocks in “crafting” this text in an attempt to engagingly animate the material-discursive processes of movement and captivity that are working on/through (living with) sexual desires with a changed and changing body. What follows has been written from, what for us appears to be, the spirit of the many encounters with our research participants and the transcripts of conversations, after and whilst revis(it)ing our analyses and reflecting on the resonance of their “voices” within ourselves (Spry, 2009, iv).

We have blended participants’ words with a fictional narrator’s analysis-based comments and questions into a fictionalised account of the first researcher getting home after re-visiting interviews. We begin with fragments of encounters with research participants streaming through her when intra-acting with the partner she fell for during a coffee date and her self in the mirrors on the walls of the place she calls home, and then the narrator converses with glimpses of participants’ life stories. It is an attempt to share yet not to finalise our findings, and to share yet not finalise our participants’ voices. It is even an invitation to let the vibrations of meanings that make up their, our, your lives resonate and recognise parts of ourselves in the tiny snippets of words and images about living in, with, through bodies.

Insights: The woman who kept a black box under her bed

Let me tell you about the woman who once had over 40 pairs of heels, sexy lingerie, and occasionally sailed shamelessly naked around her bedroom. Presented as one, yet being many. Under her bed, hidden in a black box ameliorated with red roses, on top of a book with exercises on how to free her 'inner sex goddess' and a book with feasible positions for men and women with spinal cord injury of different lesion levels—can sex ever be good enough?—, cornered by an only slightly molten massage candle, a soft black feather, and a clitoral air vibrator once sold with the promise to be "the best of its kind on the market in generating orgasms, also for women who have always believed they can't achieve orgasms"—because why working for hours to get into ecstatic spheres if you can get results in half a minute too—, wrapped in a silken blindfold, we find: handcuffs and a chastity belt, and memories alongside desires turned to dust.

One question.
How do you see yourself, when it comes to being sexual?
She had whispered: *Yes…who am I, now?*

Re-turning home, our minds, our bodies, our souls were filled with echoes.
Echoes of her answers, echoes of her questions.

What does sexuality mean to me?
It is a domain of life… something is not quite right if that domain is pushed to disappear out of someone's life completely, is it?
Tell me, can you tell me what is still possible?

And the questions she had never asked out loud.

> Desire is about experimenting with "dare to become all that you cannot be"
> (Massumi, 1992, p. 41)

What do I desire?
What do I imagine bodily pleasure to be for me, and for my partner?
How free do I feel to move, sexually?

The moment you get home, the real re-hab(il)itation starts.

Rehabilitation.
"The action of restoring something that has been damaged
to its former condition."[15]
Rehabitation.
"The action or an act of reinhabiting a country, area, house, etc."[16]
… including one's body?
Or: the process of actions in which old habits are revisited, current conditions
are explored, and new ways of being are created?

I am a living bust, positioned on a body that I am not conscious of, she said.

I enter my flat, and nearly lose my balance when I feel a tender yet fiery kiss in my neck. Next, I find myself soaring through my flat and landing on the bed.

I smile.
"Let me show you something."
I lean over, my body forming a bridge between the bed and my wheels, and I slide open the drawer under my bed.
"This is my black box," I tell him.

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[15] Definition taken from English Oxford Living Dictionaries (online).
[16] Idem.

"Open it!"
I take off the lid…
Now he smiles.
The handcuffs reflect the sparkles in his eyes.
"Yeah…I bought them a long long time ago and I never used them… I don't know whether I want to use them anymore… They have absorbed the meaning of desires not acted upon."
"Don't feel pressured to use them… We can buy new ones. New experiences, new meanings."

He starts unlacing my boots.
"Give me a minute," I whisper while covering his eyes.
"I know what that means," he grins excitedly.

I open the door to the bathroom. It does not open completely as the bed that I recently bought—an investment to explore bodily pleasure boldly and wildly—extends its presence right up to the bathroom, so I am forced to manoeuvre in tiny circles to pass through the narrow doorframe.
Once in, I try to rush out of my jeans skirt. As always, it gets stuck around my waist and I wiggle waggle myself out of it. "It is that jeans again today," I hear a participant's nurse telling me off, poking an accusing finger at me for making life more difficult that it needs to be.
I jump on the toilet. I feel relieved. My impatient, sensitive bladder is not an obstacle… when I ask for a minute in the middle of a kissing session, he knows that I will be back for more of the same and beyond.
I notice the white support handles. The foldable shower chair melts and disappears in a hole in the wall… the hole becomes the hole in the middle of the seating of the wheelchairs I saw hovering over the toilet in hospitals and some of my participants' bathrooms.
I am in my bathroom and yet I am in her bathroom. Sterile catheters sneakily pop out of my colourful storage boxes. I wash my hands, and the fragrant soap transforms into disinfectant. My hand lotion solidifies and covers my fingers with latex gloves.

I am me and yet I am her, them, us.

Imagine a woman.

> You asked me to bring an object that was important in my sexual history.
> When I told my partner I needed to think of such an object, he replied I needed to take him with me. ((laughs)) But instead…

She puts her bright red heels on the table.

> My heels. The only pair I've kept. I've always worn high heels. Day in day out. These were amongst my lower versions.

A woman with red heels she does not wear.

> They make my feet fly now and they make my legs unstable. So I've promised my friends the remaining 39 pairs in my shoe closet, once I am ready in my heart to let go. I know it's ridiculous…they are just shoes…but they are were once attributes that make made me feel feminine. I can still wear them after struggling for 15 minutes, but I can't walk with them anymore... It's ambivalent… I love them, but I can't meet the criteria anymore. That time has passed.
> Somehow, though, I have grown into not needing them anymore to feel feminine.

Shoes recalling memories of unre-reachable past moments.
Between the feeling they used to give her and the loss they now symbolise
No longer supportive for be(com)ing a(nother) woman.
Opportunities to leave behind what you knew and transform
normal(ised) // normed femininity…

A woman wearing red laced lingerie inside and a neutral set outside.

I need new nightwear, I decided.
Everything I had was grey, grandmummalike. So many things in the windows that my partner would have loved, red, a bit of lace. Then I dream…

If I had been mobile, I would have bought it for fun. Now, no… strangers see me all the way to my underwear. My closet cannot contain anything that should not be seen by the average man and woman. Basically I should purchase things you can hang over the clothesline outside.
So obviously

I told myself:

I'm not going to buy this, let's keep neutral colours. I
left with something
black and white.

A woman with a past and a since the accident.

Either you crawl in a corner, or you continue living. But it's two periods, really. Before the spinal cord injury and after… It is a wholly different life, different like black and white.
Also relationshipwise, it's a search… simply because…you are not the same person…emotionally…sensory…physically…

A woman with a body seemingly absent, yet very present…

Before the accident, I knew my body to perfection.
Can you ever know every tiny particle?

I could bend and turn.
Lithe.

How flexible can you be?

I felt good in and about my body.
I had a style of my own back then.

I was not meeting bodily ideals, but I didn't care. Now, I mirror myself to them and now there suddenly is something I cannot achieve anymore.

My legs, in the beginning I couldn't stop looking at my legs when I still had them…

I don't feel as much of a woman anymore, not as I used to feel… I am slowly re-turning, but…

and desires

I tell him, I want you to not only take care of me. ((laughs))

Intimacy, sexuality. Being sweet towards each other. I don't feel it in hurried little kisses or routine, but in things you sincerely take time for… doing things together, and not to be settled quickly. Feeling attractive. The intimacy, feeling loved… the accident didn't make me asexual and without sensations… but it is a whole process with your partner… I need the physical touch, even if it's just holding each other. I need it, from my partner. Being touched by others is pleasant but not the same… I don't want to be a pathetic potplant in a random corner...

I have become convinced over time that sex is something for every human, something natural, part of life. Something that should be normal, and…

not absent, yet struggling to be present,

> with me it is of course not so normal, given that… my body… is not what it used to be… Sex is also something to be done with two preferably, with the same partner ((laughs)) in this stage of my life, with kids, but in hindsight I would have done well experimenting a bit more. If I want to experiment now, I need to do it with my husband.

De-routinising sex requires a constant search with changing bodies and changing wishes.

> Because I have a partner, we ((laughs)) try to do something along those lines… but it remains difficult. Especially being spontaneous. I would love to wake up naked once in a while… But we don't do that. Because then you need to manage the confrontation with the nurse in the morning. Am I wearing a night gown, am I decent... Imagine that they see you not wearing anything… ((whispers)) That's really not fun. Not for me, not for my partner.

When is nakedness functional enough to pass as appropriate?

trembling in a box.

> Sex remains sensitive stuff. I guess for most women it gets uncomfortable when you call it by its name, especially problems. Although sexuality has come more out in the open than before… sex as a disabled person is still in a dark closet, a dark little corner… it's still taboo.

A dark closet?

There is shame. Before I was in a wheelchair, less. Now… I still struggle with my sexual experiences… because I cannot enjoy intimacy in the same way I used to…

> It used to be difficult…

I guess I feel more vulnerable. When things don't go smoothly… you expose yourself.

> But not anymore. No. Because we, for me it is not a problem anymore.

I'd rather talk about it with you than with friends, just because they still can, to put it bluntly

> When they ask me whether I can still have sex, I reply I can,

… an orgasm is out of my range. They still have orgasms, I don't.

> and that, of course, it feels different, and then they quickly proceed with "can you still come?" ((laughs)). People don't realise it is much more complex than "it is possible or not". There's the sensory stuff, there's the potential leaks…

And if you tell that… I really don't want the look of their "poor you" eyes. No thanks.

> Orgasms feel different, but in one way or the other… I gradually have come to experience it is mainly mental now. It is not always about touching exactly the right spot or even registering touch… It is simply also about the visual imput and the feelings underlying intimacy.

…

To be able to have sex as a woman… ((laughs ironically)) you do not quite need to perform, so yes, you can still have sex. But obviously everything depends on how you interpret ability…

The traditional zone of sexuality has become a zone of shame, dirty leakiness, blemishes to hygiene, a zone that needs to be managed to have sex

> It's weird, that that zone where you… are incontinent… is also the zone where sex needs to take place. It doesn't need to, there's other things related to sexuality, but it usually moves in that direction.
>
> Of course, a pad or a diaper, it doesn't feel feminine, it doesn't feel attractive, it's not like "come, honey, rip it off and let's start". In the beginning I thought "No! Hands off!" Actually I felt, in a particular way, dirty… simply because of the idea "accidents can happen".

The traditional tools do not suffice anymore.

> The most important stuff is supposedly to be found with men. Women have breasts, and that is supposedly important too… whereas I have the outer appearance of any other woman, but I don't feel my body… Men's sex lives should be splendid, but what a woman thinks or feels or wants, it doesn't seem to matter. It is mirrored everywhere around you: men always have sex and women don't.

A double sexual standard.
Pressing more on women with "different" from "normal" sexual possibilities
who also have the right for pleasure?

Female pleasure silently disappears out of sight.

> Whereas I disagree. But try and make that clear ((breathes in with a sigh))

To a man, she says.
And what about making it clear to healthcare professionals?

Pleasure and a body that urge for explanations.

We got this booklet, with pictures of couples where one of the two had a spinal cord injury. Pictures? Beautiful pictures, yes, to show what is still possible. But there was nothing about what a woman can feel. Not a word. Don't you believe that is utterly childish?
Apparently a woman's sexual sensations are not important.
What remains important is whether a man's penis can still get up after a spinal cord injury.
Doesn't it?

During rehab, it was like, find out for yourselves. Is it possible or not.

We need to do it with a part we don't have anymore. I am a bit twisted… I wonder…what is actually still possible and what is not… and why do we need to discover it for ourselves amongst the two of us? Normally, sexuality is something you explore with two people. And when you are well tuned in to each other, then you have good sexual experiences. But this is something special, you know?

When desire and the changed body meet…

A woman with questions.

What exactly can you still feel?

If you cannot sense your skin.

Well, I want to know how it operates medically.

Can a woman with spinal cord injury still orgasm?

Can she… hope?

…or a woman who has stopped questioning.

Yet always with a past/memories of times gone by

It will never be like before. Too much nerves were damaged.

Irreversibility of change lined out in the body.

Acquaintances asked other friends "how are they going to have sex?" It's like, you've ended up in a wheelchair, so now you are an asexual being… That is not true either, but it will never be like before. Your body simply responds completely differently. Imagine someone providing the same stimuli to my friend and to me. She will get horny and for me it will be "ah yes". Simply because the neurological wiring has become completely different. There's still a part of sexual experience left, but it is not anymore and will never be again what it was. You keep being reminded of that. Because my partner… he has a healthy libido… And you know that you, on some levels…

What is a healthy libido?
For a man?
…and for a woman?

I'm not saying I'm failing him, but if I hadn't been in a wheelchair it would have been completely different.

I am not capable of doing what I used to do.

How can you use your body?

My role is more passive, so to speak. Whereas before I could do things more actively… to call a cat a cat, before I could sit on top and now I can't. Some moments I just roll with it… but often there's a twist.

You talk about giving. What about receiving?

Blocking the road to pleasure.

> Those patterns of the past…
> They are completely blocking the road.
> For him they are completely blocking the road.
> For me too.

A woman who feels blocked, sometimes, or often.

> You really want to know to what extent I am sexual or a woman? Well, I wear a chastity belt. A belt that makes it impossible to undertake anything with women. Men cannot touch women or it prevents women from having a relationship or being sexual altogether, and well, that counts for me too. It is made impossible.

A chastity belt materialising
perceptions about body
and sexual possibilities
that are essentially felt/perceived
as limitations

> Really. Try to drag a pair of jeans off someone who is paralysed. This immobility… slipping a jumper on or off, I am not even able to do that, I can't do any of those things ((breathes deeply)) … dressing and undressing someone like me in a back-saving manner is a serious assignment. So, imagine the vibe feels good, and you happen to be both at home, as man and woman, or on a weekend trip or whatever, then THAT is still that major party pooper, which makes me think, even if my husband is up for it, like "yes, I will get those clothes off", then I sometimes give him this look "I don't feel up for this". By the time my clothes are gone, my appetite is gone too, and definitely by the time I have everything on again. ((laughs shortly))

A chastity belt coming in different shapes and sizes—materially, physically, psychologically, affecting manoeuvrability in space and time.

> We still sleep separately, separate beds, separate rooms, separate level in the house. If only we could sleep together, so you can hold each other…

An unchosen belt encircling bodies, minds, desires

And I feel ugly on top of all of that…especially when you need to get undressed.

Tell me about it. But are those men attractive when they are naked?

designed // tightened by norms of internalised desirability
// body beautiful
and touching encounters.

> When my partner helps undressing or positioning my legs…it is part of foreplay… it is part of the game, also if you do not have any deficiencies. So being assisted is less a matter of giving up autonomy or dignity or self-worth…
>
> Does him undressing you feel like assistance?
>
> It's 50/50. I don't experience it as completely foreplay…because…it needs to happen a bit more carefully… and with turning my body from left to right…The caring seeps through. It is never completely gone…

She experiences her body differently.
And so does her partner, she thinks.

> He needed to catheterise me when I wasn't able to myself yet. They had taught him to…it must be so different to, as a man, to have to look at your wife that way, at her vagina. The need to be down there for a different reason, to do something different from normal. I'm not sure whether he really perceived it that way, but that's how I feel. I do wonder, how does he see me?
>
> He was like "yes no no no I'll leave" whereas we used to go to the toilet in each other's presence. And now, it is surrounded by something medical, it seems. Although I simply go to the toilet in a different way. Also helping with undressing and redressing, those were all things that he found weird to be suddenly part of the sexual aspect.
>
> I can imagine that it is terrifyingly hard for a partner to touch someone in a sexual or intimate manner when you, when that person does not even know herself how her body exactly functions.

Bodies to be re-explored.

What if every woman was treated the same, as in: unique and constantly evolving?

Desires to be negotiated // stripped bare

> Let me… and you…
> I am not paralysed completely am I? … Aren't there plenty of possibilities to make it somewhat pleasurable? I long for touching you again. It's not because I… that… I ask him, "am I not ALLOWED to touch you anymore?" And he says yes but… it never happens. Is he having a hard time to relax and giving himself or does he find it hard for me… I guess he partly finds it hard for me…he tells me "but it is not the same anymore", and I say "yes but it can still be good, can it not?" Right? It's not because it is not the same anymore that it can't be good anymore, no? It really troubles him.

Routines and definitions of sex life disrupted

> In the past you were not capable of any less than someone else, and what you created with your partner, was done by yourselves, you know.
>
> ((sighs))
>
> Whereas now, even if you want to create something together… I am basically blind with my body. Being paralysed is being blind with your body.
>
> I can't
> feel it…
> I can't
> turn…
> I can't
> do
> what I would desire to do.
> You know, those spontaneous things
> you would simply do
> if you are yourself.
>
> I would go and sit on his lap, spontaneously… that would make my man think "hmmmm". Now I'd need to tell him "come and sit on my lap". And then…I don't know how. We should hug much more often, now it is too exceptional…but I guess that happens in all families, with kids… What I also miss, I told you what my paralysis entailed and that my hands, my fingers are paralysed, and you said, "Can you still carress?" I thought, "Does she need to bring up exactly that topic?" I used to love massaging my partner. We focus on what I still can do, but there's obstacles to spontaneity.

> Good sex… I miss it. It was not the most important aspect of our interactions, but it came automatically…

Desires she needs to—

// The wind closes the door with an explosive soft noise. //

> “Damn they are there again.” Actually I find they come way too early. There’s so many little things I always want to do before... Anyways, I need to accept it. Very well then. They come to put me in bed. The good thing is that my husband doesn’t have to do it, that he doesn’t have an extra job.

—hide.

> You don’t wear whichever night gown because you need to let yourself be put to bed by a man, a male nurse, so you do not , not once, put on a beautiful, fun, sexy thingie because you need to, you know, you do not have any privacy on that level. You need to be careful of what people find in your house. Because there’s constantly people
>
> One, two, many.
>
> in your house for cleaning and whatever. Also, you are not out of your clothes that quickly, you are not as quickly…in your clothes, you need to look decent for the nurses. Imagine you had been up to something during the night; you’d need to make sure you are clean and dressed again by the time the morning comes.

The desire for sexual pleasure fuses worlds that are obstinately held separate.

> I haven’t gotten myself to ask the night nurse yet “you know what, forget about the night gown, I’m not going to wear it”.
> Also I wouldn’t dare to, if the nurse comes in, to not wear a night gown…would you?
> Although, I believe it should, I should get over it, you know?

I believe you I should be able to, to loosen up about your… my body.

But I can't, not really.

Shame, I guess. I am too ashamed. Much more than necessary

… But I need to constantly lie here with my bum naked, do you know? Without me really wanting it? While really not liking it?

They do it all the time. To. You.

It is THEIR domain. Really. When I lie there in bed and the nurse bathes me, it is HER work territory, my WHOLE body.

—fight for?

It was already too much for her to be asked, you have that tube here ((shows stomach catheter)) that needs to be attached to my bedside, so the urine flows in this bag. That tube was unimaginably short. Because my partner, if he'd simply want to pull me a bit closer, I'd be tied down to a cable. Actually… like prisoners in the old days, in cartoons, they walk with a chain around their legs, with a heavy ball to prevent them from getting away. Isn't this much worse? First, I lie here, paralysed, in my bed. I am, until here, not capable of turning myself, really not, I am unable to do that, my body can't do that, it is too high a goal for me. Alongside the fact that I can't turn towards my partner, I am tied with a cable, stuck to one side of my bed, with assist rails giving me the only chance to transfer myself a tiny bit, or to stretch my fingers when they are spastic. So if my partner desired to lie a bit closer, for once, because he is always tired ((laughs)), then he first needs to come and unfasten that cable. So he needs to crawl over me, out of bed actually. ((sighs)) I'd love to talk to other couples about how they organise all of this. So

> I told the nurse—gosh I really need to be articulate and assertive!—I would like you to attach a longer tube. “Why is that necessary? There is right enough space, isn’t there?”
>
> Repeatedly and loudly denied. (Kafer, 2003, p. 85)
>
> I reply, “Yes, well I’d love to, once in a while, move a bit in the other direction or…” “But you can’t move.” “No,” I say, “yes if my partner would love to lie a bit closer and turn me over…” Help, do I need to go and explain everything? Why I’d just like to slide in my bed for simply five centimetres?

Justifying desires.
Fighting for a voice
and keys to act on desires.

Keys kept by many, or lost and found.

> Sometimes I feel the key disappeared the day I dove in the swimming pool, slipping away in the drain.
>
> Sometimes, though, I see something flickering ashore. My partner has already discovered things we hadn’t discovered before, which made us both realise that it can still be fun, you know, as in worthwhile all the effort if we do come to… And you never know, there might be so much more possible than we have yet discovered…but where do you start searching?
>
> I guess it feels like discovering sexuality for the first time… It can be so much fun and beautiful and exciting and even new… When we can talk about everything, it’s clear sailing.

Support handles turn into bamboo and entangling twigs of a willow tree.
The smell of rosemary and sea salt coffee scrub and the cold water enter my awareness.

One last look in the bathroom mirror. I notice some toothpaste splashes I cannot reach to wipe clean.

I see a woman again, she had said in the changing room.

With a not so elegant jump I manage to get on the bed, automatically triggering me to start composing a smile to cover it up, but I roll over and I forget.
A flash of passion and a promise for more, and then, like a soft stream his fingers trickle down to the upper band of my compression stockings. Gently he unveils the previously contained terrain of lovemaking. The stockings have imprinted their presence, leaving dark red circles around my thighs and above my feet.
The sound of hands getting warm for touching.
We rub, tickle, and caress life back into them.

How do you touch?

"Let us agree that we will not focus on achieving something, shall we?"

What opens up when you let go of …?

Let us play and dive deeply into our closeness.

(In)Conclusion

The words above are all ripples of connection and uncertainty, dried sadness and flowing desire, feeling captive and feeling life ownership, experienced by women with changed bodies and changing expectations, but deep inside their ever-present needs for attraction and bodily intimacy. The many words about what is not, or no longer and what will never be anymore make the few words about pleasure at present stand out. We hear the body scream to be seen as still a source of pleasure and not just as damaged vulnerable flesh covering breakable bones and freely flowing or constipated excreta to be regulated—a (medicalised) body that for women with SCI gains such a central focus in creating their living (together) yet at the cost of not only sexual pleasure, but also intimacy more broadly, i.e., intimacy with oneself and with others, including one's romantic partner.

Between the lines, we read how re-exploring changed bodies in the search for sexual pleasure and intimacy is challenged not only by the changed materiality of the body itself, but also by the women's own (and their partner's) internalised expectations and (and due to shame not always shared) definitions of satisfying sexual pleasure. These expectations are built up throughout their life history and often reflect the performance-based and genital-focused approach to sex that is widespread in Western society (i.e., the constriction of sex to penetration with explosive sensations preferably leading up to simultaneous orgasm, with a climax as necessary for satisfaction, the best sex as arising spontaneously, full of initiative of independently functioning and fit partners; Tepper, 2000). These normalised and normalising beliefs about rarities and normalities become all the more visible because their bodies do not/no longer allow for conforming to this discourse.

This is all aggravated by (internalised) ideas about appropriate bodily exhibition (cf. erotic and thus 'non-functional' nakedness or clothing exposed to healthcare professionals) and the weight of body management requiring "intimate labour" (cf. control of 'accidents' of the leaky body; Liddiard & Slater, 2017; Shildrick, 2009) performed by themselves and their partners, alongside others who move and work outside the context of romance and sexuality, seeing bodies as utensils for daily living.

These lines of thoughts and touch all overlap and are brought together in the metaphor of carrying a chastity belt locked and tightened both by the women themselves and others in both discursive (cf. negotiation about length of overnight catheter) and material practices (cf. body that is moved and touched in particular ways). These accounts highlight again that (the experience of) sexuality of women with SCI, although usually occurring in private settings, is insanely regulated by others and selves.

The coffee cup story is clearly present and multi-layered. How, then, do we move on to the search for sexual pleasure? Will we continue to silently negotiate with the crowd of echoes in our head for hours before going for a coffee to try and predict what will happen when we enter the space where we can access something that will make us feel warm inside? We should not only ask how free people feel to express and enact what they desire sexually (Foucault, 1997, p. 125-6). We should also ask how free they are to *imagine,* beyond what they are aware of. What makes people's imaginative manoeuvrability, i.e., imagination related to their potential for sexual pleasure, flow, close, open up?

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Chapter Six

(In)Conclusions

This dissertation explored lived experiences of being a woman with sexual desires living in and with a body affected by spinal cord injury, centred around two main research questions: (1) How do women perceive their sexual experiences and well-being, i.e., their lived experience of their bodies and intimate relationships in the past, present, and future, to have changed after acquiring SCI?; and (2) How are their views affected by material-discursive practices around sex and bodies enacted by the women themselves and their environment? The section on "Manoeuvring in the dark" below will explain the title of this dissertation, provide some answers to the research questions through an overview of what participants shared about their desires and what had changed since their injury, and of the material and discursive practices at play in the assemblages of being a woman with sexual desires living in and with a body affected by SCI. The next section on "Re-creating (new) stories about sexuality and the body" will discuss the implications of the findings and methodology for research and for the support of women with SCI in their bodily and sexual re-exploration journeys.

Manoeuvring in the Dark: Main Findings

Over the course of wandering through space and time with the participating women reflecting on how they related to their body and sexuality, analysing their stories and crafting the previous chapters, the concept of *imaginative manoeuvrability* was chosen to capture the gist of this dissertation. Imaginative manoeuvrability has been concisely defined as "imagination related to one's potential for sexual pleasure" in Chapter Five but can refer more broadly to the potential scope for movement/possibility that one experiences to have when it comes to pleasurable and satisfactory intimacy with one's self and other(s) through one's body. Manoeuvres can be seen as (series of) movements in a particular context for living, often requiring exercise-to-come-to-skills and care. Imaginative manoeuvrability, then, entails the *experience* of *feeling able* to move within and even create a particular context in a space with borders coming in the shape of matter and discourse, or rather, a space that is embedded in material-discursive practices about sexuality, (dis)ability, desirability, pleasure. Whereas the focus remained on how free the women in my research felt to manoeuvre towards experiencing pleasurable and satisfying bodily intimacy with a changed and changing body, the previous chapters also aimed to disentangle how their lived experiences of movement and captivity in their "re-hab(il)itation" journeys (cf. Chapter Five) were affected by the materiality of their lives and material-discursive practices they encountered and thus how meanings about sexuality and the body can come to be. That is, we also explored how one's imagination/felt potential for movement does not stand on its own but is constantly challenged and assembled by the context one lives and moves in, by looking for semiotic flows, material flows, and social flows streaming underneath the search for sexual pleasure and intimate connection. The "darkness" in the manoeuvres of the title hints at the not-knowing, stemming from the unanswered and/or unheard and/or unasked questions the women (did or did not) have alongside the private, hidden nature of (re-exploring) sexuality and the body as pleasure (residing in the realms of one's thoughts and bedroom walls).

Changed materiality of the body as a sexual turn(-off)

Most participants identified the onset of their injury as the main turning point in their 'herstories' of achieving sexual pleasure and feeling sexually well (cf. Research Question One). Importantly, they stressed that acquiring their injury did and does not equal the sudden disappearance of desiring sexual pleasure, but sexuality was generally less explicitly present in their lives than before and/or was evaluated as different and different as less satisfactory for themselves and/or their partners. To capture how they often felt limited in their potential to have a life with sexual and *intimate* fulfilment and to re-explore their body as a source of pleasure since their injury, the *chastity belt* was put forward as a metaphor: a locking object worn around the waist and genital area to prevent sexual intercourse, historically designed for women to protect against rape or to discourage lovers, or so it has been described by historical writers (Classen, 2007), later used as medical devices against supposedly harmful masturbation (Stengers & van Neck, 2001), and nowadays predominantly used in BDSM contexts by both male and female wearers to surrender control—the difference being that the modern chastity belts are worn voluntarily whereas the historical (and at least partly mythical) belts were forced upon women to keep them pure and faithful (Rosenthal, 2012, p. 11). The lived metaphor of wearing an unchosen and unwanted chastity belt was first suggested by one of the participants and later endorsed by the three other participants taking part in the focus group discussion, as well as during informal feedback encounters with the participants of the first data gathering round (cf. mainly Chapter Five). I emphasised *intimate* fulfilment above, as the women stretched sexual wellbeing open to intimacy, touch, sleeping together, feeling desire to be physically close to their partner and emotionally connected, feeling attractive, etc.

Participants directly linked the feeling of wearing a chastity belt to mainly the materiality of their body. The stories they shared during individual life story interviews, 'on-the-road' conversations during fieldwork and the group discussion were often about bodies that had changed due to spinal cord injury: bodies that felt different from before (or could not be felt anymore at all), that moved differently (or did not move anymore, or uncontrollably), and looked different (or with less perceived options to manipulate appearance). A body that is marked by loss of sensation, through which stimuli that used to trigger intense responses such as sexual desire now do not have the same intense effects. Yet, a body that is simultaneously omnipresent in taking up space in their every-day-minute-second lives, whistling them back, needing care and expert knowledge (taking away possibilities to open the lock of the chastity belt themselves), and always potentially losing bodily fluids. Its unpredictable leakiness triggering fears of affecting attractiveness, making the traditional zone of sexuality messy and dirty, and making women less feminine. A body less mobile and more out of their own control, carried and moved by others and/or supported by necessary tools. A body rarely touched by themselves or touching others, and often if touched by others not felt. Something breakable that scares others to touch it. Body care by self and others experienced as labour-consuming and effort-asking management, occupying mind space, physical space and time. Care becomes part of the intimate and sexual relationship. It is always there (however partners are embodied), but more intense, more consciously, more rational, more necessary here. All of these perceptions of the changed body intermingled with experiences of their body as something not completely theirs anymore. This feeling of their body as not completely theirs anymore could also be traced in language. The participants notably often described body parts with demonstrative rather than personal pronouns (e.g., "those legs" as opposed to "my legs"), although the multiple analyses of the data did not cover this facet of embodiment deeply enough to elaborate on it extensively. The distancing language could signal processes of distancing from one's own body or of not identifying with one's body, or "simply" of seeing the body as an object, a tool—a function of the body that one often only becomes conscious of when one explores or bumps into bodily limits.

For many women, the current materiality of their body and their meaning-giving and thus related experience concerning this materiality turns intimacy into something calculated and reasoned—not seldom described as less spontaneous, and less spontaneous explained as less satisfying than before—rather than a space of feelings and desire (cf. infra about the myth of sexual spontaneity): the bladder that needs to be emptied and the bowels to be checked prior to and after physical closeness to minimise risks of leakiness, feasible (read: lowest labour-intense) positions and accessible locations need to be negotiated and determined, time is managed due to longer time and assistance needed for undressing and re-dressing, etc. By the time this checklist has been completed, desire is expected to be gone. When we returned to moments of desire, often desires to expand and express sexuality were found to be in conflict with feelings of discomfort, anticipation of shame, and perceptions of partners being at loss in how to fulfil sexual desires. For instance, for one woman there was the desire to spontaneously change places in bed, which was difficult to accomplish not only because of the materiality of her body that makes it impossible to jump in bed by herself, but also because financial reimbursement from the insurance company and national health insurance funds was only given for the single-size (as opposed to a two-person size) version of the high-low bed she needed—a bed that cannot be easily moved around in the bedroom. There was the desire to wear sexy lingerie now and then, yet the recurrent returning from the shop with a grey night gown "you dare to hang on the washing line outside" and which would be decent enough for the healthcare professional to be seen and put on (participant's quote). There was the desire to be naked outside a medical context and surprise the partner under the sheets, yet quickly silenced by the shame to ask for assistance, coming from (internalised) ideas about appropriate bodily exhibition in public and private and the presumed lack of space for erotic and thus 'non-functional' nakedness or clothing in healthcare contexts. Clearly, deep-rooted desires to make love and be loved exist alongside deep-rooted discourses (grounded in social and structural oppression, cf. infra) about what pleasure should be and how bodies should appear.

Through the entanglement of all the above components of embodiment, the women experienced the initiation and even overall of closeness and pleasure with others and themselves to be more difficult or risky than before their injury—a difficulty or riskiness ascribed to the changed materiality of their body, but also potentially fuelled by internalised constructions of sexuality, agency, etc. (cf. the section on material-discursive practices below and Siebers (2008) on internalised oppression).

Material-discursive practices tightening the chastity belt

Between the lines, we read how re-exploring pleasure through the body and even fuelling sexual desire are challenged by material and discursive practices that affect the women's relationships towards (living with) their body and risk tightening the chastity belt (cf. Research Question Two). Rather than offering an extensive list of material-discursive flows, I will describe three of them that were most present in the encounters with the ten participants and share some insights about how they work (cure and care practices; chronic condition of standardising sexual and bodily pleasure; intersecting gender roles), without aiming to strictly delineate them because they work together and intra-act. I will also briefly discuss how all these flows can potentially become bindings, i.e., how these flows can tightly bind the chastity belt to/with the women('s bodies).

Cure and care practices

Firstly and most notably at work—and resisted—are the *healthcare* practices the women are surrounded by. Their presence becomes most apparent when participants describe others tactually approaching their (the women's) whole body as their (the others') "domain" or "territory" (cf. Chapter Five), when they worry about consequences of changing body management (Chapter Three) or body movements (cf. Chapter Four), and when they talk about verbally negotiating their desires for experimenting with body appearance with care providers (cf. Chapters Two, Three and Five). These healthcare practices are characterised by a focus on protection, preventing further bodily deterioration, controlling damage, curing and caring. Importantly, this is a perspective on the body which is not inherently harmful in itself, but nevertheless carries the risk of becoming binding and imagination-limiting.

It is a web of material-discursive practices to which women with SCI are exposed much more frequently and explicitly than temporarily able-bodied women due to the materiality of their bodies, and which are, therefore, likely to affect them more deeply and longer lasting. Their bodies and by extension the women living in/with/through these bodies (cf. Chapters Three and Four on how self-expression and self-esteem are linked to encounters with/experiences of the body) are partially lived and owned by others, by necessary touch of others (e.g., due to the need for assistance with washing, undressing, toilet, transfers), the refraining from touch by others (as a participant recounted missing touch from her partner since her SCI and ascribed the decrease in touch to a fear on his part to trigger pain: "as if I am suddenly breakable"), and other forms of reliance that pass on a discourse about the body as breakable including treatment and advice.

These practices, referred to as medicalisation in Chapter Three, are performed by healthcare professionals, close others and the women themselves, and—over time—permeate encounters with their bodies and become so natural that the impact on one's relationship with one's body, one's sexual self, and one's romantic/sexual partner is rarely questioned or challenged. As Shildrick and

Price (1996) argue, following Foucault's deconstruction of the power "[circulating] in the procedures of normalisation by which on the one hand the body is inscribed with meaning […] and on the other hand rendered manageable" (Foucault, 1977, p. 136), "the effects of healthcare as a disciplinary regime can extend into other most private and personal aspects of life" (Shildrick & Price, 1996, p. 434).

In the stories, we hear (about moments of) people (being) reduced to bodies that need to be looked after, with their voice or choice in the process of care be(com)ing overlooked. We hear people who tend to be positioned or risk positioning themselves more as a person who needs assistance and is dependent on the other person than a full-blown partner being in control over her own body in a relationship of mutual interdependence (to help maintain the balances of caregiver vs. romantic partner and care-asker vs. (independent) woman, three of the five participants who need daily intimate, SCI-specific support had already arranged the paid assistance of healthcare professionals to take "weight" off their family's shoulders). We hear women who approach their own bodies through the eyes of others, a self-performed practice they are not always aware of: choosing clothes they do not particularly find attractive but which facilitate undressing by others, a practice which was challenged when they were invited and funded to contact a tailor and discover that skirts, lingerie etc. can be both aesthetical *and* practical; predominance of the body needing medical care and protection when reflecting on sexuality *and* the sudden awareness of how "relaxing" it is not to be occupied with their body as a source of worries "for a change" (mentioned in the make-over trajectory); limiting exploration of the body in movement and appearance because of dominant voices declaring deviations as "dangerous" or "no go zones" (cf. Chapter Four for the blockage in dancing, Chapter Three for rarely questioned medical expert or parents' advice) *and* transgressing these boundaries by questioning why these border zones were brought to life and slowly explore how life can be lived safely yet more playfully.

These lines of thought and touch become visible not only through language but also when we have a closer look at the materiality of many of the women's lives, which was a facet of special interest during this doctoral research. In the background of the participants' stories and in their homes, we find the weightiness of matter in how these women 'roll' (cf. Chapters Two & Five). The more I got access to the lifeworlds of my participants, the more I noticed the bathrooms: clinically white fold-up chairs or chairs with a huge circle in the middle functioning as both toilet and shower chair, urinary catheters out in the open, antibacterial lotions: all far from aesthetic or erotic pleasure. Then the bedrooms: often two single beds that cannot be bridged because one of them has the function of being adjustable to the healthcare professional's height, with handrails that reminded one participant of a prison. The daily structures: bladder and bowels managed and the whole body washed by medical hands, coming in after loud and early ringing of the doorbell. Healthcare professionals (and students) trained in performing the same actions on the patient's body all over again, for the sake of their skill-development and their knowledge-gaining, for the sake of their sensation. Clothes chosen for their practicality rather than aesthetics. Sofas too high to get on without help from a partner. Although not explicitly talked about except for the materiality of their changed bodies, matter did seem to matter in how my participants lived their intimate lives, embodiment clearly intra-acting with a much broader material world.

Chronic condition of standardising sexual and bodily pleasure

Secondly, accounts of failing intimacy were coloured and desires overshadowed by static definitions of satisfying intimacy that made it difficult to re-explore possibilities with a body that did not meet the norms of full bodily sensation and control anymore. That is, by what could be called *the chronic condition of being sexual in a world where sex is highly yet often invisibly normed and regulated*, becoming all the more visible when we delve into women with SCI's stories because their bodies do not allow for conforming to this discourse. My research participants' own (pre-SCI) internalised expectations about when, where, how, and to what goal to have sex and definitions of satisfying sexual and bodily pleasure built up throughout their life history reflect the performance-oriented and genital-focused approach to sex widespread in Western society, i.e., the constriction of sex to penetration with explosive sensations preferably leading up to simultaneous orgasm, with a climax as necessary for satisfaction, the best sex as arising spontaneously, full of initiative of independently functioning and fit partners (Tepper, 2000; Dune & Shuttleworth, 2009). Examples of how this chronic condition was playing out in the participants' stories about their intimate lives ranged from hair/body styling and hiding procedures to achieve a physical appearance in accordance with the perceived norm (cf. especially Chapter Three), over emphasising the loss of spontaneity (due to the intimate physical and psychological "labour" required in preparation of sexual encounters, stretching far beyond mere time planning; Liddiard, 2014) and lasting burning questions about orgasm-ability, to not disclosing about spots of the body that are without neurological sensation to a new partner and faking orgasms so as not to disturb the relationship which was experienced as good as it was and hence implicitly questioning their potential to fulfil their role as sexual partners (cf. especially Chapter Five).

This "chronic condition" feeds feelings of being "too" abnormal or "not enough" to be recognised as a sexual being and viable satisfyingly sexual partner by potential sexual partners (cf. especially Chapter Three). Spinal injury challenges conforming to what "confer[s] value in the modernist western conception of the sexual subject", namely "those familiar categories that establish autonomy, that comprise notions of self-determination, separation and distinction, and which demonstrate corporeal wholeness" which are "precisely the qualities in which the universalised disabled body is deemed to be lacking" (Shildrick, 2009, p. 128). At least equally present as the sense of abnormality or insufficiency in the stories of the women are the uncertainty and the feeling of being at loss arising when confronted with the inability to comply with normative demands of sexual performance and sensations that once were within reach (cf. especially Chapter Five). It is a feeling of being in the dark that stretches far beyond the perception of being a "misfit" in a normalised world (Garland-Thompson, 2011). Rather, this being at loss is related to not knowing how to move and manoeuvre in existing intimate spaces and how to create new, non-normative pathways.

The participants' repetition of sexuality not being "the same as before" and/or "not enough" as well as their feelings of being at loss could be understood as following desires of "recognition" in this wider cultural context of being sexual human beings (Davies et al., 2013) and desires to be recognisable for themselves following "lived body disruption" as who they were before their injury with their former abilities to sense and act (Toombs, 1995, p. 9; see also Gallagher, 2005). These dimensions of the "desire to continue in one's own existence" are entangled (Davies et al., 2013, p. 681). One can try or claim to create new paths, but it is impossible to escape the normative or to completely leave behind what once was so intimately embodied as the known is inscribed into one's body with "citational chains, or repeated acts of recognition" (Davies et al., 2013, p. 682; referring to Butler, 1997). Each moment in the present carries in itself the past somehow, and it is through recognition that being is made to make sense.

Holding on to normative expectations about sexual and bodily pleasure, feeds into evaluating one's body with SCI and potentially one's whole being as lacking (cf. especially Chapter Three) in line with previous research that suggests that holding on to sexual myths can lead to problems with sexual self-esteem and well-being (Dune & Shuttleworth, 2009; Gurevich, Mathieson, Bower, & Dhayanandhan, 2007) and sexual satisfaction (Gossmann, Mathieu, Julien, & Chartrand, 2003; Shuttleworth, 2006). Moreover, it brings exploration of the body as it is at present to a halt and stops expansion of one's imagination of what could become and one's subsequent playing with encounters with the body.

Intersecting internalised gender roles

Intersecting with these flows-potentially-becoming-bindings, we find, among others, internalised *gender* roles. First answers to questions about the women's sexual wellbeing or their body image not seldom diverted to their (perceived) partner's angle (e.g., "my partner says my legs are heavy", talking about partner's "healthy libido" but lower prioritisation of one's own needs) or revolved around giving yet rarely receiving: being a good mother, delegating the household chores, being a good partner, worries about giving sexual pleasure, etc. This suggests that the intimate labour the women perform invisibly in their everyday lives and in my research is indeed highly gendered, following Liddiard's (2014) conclusion on "the work of disabled identities" that much of the work done by the women with physical impairments in her study is shaped by or "rooted in their social and political positioning as disabled people and—as with the motivations of non-disabled heterosexual women—by normative notions of womanhood, femininity and (hetero) sexuality" (p. 125).

While acknowledging this performed work as a form of sexual agency, Liddiard also states it is a form of psycho-emotional dis/ableism because it is experienced as required by her (female and male) informants "in order to survive; to be loved; to be human; to be included; to be 'normal'; to be sexual; and to be valued" (2014, p. 125). Patriarchal constructions of femininity seep through in the labour that my participants performed in their intimate relationships, with intimate labour being emotional, mental (managing time and negotiating priorities) and physical (managing one's body). This intimate labour infused with patriarchal constructions of femininity was most visible in the women's work as care receivers (taking up a subordinate position; e.g., by refraining from asking partners for help to do a transfer to a sofa where they could cuddle when seeing his exhaustion, by refraining from pushing through the wish to re-design the house so they could sleep in the same bedroom). It was also present in the women's "sex work" in their encounters with their partner, friends, and the researchers, with "sex work" described as "the unacknowledged effort and the continuing monitoring which women are expected to devote to managing theirs and their partners' sexual desires and activities" in Cacchioni's study on the sexual problems of heterosexual women (2007, p. 301). Also their "aesthetic labour" was infused by an "'infatuation with an inferiorised body' against which women will always feel inadequate" (Liddiard, 2014, p. 123; citing Bartky, 1990, p. 40) and which is even more complicated for those women whose bodily difference is "wholly intolerable within the rubric of the normative body"

(Liddiard, 2014, p. 123). This was shown in, for instance, participants' strategies to hide body parts affected by muscle atrophy; actions to look more feminine and/or less disabled, which were categories difficult to reconcile for some. More implicitly, these gendered roles could also be traced in how participants reflected on encounters with (male and female) healthcare professionals, where they experienced steering the care practices (e.g., asking the nurse to keep the catheter tube long enough to be able to turn over to their partner in bed, asking for a specific sequence of actions in washing) as negotiating or arguing, and where they indicated to feel pressured to always be graceful, clean, and chaste (cf. participants being put off from sex by the mere prospect of being found naked, dirty, or in a sexy outfit by the nurse in the morning).

Flows potentially becoming bindings

All these flows-potentially-becoming-bindings risk limiting or disabling the range of options that women perceive to have when it comes to manoeuvring in intimate spaces. Moreover, I argue that pursuing in performing intimate labour uses valuable oxygen or fuel that could otherwise be used to expand one's imagination and manoeuvre their intimate spaces otherwise. This dissertation has shown that the above-discussed lines of touch and thought intertwine and tighten the chastity belt put on and locked by others (including their partners and people who move and work with the women outside the context of romance and sexuality) and the women themselves. When posing that the women in my research (including myself) themselves were contributing to the tightening of the chastity belt, I am not individualising their experiences to the extent that a return should be encouraged to "individual, medical, bio-psychological, traditional, charity and moral models of disability" which "locate social problems in the head and bodies—the psyches—of disabled people" (Goodley, 2011, p. 716; Liddiard, 2014). Rather, it adds to existing knowledge of psycho-emotional dis/ableism and especially how this relational form of oppression twists and twirls within the intimate spaces of people's lives.

The entanglement of the flows-becoming-bindings and how the women and their close others intra-act with them fuel (de)sexualisation of one's body and either give or draw away oxygen for desire to develop and grow, be it specifically sexual desire (cf. Chapters Three & Five) or more general desire to explore one's body (cf. Chapters Three & Four). The risk resides in the fact that the chastity belt and its flows-potentially-becoming-bindings can be present every day, minute, second of people's lives yet remain barely noticeable having become so natural (cf. Chapter Three on naturalised truths of the body), unless questioned (cf. Chapters Two to Five). The more affected by these flows, the more distant and abnormal that the (search for) expression of sexuality and the experience of the body as pleasure becomes for the women and the people they are surrounded by, and the more challenging it is for them to manoeuvre in intimate spaces—intimate yet shaped by external-becoming-internal flows that are not inviting to experiment, desire, and imagine differently.

Expanding manoeuvrability

Throughout the encounters with the participants, the conceptualisation of the body as irreversibly changed was omnipresent. Moreover, this experience of the body as categorically different was recurrently framed as detrimentally affecting the experience of sexuality: the changed body was creating obstacles and bringing into existence uncertainties about what can still be expected. Together with the flows-potentially-becoming-bindings discussed above that are woven through the women's daily life stories, these components of living life with SCI affect how much space is created to manoeuvre with and through the body as (a source of) pleasure as they inform the intentions with which bodies are approached by the women and their environment: the body as flesh with deviations from (society's and/or one's own previously known) normality or the body and encounters with the body as spaces of playful creation. Moving towards re-exploration of the body only becomes possible when the present is re-written—individually *and* with one's partner and all the possible components in the assemblage of intimacy—despite the tension with the normalities of the past (pre-SCI and post-SCI), however fragile and temporary those moments of flight are. It involves rolling to the edges of one's framework of what makes up satisfactory sexual encounters, looking into the desires that are flowing underneath the "ability" which one is "craving for" and "attached to" and which "contributes to the formation of internalised ableism … an *eternal insufficiency*" (italics in original; Campbell, 2019, p. 8), and exploring beyond what was dominant in one's past normalities, as "an individual [that] ceaselessly divides itself and changes its nature, making itself multiple" (Deleuze, 2004; paraphrased in Dosse, 2010, p. 158).

Over the timespan of the research (inspired by the research activities as well as other events in the participants' lives), it became clear that sexuality and experiencing pleasure through the body was still seen as an ongoing journey of becoming-in-the-world for most, with the broken body implying endings yet also holding the potential for openings and new beginnings. Every constructed story also contained a vital moment of becoming different "beyond the boundaries of the sets [they had] been distributed into" (Williams, 2003, p. 60). The women's re-exploration of their potential for pleasure and satisfaction was fuelled through (personal and virtual) encounters with people who were approaching intimacy and sexual pleasure differently and with whom they could (partly) identify; by communicating about both grief and desires with their partners (this research was reported to be an excellent opener for the topic among others including films, books, encounters with other people with SCI); by creating a physical context that facilitates intimacy and experiencing the body as pleasure, by means of material accommodation (e.g., accessible sofa, accessible double bed, making plans to design a bedroom for personal hygiene/care and a bedroom for being lovers); by being invited to explore remaining and new bodily sensations; by being repeatedly invited to experiment with body movements in a safe space yet outside the comfort zone; by being touched and/or moved by others in a particular way, inscribing in the bodies new movements and vitalities; by returning to desires to be intimate and reflect on them as fully legitimate topics to discuss with healthcare professionals; by questioning where shame and discomfort comes from; by becoming more confident about performing ownership of their body; etc.

Most notably through it all, participants expanded their manoeuvrability with minor-yet-impactful physical or imaginative actions both directly or less obviously related to sexuality performed by themselves and simultaneously in relation to the material-discursive world around them. In these shifts, disability is returned to as "set[s] of practices and associations that can be critiqued, contested and transformed" (Kafer, 2013, p. 9), and space is created for manoeuvring. Whereas lines of force are still working to keep the subject submissive, lines of flight crack the boundaries of normative systems and open up potential for transformation, bringing the subject closer to entering into "a relation to oneself which resists codes and powers" (Deleuze, 1988, p. 103).

Re-Creating (New) Stories about Sexuality and the Body: Recommendations for Research, Support Practices, and Throughout/Beyond

The project has shown how a body and the person living in/with it can become something to be contained and managed physically, medically, aesthetically, socially, and psychologically to such an extent that they become desexualised and voiceless, yet also, however fragile, the potential for acts of resistance and movement in imagining the possibilities of living with a body that does not comply with normative standards (anymore). It highlights some of the socio-cultural and material processes that affect the search and desire for the body as a source of pleasure and creation, and by doing so opens pathways for taking up response-ability for everyone involved.

Research in multiplicity

"There are no stories out there waiting to be told and no certain truths waiting to be recorded; there are only stories yet to be constructed," Denzin says about interpretive ethnography (1997, p. 267). The title of this dissertation touches upon the constructed and transforming nature of the stories that were created and re-created by the participants who shared their memories, emotions and meaning-making with me, co-researchers/assistants and each other through discourse and matter: stories the participants had partly already created for themselves (making sense of their experiences of intimacy and their body over time) alongside stories they had partly shared before (for instance with their partners, healthcare professionals) and stories they had only started to voice during the research; stories returned to in the encounters organised by my research and retold, elaborated upon and revised; stories always somehow in relation to the topic of intimacy and sexuality, shining light *and* casting shadows on different aspects of my research topic. Rather than approaching our multiple encounters as parts of a longitudinal research design in a quantitative sense involving repeated observations of the same variables, the women recounted, touched and retouched, unfolded and refolded those parts of their experiences they found to matter at those particular moments in time. They told (new) stories, stories constructed at those moments yet always carrying with them parts of stories created earlier, and stories covering (meaning-making of) memories and thoughts about intimacy and pleasure at present as well as imaginings of futurities. I, too, as a researcher created and re-created (new) stories, selecting and assembling, commenting and translating what I had seen and heard and felt into words and dance and photographs, constructing seemingly fluent stories yet consciously choosing which parts I considered ethical and essential to show in this dissertation to portray participants' manoeuvres (including my own)… often stuttering, wandering and wondering on the way.

I wandered and wondered, when grappling with dilemmas during data gathering, being engaged as I was with the women I was meeting. The data gathering moments were moments of intimate labour for my participants, where they-I-we dug into memories of thought and senses not often explored before. It seemed easier for all of us to converse about the physical, practical ways of living, with dry descriptions about how the women dealt with their bodies, than about their impact on intimacy and sexual pleasure. I often noticed a focus on household delegation, motherhood, partnership, volunteering activities, etc., and only then came stories of sexual satisfaction and wellbeing. How far could I go in interpreting this as "display work" to come across as a content partner or to even be a content partner and cracking this display (Hochschild, 1983, p. 10; Liddiard, 2014, p. 121), or in being at peace with participants making this *choice* of prioritisation? Or how far could I go in digging into topics that participants only mentioned lastly, silently, or hesitantly?

I wandered and wondered, when confronted with my research materials, traces of the "touchpoints" between myself and my participants. I had asked them about sexuality and intimate relationships, with a broad lens… I had not made pleasure the primary topic. And I was shocked to hear and feel their—and our—chastity belts, postponing the analysis of the materials until colleagues, publication and conference deadlines, and participants' enthusiastic engagement pushed me to dive in. Staying in touch with the participants during this process (by e-mail, by bumping into each other during events not related to my research, even by joining one as a fellow-speaker on a sexual and reproductive rights conference) helped to see the lines of flight that were present in the stories because they showed me how alive and complex they were. At multiple points, people do move, order their coffee and find a way to take it to its destination, which is not an endpoint, as transformation is inherent to this flowing liquid that shimmers and dances in dark or gold depending on the incidence of light (cf. Chapter Five). How necessary might it be to make pleasure the entrance and explicit focus of conversation in order to invite people to talk about their body as a source of pleasure, how essential could it be to make pleasure the wave on which to take people on a journey, a wave which can also be(come) normalising?

I wandered and wondered, as you might already have concluded from the apologies and necessities opening this dissertation. Approaching the stories of the women in my research entailed a constant search for ways to approach the stories and pass them on that would respect the fluidity, temporality, layeredness of their experiences; i.e., the dynamics of being human. How to portray vulnerability hand in hand with resilience and agency? Ripping apart stories in tightly defined themes would mainly give rise to heaviness—heaviness which cannot and should not be disregarded, but what would it open up? This search drove me to engage in qualitative inquiry through hybrid writing, creating mixtures of poetry, narrative and "raw" research material, and ultimately a monologue in polyphony, with my "textual experiments…not so much about solving the crisis of representation as about troubling the very claims to represent" (Lather, 2001, p. 201). Throughout my journey I have increasingly *not* worked with the category of "disability", but with processes of dis/ablement. The writing experiments have become products of anti-essentialising research-in-becoming despite the solidifying nature of language, steering away from glueing labels on people and away from explaining their experiences solely from those labels.

In my wandering and wondering (re)search and (re-)creation practices from data gathering rounds over analysis to sharing research findings, I found it helpful to approach research as ethical encounters (Davies, 2014; Davies, Masschelein & Roach, 2018). With "ethical" I do not refer to the procedures I adhered to in order to obtain approval from three ethical committees, as these did not cover what Liddiard (2014) calls "the ethics of narrative", i.e., the ethics of "asking (disabled) people to tell intimate and sensitive stories, and of hearing, interpreting and retelling people's stories" and which are "particularly pertinent given the extent to which disabled people's lives and bodies are routinely objectified, harmed and denied privacy through oppressive social and cultural practices" (p. 120). Movements were started that are neither without obligation, nor without "response-ability", i.e. "the possibilities of mutual response … for worldly reconfigurings" (Barad in Dolphijn & van der Tuin, 2012, p. 55). Taking up these "obligations of having met" (Haraway, 2016, p. 130), I have tried to stay away from "thinging" and embrace being and becoming within the constraints of language, in line with Smith's call to "say no to the thinging of us and say yes to the being of us" when working with people who are, in his work, marked by sanist ideologies and practices (personal communication at ICQI about sanism, i.e., the oppression of "mad" people by people who consider themselves as not crazy, 2019). To "thing" is "to create an object by defining a boundary around some portion of reality separating it from everything else and then labeling that portion of reality with a name" (Carreira, 2011). Rather than looking *at* people and setting up boundaries around them and between us, I looked *with* them at the world (Haraway, 2016, p. 130). We live in and co-create "a world vibrating of meanings" (Dahlberg, Dahlberg, & Nystrom, 2008, p. 172), and it is the researcher's response-ability to engage with this world of meanings. I did it "Slowly", which Ulmer describes as "a state of being in which scholars choose to live writing and research through locality, materiality, and artisan craft" (2017, p. 201) and which "facilitates the study of the 'existence[s] that shape our everyday relationships to ourselves, to others, and to the world'" (Coole & Frost, 2010, p. 5; cited in Ulmer, 2017, p. 202). Lived experience is evolving and evolving knowledge cannot be but lived.

That is also what I recommend for future research(ers): allow multiplicity. Multiplicity in who participants are. Multiplicity in how you can relate to participants. Multiplicity in what can be "data". Multiplicity in what can become, turn and re-turn during research. Studying lived experiences of sexuality and intimate pleasure of women with SCI should not just be research about a medical/bodily problem, or as just a social problem brought about by normative/normalising practices around sexuality, body, gender, age, ability, economy etc., as all flows create multiple and intersecting levels of barriers, oppression and injustice, amplifying each other, and affecting these women's experiences and imaginative manoeuvrability. I do not wish to limit what else can be done; I can only say that I am curious to find out more about how the convergence of these flows might play out in multiple contexts such as private bedrooms, healthcare settings, classrooms, media, etc. and what the body as pleasure and creation, amidst this convergence, can mean and be(come)? Methodologically, I wonder how body work—any activity drawing on the body that helps one to get to know more than one thinks one knows—can be put to use, alongside language, as a research and re-exploration tool.

Support practices

The question is not *whether* people can still have pleasurable and satisfying intimate lives, but *how*. While risking to get out of balance on the cord of cure and care practices and steer readers' memories of my dissertation in a medical direction, I feel obliged to dedicate a section to support practices. All participants indicated at the beginning of the research trajectory that they wanted to participate exactly because they felt that there was a lack of attention for sexuality after SCI (in the first place in healthcare, and more broadly in society) and they wanted to make the search for pleasure (which, for them, was often marked by uncertainty and feeling at loss) easier for other women with SCI. They emphasised that information—both technical information about the body and lived experience information from other women with SCI—was an important first step. In what follows, I offer some thoughts about experimenting with approaching intimacy as an assemblage, reviewing rehab(il)itation of the body, and consciousness creation about the flows-potentially-becoming-bindings (cf. supra).

Serving as an antidote to deficit-science and an opening of possibilities, the concepts of becoming and assemblages can be used to work with people and their lived experiences of the bodies they live in/with/through (De Schauwer, Van de Putte, Blockmans, & Davies, 2018). SCI cannot be extracted as a self-contained, static condition, as the lived experience of SCI is itself a continuous coming together of meaning-making and actions (which also include non-actions) in a myriad of contexts (including healthcare contexts and relationship with one's partner/potential partners). Intimacy, too, is an assemblage (see Chapter Five). Making up participants' intimate lives include, besides the materiality of their bodies also touch (how, by whom, when, for what purpose), their medically sterile or cosy bathrooms, the function of the bedroom where they sleep together in the same bed or on a different level in the house and which is also often used for bowel emptying in the morning, the information about sexuality that is available and presented to them, the conversations they have or do not have about sexual desire, their own and their partner's meaning-making of satisfying and pleasurable sexuality and intimacy in the past and at present, etc. Hence, when working with women with SCI, it is important to keep in mind that the neurological damage and its physical implications following SCI are only parts of the becoming assemblages the women are, with "becoming" with all these flows not equalling change with a pre-set path and a pre-set goal.

As posed in Chapter Five, rehabilitation is predominantly defined as "the action of restoring something that has been damaged to its former condition"[17] and rehabitation as "the action or an act of reinhabiting a country, area, house, etc."[18] One could ask whether rehab(il)itation in practice includes re-habiting one's *body* enough. And what becomes possible if rehab(il)itation is envisioned as "a process of actions in which old habits are revisited, current conditions are explored, and new ways of being are created" (see Chapter Five, p. 115)? The journey of rehab(il)itation is a journey of re-exploring and re-owning one's body that goes beyond damage-control and body positivity (celebrating that all bodies are good, valuable bodies). Rehab(il)itation creates a path for exploring a changed body and new bodily encounters, where the focus is not on achievement but on letting go of sex-, body-, and intimacy-related definitions of the past and breaking through (internalised) social conditioning. Creating new stories about sexuality and the body is not merely a matter of self-esteem and definitely not "dealing with" and "accepting" a new life. Re-habitation of the body that feels completely different from before—what you sense, is not recognisable and knowable in the same ways—requires a tremendous amount of exploration work, asking energy and trust. Rehab(il)itation is also about learning to break through internalised angles on the body (beyond the oppressive disability-related myths talked about in most studies of disability) and citational material-discursive practices that give the brokenness of bodies master status and form the roots of the experiences of wearing a "chastity belt" and of finding it challenging to imagine a sexually fulfilling life.

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[17] Definition taken from English Oxford Living Dictionaries (online).
[18] Idem.

In cure and care practices more awareness is needed about the power of healthcare contexts, both in shaping meaning-giving to the disabled body and in opening up what can be done when much seems lost. On the role of healthcare practices in co-creating and challenging the "naturalisations" of truths of the body, Shildrick and Price (1996) say that:

> If we can demonstrate that what has been naturalised as the truth of the body is merely the discontinuous outcome of a complex series of normalisations, in which health care has been pre-eminently implicated, then it becomes possible to dissolve devalued identities and theorise new constructions of embodiment. (p. 439)

This also applies to working towards new constructions of sexuality. The experiences discussed in this PhD project have shown that material-discursive healthcare practices carry the risk of contributing to the de-gendering and de-sexualisation that people with mobility impairments are often exposed to (Liddiard, 2018; Shakespeare, Gillespie-Sells, & Davies, 1997). Sexuality and intimacy are too easily assigned to a colleague's response-ability, and it should be questioned what the consequences are of this splitting of response-abilities in care. Sexuality and intimacy are aspects of being human that should have a place in all healthcare domains.

Part of the challenge is to re-story the body and encounters with the body in everyday and every night life, i.e., to over-write previous experiences and normative ideas. This creation of becoming with new conditions of embodiment does not happen in a vacuum where the person with the changed body is the sole actor. It is mandatory that awareness is raised amongst healthcare professionals and emotionally close others of women with SCI about the material-discursive practices around sexuality and bodies that challenge the women's *and* their own imaginative manoeuvrability. This includes attention for "the nexus of structural, psycho-emotional and material dimensions of disability" and disablement (Liddiard, 2014, p. 122; Thomas, 1999) as well as attention for deep-rooted scripts about sexuality, gender, touch, interdependence, etc. and power dynamics in healthcare that become visible in the intentions with which women with SCI and their bodies are frequently approached.

Supporting women to expand their manoeuvrability in intimate spaces concerns how to give oxygen to imagination so it leaves its "dark little corner" (participant's quote, Chapter Five). It necessitates questions such as: "How do we not ignore experiences of the body as irreversibly damaged but work with it?" and "How do we set in motion the search for sexual pleasure if normalising material-discursive practices seep in and if also women with SCI themselves become their own barriers?" How can re-encountering one's body and re-storying one's meaning-making be supported? What does intimacy mean to them, what do they desire, what can inspire them to get in touch with their imagination and go beyond what they are aware of? It involves supporting women to travel through processes of thinking, moving, and feeling outside territorialising lines of medicine and differentiation (i.e., "the practice of distinguishing multiple differences among people according to their category memberships"; Van de Putte, De Schauwer, Van Hove & Davies, 2018, p. 898) and in this way boost critical consciousness of how they move and experience their body in interaction and how they want to and can express themselves.

The findings urge, in the first place healthcare providers, both in rehabilitation centres and when women with SCI resume life outside the safely delineated walls of the hospital, to consciously work with the physical, social, and psychological challenges that (can) arise when women want to (re-)explore intimate pleasure. Women with SCI can be supported to leave behind pre-SCI and more broadly normative thought and experience patterns, and to regain ownership of and sense of agency within body and life. Healthcare professionals can take up their response-ability by making sexuality and bodily pleasure more accessible as a *conversation topic* (especially facilitating encounters with other women with SCI who can share their experiences, alongside more visibility of available information, etc.) and as an *activity* (e.g., through massage (using different body parts), dance (blindfolded, with mirrors, etc.), breathing workshops with and without partner, wheelchair skill training combined with shopping for clothes, etc.), thereby gently paving the way for re-encounters with themselves and giving them tools to continue building knowledge about how to re-explore their bodies as a source of pleasure for themselves and their partner. The inclusion of desire and pleasure in discourses about sexuality and the body serves to empower people to be sexual agents, to be initiators and negotiators (Fine & Asch, 1988, p. 33). Further preparation to life outside the hospital, e.g., when offering support in making homes accessible, should incorporate (regaining) physical intimacy as a standard, essential part of daily life. Throughout rehab(il)itation, work around the re-conceptualisation of pleasure, time (how can the need for more time also create possibilities to be present for each other), and (in)(ter)dependence (what are the possibilities to experience entanglement) could be useful.

Healthcare practices are more than bodily hygiene and care provision: they involve, trigger, or touch upon privacy, shame, (not) allowing femininity, exposure, vulnerability, defenselessness, uncertainty, etc. How can the care asker maintain ownership of his/her body despite the intimate care provided by others? How can the intrusion of the sterile vibe (of the functional context in which body care and assistance is provided) into the lifeworld of the care asker be minimised? What objects, including those that are less obviously associated with sexual pleasure and intimacy, can make a world of difference in encountering self and other? Where else do healthcare professionals, women with SCI, and their partner(s) have the ability to respond?

Beyond

Women often slip through in studies on sexuality with disability; pleasure slips through in studies on sexuality with disability; people with bodies labelled as “deviant” slip through in sex education and media; humanity slips through in healthcare pressured by time and “efficiency”; the complexity of the assemblage of intimacy slips through everywhere. We leave people alone with the task to find out what intimacy, including sexual pleasure, the body as pleasure, and connection, can be, whereas there are many entryways.

In February 2019, a presentation about my research was scheduled in a session on “Living/becoming with chronic conditions” alongside presentations about quality of life of people with HIV and dementia at a conference of qualitative inquiry (*ECQI2019*). I felt shivers running through my spine upon noticing that my talk, despite its focus on deconstructing sexuality rather than deconstructing disability, had been boxed up based on three words in my 246-word abstract referring to one particular feature amongst the many features of my research participants: spinal cord injury. It was a session clearly created to group research projects that somehow involved people with chronic conditions in a medical sense. This action of producing a certain type of people drove me to sketch a more complete picture of “those living/becoming with chronic conditions”, and question whether human beings, regardless of how they are embodied, do not all live and become with chronic conditions.

Aren’t we all chronically striving towards belonging and loving and being desired and touched? And do we not all become and live with the chronic condition of—often unconsciously—striving to experience “sexuality embodied in the genitals” (Tepper, 2000, p. 288) with as much variety with regard to locations and positions as possible, and isn’t it simply enlarged in my study because my participants’ bodies make it challenging to comply—most of their bodies neurologically damaged in the “traditional” zone of sex resulting in minimal or no sensation in the genital area, often with leaky bladders and bowels, and less options mobilitywise? Aren’t we all (culturally) disowned of our body? How many times do we, do you, in your personal life and the lives of others, encounter images of sexual pleasure that are insanely normed and normalised? Aren’t we all striving for climaxes and impressive stories? And simultaneously, aren’t we all chronically routine animals?

Why is re-encountering and re-exploring our body so difficult? How many people self-explore? Which adult touches his or her own body purely or primarily to experience pleasure? How often do we take time to consciously experience our bodies as vehicles for sexual pleasure and intimate connection? How many people play with sensations and fantasies? Re-encountering one's body and re-exploring pleasure and connection with one's self and others is not (only) about masturbation and achieving orgasms, but about subtle and intense carresses of your arms or face or any other spot, enjoying a shower scrub whilst being fully present instead of the quick functional hand movements and touches; the buying of massage oil or lingerie you like just for yourself, etc.

What alternatives can we imagine to experience pleasure and fusing with self and other? An important question is: what does intimacy mean? And what did intimacy mean? Why were some activities and sensations and positions so fulfilling? What was the meaning underneath? If activities that once were common and pleasurable are not comfortable for one or both partners, in what other ways can the intended feeling be co-created? Maybe it feels weird to intensely enjoy the touching of one's ears. Maybe our partner gets more easily excited about ten minutes of play with a clitoris than an earlobe. Maybe it feels passive and less powerful to see your thighs following rather than initiating movements. Maybe it feels wrong for a partner to still find it erotic to touch thighs, a belly button, breasts even though the partner cannot register touch in those places anymore, whereas, regardless of sensory registration, touch in those places can still do and move something. You see it, you know it, you bestow it with meaning. Or you don't see it, you know it maybe, and you enjoy complete surrender. And both partners experience pleasure and intimacy.

What can happen if we can learn to see erogenous zones and intimate pleasure as free(d) from a continuum stretching from rarities to normalities and free(d) from deeply anchored individual expectation patterns about what was before and what once was possible—patterns of thinking and moving and feeling and sensing? Acknowledging the missing of something is essential, to then look into how one can manoeuvre towards what one desires, be it on different paths than the well-trodden ones. There needs to be an encounter with the new body to bring movement in intimacy again, and to re-story the body as a source of pleasure and a medium to co-create connection.

To fuel the expansion of imaginative manoeuvrability, I would like to cite a feminist/disability activist/researcher/writer I admire for her vulnerability and audicity. Van Ertvelde counts the number of times that, over the timespan of her life, her short right arm has been touched, “the one that doesn’t look like what you’d expect from an arm” (2019). And she comes to the conclusion that her arm has been more often groped by doctor’s fingers than caressed by a lover…which means that significantly more people have touched her vulva than her arm, which is both a very sensitive spot and one of the places that make her most deeply herself. She explores why and realises that she herself has been contributing to this pattern. She accommodates to others, in order not to make them uncomfortable, by not offering her arm as part of encounters. In a newspaper column, she critiques how this discomfort with difference is maintained by several external and internalised flows, and I wonder what can open up if what she envisions for sexual education, can be extended to support practices and research:

> Imagine how much beauty can enfold when sexual education starts from bodily difference, from bodies that change. Maybe sex then, for everyone, becomes less of a series of fixed actions you need to master, and more about encounters between whole bodies that explore which emotions and sensations they evoke in each other. (Van Ertvelde, 2019)

“Society promotes narrowing our desire … and we need to create a cultural imaginary in which we are all desired,” Disability Studies scholar Dan Goodley neatly summarised his talk about what it means to be human (personal communication, 2019). Exactly because they have the potential to destabilise what we think of as normal, diversions from normative corporeality drive us to ask what we desire and how we desire it; they even intervene and compel us to rethink what we desire.

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Appendix 1

English Summary

Introduction of the Research Project

Satisfying sexual activity and intimacy are supposed to be vital for romantic relationships and one's well-being, for fuelling feelings of belonging and connection, and for acceptance of one's self and others (Shakespeare, 2000; Shildrick, 2013). Moreover, sexual health has become an "integral component of the right to the enjoyment of the highest attainable standard of health" (WAS, 2008, p. 2), and, hence, should be acknowledged and promoted for everybody (WHO, 2015). Yet, people who do not conform to (unachievable) standards for a socially appropriate and satisfying sex life (including, among others, able-bodiedness, able-mindedness, heterosexuality, femininity vs. masculinity, youth, skin colour, independence) are still silently excluded from the "notion of sexual subjectivity" in research, education, media, and healthcare (Shildrick, 2004, p. 1; Tepper, 2000).

This seems to apply especially to women with spinal cord injury (SCI). Although they have, in comparison to temporarily able-bodied (TAB) women, the same desires and needs for sexuality and intimacy, their 'sexual subjectivity' is less recognised. Nevertheless, their body and neurologic functioning has been used as a quasi-experimental 'case' to better understand the link between sexual functioning and the nervous system. In the context of these studies, survey studies have shown that they tend to have a significantly lower body image, sexual self-esteem, and sexual satisfaction (Beckwith & Yau, 2013; Moin, Duvdevany, & Mazor, 2009).

On the one hand, research focusing on neurological functioning offers explanations by drawing on obstacles following physical deficits. This kind of research, however, reinforces medicalised and performance-oriented views of sexuality and fosters healthcare practices that—once rehabilitation and medical interventions have reached their limits in fixing and modifying the body—ultimately run out of options in (re-exploring) sexual expression and pleasure (Tepper, 2000). On the other hand, research mainly fuelled by disability and social justice studies urges us to attend to the disabling impact of social/cultural/environmental factors on sexual identity formation and possibilities for sexual expression. In doing so, it risks leading to reverse essentialist approaches by neglecting the reality of living with physical limitations and discomfort and hence overlooking their potential impact on sexuality, as well as by using disability as a category to group people and assuming these people share the same views, experiences, and priorities, with analysis often limited to comparing people 'with' and 'without' disabilities, producing binary data. Both research trends also risk endorsing a deterministic view of living with a body that is often approached as undesirable in terms of "physical, cultural and social capital" (Hughes, Russell, & Patterson, 2005; Houston, 2019), a view in which there is no other role available than either being "victims of their malfunctioning bodies" or merely undergoing oppressive flows (Shakespeare, 2000, p. 162).

Research that voices the lived sexual experiences and desires of women with SCI and positions them at the intersection of and in intra-action with matter and normative practices (about gender, sex, bodily pleasure, disability, etc.) remains scarce (Kafer, 2003). This absence within the scarcity of qualitative research addressing the sexual well-being of women with a chronic injury in general—especially in the context of a growing focus on pleasure in research about sexuality and embodiment—is unacceptable as this ever-growing minority is likely to encounter many barriers in experiencing intimacy and their body as a source of pleasure.

This PhD-project entails an in-depth, contextualised exploration of how women with spinal cord injury (SCI) relate to their body and the manoeuvrability that they experience to have when it comes to pleasurable and satisfactory intimacy with one's self and other(s) through one's body. It is a qualitative inquiry that focuses not only on what it 'means' for participants to live with a changed body, but rather on how re-exploration journeys of their body as pleasure can close and open up in interdependence with the people around them, with the discourses they are exposed to and intra-act with, and with the materiality of their lives.

Two research questions, which are addressed in all chapters to varying degrees, are helpful to stay focused:

> (1) How do women perceive their sexual experiences and well-being, i.e., their lived experience of their bodies and intimate relationships in the past, present, and future, to have changed after acquiring SCI?
>
> (2) How are their views affected by material-discursive practices around sex and bodies enacted by the women themselves and their environment?

In short, the research brings us some insights about material and discursive challenges to feel and be sexual and to experience the body as pleasure, based on lived stories of women with spinal cord injury that serve as a "window on the social" (Thomas, 1999, p.75). This dissertation is not to be understood as a universally-applicable template of "what it means to live as a woman with spinal cord injury" or as a text about some distant "other". Rather, it contributes to knowledge about what can create blockages and openings in the search of women with SCI for intimate and bodily pleasure and serves as "a potential site for collective reimagining" (Kafer, 2013, p. 9).

The method of knowledge making/gathering that was used in this PhD-project could probably best be described as auto/ethnographical. The dissertation reflects a process of constantly zigzagging between participants' stories and my own experiences on the continuum from ethnography to autoethnography (Denzin, 1997). Data gathering methods aimed to provide the participants with different routes or opportunities to reflect on their experiences of the bodies in/with/through which they live and on their intimate relationships in the past, present, and (what they expect and hope for the) future, sometimes resulting in a transformation of their sense of self and their bodily expression potential.

After ethical approval, three data gathering rounds were organised between April 2015 and March 2017. The first round involved in-depth individual life story interviews with ten women with traumatic spinal cord injury and explored the meaning of sexuality throughout their life and how these meanings evolved in relation to their environment. These life story interviews all evolved from one main question: “Could you please tell me your life story with a focus on your development of relationships and sexuality?”. To foster the conversation participants were also asked to bring an “object that marked” for them “an important stage or moment in their relational or sexual development”. In all interviews, the spinal cord injury was the turning point between a past of satisfying sexual experiences and a present dominated by a changed, psychological and physical labour-consuming body. The interviewees meandered around how they saw and lived with their bodies and what was not anymore and would never be, but seldom talked about recent experiences of bodily pleasure.

These findings led to a second data gathering round that aimed to create a context for re-encountering their body in which four women with SCI participated. Encounters were arranged as ‘on-the-road’ conversations during body-centred activities with a self-chosen friend (“a person with whom you feel you can discuss your body and desires”) including searching for clothes/accessories just outside their comfort zone with a stylist, make-up session, and photoshoot aiming at dynamic pictures; and follow-up joint interviews. These activities led organically towards discussing embodiment of difference, embodiment of femininity, struggles in maintaining ownership of their body, and how both SCI and body-centred work had changed their relationship with their bodies and their perceived possibilities to achieve intimacy and sexual pleasure.

The third round of encounters was a focus group discussion—with the four women with SCI from the second gathering round—about the preliminary findings of an inductive thematic analysis of the stories that were shared throughout the doctoral research. The focus group discussion was centred around topics such as sexuality as a journey, SCI as life changing, disownment of the body and the chastity belt as a metaphor for feeling (sexually) blocked.

The autoethnographic parts were fuelled by, alongside the encounters with research participants, two experiences. First, I became a "vulnerable observer" (Behar, 1996) during a one-month internship at a rehabilitation centre in Flanders, which started as a participatory observation (them), but turned into an observing participation (us). Second, I became more conscious of the process of becoming a woman feeling more free to move during a dance project that triggered me to work with and reflect on my own body as a research site.

Throughout data gathering, analysis, and presentation, I have aspired to stay in the lines of "an ontology of becoming(s) rather than being" (Deleuze & Guattari, 1987; paraphrased in Braidotti, 2010, p. 5-6). That is, I endeavoured to approach the women's meaning-making and embodied experiences of intimate relationships and sexuality as well as of their body as complex and never final. Phenomenology—and more specifically interpretative phenomenology (Smith, Flowers, & Larkin, 2009) and post-intentional phenomenology (Vagle, 2014)—was used as a method of analysis and as a way to enable me to both ground my inquiry in the life world of the women I have worked with and, on a broader level, take into account the material-discursive practices at work.

Chapter Overview

Chapter One, *General introduction*, outlines the research project. It starts with a plead for thinking and acting beyond binaries in human embodiment yet also underscores the necessity to acknowledge the history-continuing-into-the-present of neglect of sexuality when covering disability and of disability when covering sexuality in research, healthcare, media, education. It sets the scene for researching sexuality and living with SCI by outlining research trends about the "technically" sexual body (research focusing on the impact of physical deficits on sexual functioning) and the "lived" sexual body (research focusing on the social relational context in which sexuality is shaped and practiced; how individuals' space to freely express themselves sexually is restricted through processes of dis/ableism). It also outlines theoretical contexts (including sexual script theory, the postmodern shift in Disability Studies, New Materialism) and methodological choices, as well as participant information.

In Chapter Two, *Encounters with the white coat: Confessions of a sexuality and disability researcher in a wheelchair in becoming*, I reflect on my own becoming during fieldwork in a Flemish rehabilitation hospital: a context where I was surrounded by people with supposedly “broken” bodies (Shildrick & Price, 1996), and in which implicit attitudes held by myself and others towards bodily difference became visible (and tangible for me). The chapter is an auto/ethnographic portrait of my own becoming of a vulnerable observer. The discovery of a research practice of playfulness and wandering with participants as peers in humanity is central. It is a practice that I have embraced fully and continued to experiment with throughout further data gathering encounters.

Chapter Three, *"So I made this click not to look at a guy that way ever again": About desexualisation, disownment, yet also rethinking possibilities of a young woman(‘s body)*, revolves around how the presence, persistence, and permeability of normativities can influence sex- and body-related thoughts, feelings, and motivations to act or not to act; the need for obvious alternatives to expand manoeuvrability; and the fragility of imagination. The chapter presents an exploratory phenomenological analysis of a young woman with a spinal cord injury’s becoming-in-the-world as a person with a physiologically “broken body” (Shildrick & Price, 1996). Over the course of three in-depth interviews, the young woman initially frames sexuality as not practical, as not a self-explanatory aspect of living as a woman with SCI, and as not a priority, but she confirms to still long for and desire intimate connection. The chapter shows how a body and the person living in/with it can become something to be contained and managed physically, medically, aesthetically, socially, and psychologically to such an extent that the body becomes desexualised and the person (sexually) voiceless. But the data gathering moments also revealed that encounters with alternative ways of living may challenge naturalised boundaries and may carry in it the potential for acts of resistance against desexualisation and sexual silencing. The themes that most clearly illustrate the dynamic and intra-active nature of this one participant's (self-)(de)sexualisation were: (1) (ab)normalising the body and (dis)ownment of body and life through medicalisation, and (2) the naturalisation and persistence of normativities in social encounters that feed into one's positioning of one's self as a(n) (a)sexual being and into one's perceptions of what is possible, socially appropriate, and imaginable when it comes to experiencing sexual pleasure and intimacy. These two themes also returned in the encounters with the other participants of this dissertation.

In Chapter Four, *Retouching and revisiting the strangers within: An exploration journey on the waves of meaning and matter in dance*, I disentangle how the experiences of my be(com)ing a woman feeling free to move smoothly in and with my body and free to express myself intimately were developing, and how these experiences were unmade and re-made through the intra-action of matter, movement, and the meanings I had come to give to my body and encounters with others. It is an autoethnographic chapter exploring the value of research data based on working with materiality on top of and alongside the value of language in the search for knowledge about bodies and bodily relationships. It explores how (working with) matter can transform living in, with and through a body, and how it affects and is affected. The text is centred around 'touchpoints', i.e., encounters through touch, as experienced by myself as a dancer on wheels, and diffracted and narrated through poetry and stills of moving images interwoven with theory. These encounters are seen as mo(ve)ments in an assemblage that holds both danger and transformative possibilities.

Chapter Five, *Flowing desires underneath the chastity belt: Sexual re-exploration journeys of women with changed bodies*, submerges the reader intimately in a bath of desires and questions—both told and untold. It is mainly based on the glimpses of life shared in the individual life story interviews, body-centred fieldwork, and the focus group discussion with four women with SCI. All these qualitative data gathering efforts were analysed by drawing on post-intentional phenomenology and plugging in the concepts of containment and sexual and intimate pleasure as becoming. The chapter explores participants' desire for sexual pleasure within their wider search for the intimate (re)exploration of their changed and vulnerable bodies and digs into the potential scope for manoeuvres they recounted to experience in their journey of rehab(il)itation of their own body. It aims to rethink how bodies and material-discursive practices around sexuality, touch and (health)care as well as women's 'own' meaning-giving of sexual pleasure and their body may (not) contribute to bodily pleasure and frame their seeking and experience of sexual pleasure. The chapter is written as a monologue in polyphony, asking the reader to imagine a woman, blending the words of participants with those of a fictional narrator who makes comments and asks questions based on the analysis, and starting and ending with a fictionalised autoethnographic account. The format is a conscious experiment of reporting qualitative research in such a way that it finalises neither research participants and their experiences nor the flows that potentially become bindings, i.e., it tries to present people and the assemblages of intimacy they are part of as continually in a state of movement and becoming. Every woman has multiple lines of thought about their body, pleasure, and sexuality; the women featuring in my research are simultaneously diverse within themselves and among each other *and* are affected by normativities and longing for belonging and for being desired that trigger touchpoints with any reader.

Chapter Six, *(In)Conclusions*, offers some conclusions without finalising either the voices and experiences of the women with SCI who participated in the research or the findings that were discussed. It hints at potential knots and openings in re-encountering bodies that were different from before—and that were labelled as dysfunctional by Western medicine—, and it tentatively explores what these processes tell about our collective (ideas about) chronic conditions. It also offers some pathways for taking up response-ability for everyone involved, including (wo)men with SCI or other different bodies from before, partners, researchers, support practitioners, and people acting beyond these professions.

Manoeuvring in the Dark: Main Findings

The PhD has become a project about moving within and beyond the realms of conditioning and extending the scope of *imaginative manoeuvrability* in intimate spaces. *Imaginative manoeuvrability* refers to the potential we (experience to) have to move and participate in intimacy and pleasure through one's body, in spaces created by ourselves yet always in intra-action with the materiality and discursive practices about sexuality, (dis)ability, desirability, pleasure that we are exposed to in our lives. Whereas the focus of the Phd-project remained on the participants' lived experiences of movement and captivity, I also explored how the women's felt potential for manoeuvres did not stand on its own but was challenged and assembled by the material and discursive flows streaming underneath their (re)search towards intimacy and pleasure through their body. The "darkness" in the manoeuvres of the dissertation title hints at the not-knowing—stemming from the unanswered and/or unheard and/or unasked questions about their body that the women did or did not have—alongside the private nature of (re-exploring) sexuality and the body as (a source of) pleasure, still often hidden in the realms of one's thoughts and bedroom walls.

The changed materiality of the body after acquiring spinal cord injury is discussed as a turning point in experiences of the body as (a source of) pleasure and of intimate fulfilment. Sexuality was generally less explicitly present in participants' lives than before their injury and was evaluated as different—and different as less satisfying for themselves and/or their partners—, but they emphasised to still desire intimacy, being physically close to their partner and emotionally connected, and longed for touch, sleeping together, feeling attractive, etc. The chastity belt was put forward as a metaphor for the challenges to achieve intimate fulfilment with a body that felt different from before (or could not be felt anymore at all), that moved differently (or did not move anymore, or uncontrollably), and looked different (or with less perceived options to manipulate appearance). The feeling of wearing a chastity belt was mainly linked to a body that required emotional and physical labour in their lives and thus was omnipresent yet did not feel completely theirs anymore due to being different from what they had become used to before their injury and due to necessary daily assistance. Intimacy was described as something calculated, reasoned, planned, and less spontaneous, rather than a space to re-explore pleasure.

The re-exploration of pleasure through the body and the fuelling of sexual desire are challenged by material and discursive practices or flows that affect the women's relationships towards (living with) their body and that risk tightening the chastity belt. Three of these flows are described yet not strictly defined as they work together: cure and care practices, standardising sexual and bodily pleasure, and intersecting gender roles.

The *cure and care practices* are characterised by a focus on protection, preventing further bodily deterioration, controlling damage, looking after. While this perspective on the body is not inherently harmful in itself, it carries the risk of minimising (wo)men's feeling able to be sexual and to see the(ir) body as a potential source of pleasure and creation. The cure and care practices are performed by healthcare professionals, close others and the women themselves, and—over time—permeate encounters with their bodies and becomes so natural that the impact on one's relationship with one's body, one's sexual self, and one's romantic/sexual partner is rarely questioned or challenged. The medical(ised) body is present not only in the language of participants and their environment, but also in the materiality of their lives: i.e., clinically designed bathrooms and bedrooms, neatly timed body management by healthcare professionals with limited flexibility, clothes chosen for their practicality rather than aesthetics, and sofas too high to get on without help from a partner.

The re-exploration of sexuality and bodily pleasure was also affected by participants' own (pre-SCI) internalised expectations about when, where, how, and to what goal to have sex and their meaning-making of satisfying sexual and bodily pleasure built up throughout their life history. These *standardised* expectations reflected the performance-oriented and genital-focused approach to sex that is widespread in Western society, i.e., the restriction of sex to penetration with explosive sensations preferably leading up to simultaneous orgasm, with a climax as necessary for satisfaction, the best sex as arising spontaneously, full of initiative of independently functioning and/or fit partners (Tepper, 2000; Dune & Shuttleworth, 2009), or what could be called *the chronic condition of being sexual in a world where sex is highly yet often invisibly normed and regulated*. The confrontation with the inability to comply with these *normative demands of sexual performance* and sensations that once were within reach feeds feelings of being overly abnormal or insufficient to be recognised as a sexual being and viable satisfyingly sexual partner by (potential) sexual partners as well as feelings of being at loss, of not knowing how to move and manoeuvre in existing intimate spaces and how to create new, non-normative pathways.

Intersecting with these flows-potentially-becoming-bindings is the highly *gendered* intimate labour performed daily by the women. This intimate labour can be emotional (e.g., focusing on what they can give rather than receive in terms of pleasure, or as care receivers taking up a subordinate position both in romantic/sexual relationships and towards healthcare professionals), mental (e.g., managing time and negotiating priorities), and physical (e.g., hiding body parts affected by muscle atrophy, perform actions to look more feminine and/or less disabled—two categories difficult to reconcile for some). Much of this labour is shaped by or "rooted in their social and political positioning as disabled people and—as with the motivations of non-disabled heterosexual women—by normative notions of womanhood, femininity and (hetero)sexuality" (Liddiard, 2014, p. 125).

The entanglement of the lines of thought and touch described above and how the women and their close others engage with them, fuel (de)sexualisation of one's body and either give or draw away space and oxygen for desire to develop and grow, be it specifically sexual desire or more general desire to explore one's body for pleasure and as a source of pleasure. The risk resides in the fact that flows-potentially-becoming-bindings can be present every day, minute, second of people's lives yet remain barely noticeable as they have become so natural, unless they are questioned. The more affected by these flows, the more distant and abnormal that the (search for) expression of sexuality and the experience of the body as (a source of) pleasure becomes for the women and the people they are surrounded by (including romantic/sexual partners and people who move and work with the women outside the context of romance and sexuality), and the more challenging it becomes to manoeuvre in intimate spaces—intimate yet shaped by external-becoming-internal flows that are not inviting to experiment, desire, and imagine differently.

Re-exploration of the body involves looking into the desires that are flowing underneath the "ability" which one is "craving for" and "attached to" and which "contributes to the formation of internalised ableism … an *eternal insufficiency*" (italics in original; Campbell, 2019, p. 8). It involves stirring all the possible components in the assemblage of intimacy, despite the tension with the normalities of the past (pre-SCI and post-SCI). It involves rolling to the edges of one's framework of what satisfying sexual encounters and the body as pleasure can be.

The women's re-exploration of their potential for pleasure and satisfaction was fuelled through encounters with people who were approaching intimacy and sexual pleasure differently and with whom they could (partly) identify, by communicating about both grief and desires as fully legitimate topics with their partners and healthcare professionals, by creating physical contexts that facilitates intimacy and experiencing the body as pleasure, by questioning where shame and discomfort comes from, by becoming more confident about performing ownership of their body, etc. Most notably through it all, participants expanded their manoeuvrability with minor-yet-impactful physical or imaginative actions both directly or less obviously related to sexuality performed by themselves and simultaneously in relation to the material-discursive world around them.

Re-Creating Stories: Research and Support Practices

For future research, I recommend allowing multiplicity. Multiplicity in who participants are. Multiplicity in how a researcher can relate to participants. Multiplicity in what can be "data". For instance, how can body work—any activity drawing on the body that helps one to get to know more than one thinks one knows—be put to use, alongside language, as a research and re-exploration tool? Multiplicity in how research can be analysed and shared. Studying lived experiences of sexuality and intimate pleasure of women with SCI should not just be research about a medical problem, or as just a social problem brought about by normative/normalising practices around sexuality, body, gender, age, ability, economy etc., as all flows create multiple and intersecting levels of barriers, oppression and injustice, amplifying each other, and affecting these women's experiences and imaginative manoeuvrability. How to approach participants' stories and pass them on in ways that respect the fluidity, temporality, layeredness of the story tellers' experiences; i.e., the dynamics of being human?

In healthcare practices more awareness is needed about their power, both in shaping meaning-giving to the disabled body and in opening up what can be done when much seems lost. Sexuality and the body as pleasure are too easily assigned to a colleague's response-ability, and it should be questioned what the consequences are of this splitting of response-abilities in care. Furthermore, the question is not *whether* people can still have pleasurable and satisfying intimate lives, but *how*. Still too often, people are left alone with the task to find out what sexuality and bodily pleasure can be(come). The research findings suggest that openings in imaginative manoeuvrability can be created. Firstly by approaching intimacy as an assemblage that stretches far beyond neurological (dis)functioning. Secondly becoming more conscious of the naturalised routines in support practices (which, besides care provision, involve, trigger, or touch upon privacy, shame, (not) allowing femininity, exposure, vulnerability, defenselessness, uncertainty, etc.). Thirdly by envisioning rehab(il)itation as a process towards regaining ownership of a changed body and exploring new bodily encounters. A process where the focus is not on achievement but on questioning (internalised) social conditioning and re-writing sex-, body-, and intimacy-related definitions. This can be done, among others, through making sexuality and bodily pleasure more accessible as a conversation topic (with special attention for conversations with other women with SCI) and as an activity.

Diversions from normative corporeality drive us to ask what we desire and how we desire it, exactly because they have the potential to destabilise what we think of as normal. For all people involved, this dissertation has been a carefully constructed yet simultaneously vulnerable project of stuttering, wandering and wondering, driven by the intention to create open spaces to discuss and learn from encounters with and through the body.

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Appendix 2

Nederlandse samenvatting

Inleiding tot het onderzoeksproject

Seksuele activiteit en intimiteit die voldoening geven, zijn volgens talrijke onderzoeken van vitaal belang voor romantische relaties en persoonlijk welzijn, alsook voor het aanwakkeren van gevoelens van connectie, voor het gevoel van ergens thuis te zijn, en voor de aanvaarding van zelf en ander (Shakespeare, 2000; Shildrick, 2013). Seksuele gezondheid wordt dan ook beschouwd als een integraal component van het recht om de hoogst mogelijke gezondheidsstandaard te genieten (WAS, 2008, p. 2) en zou in principe moeten erkend en gepromoot worden voor iedereen (WHO, 2015). Mensen die echter niet voldoen aan (onbereikbare) standaarden voor een sociaal gepast en voldoening gevend seksleven (waaronder een lichaam en gedachtegangen zonder gelabelde beperkingen, heteroseksuele oriëntering, een strikte visie op vrouwelijkheid vs. mannelijkheid, jeugdigheid, huidskleur, onafhankelijkheid), worden vaak niet gezien als 'seksuele subjecten' in onderzoek, onderwijs, media, en de zorgsector (Shildrick, 2004, p. 1; Tepper, 2000).

Deze ontkenning van seksualiteit of seksuele aantrekking lijkt van toepassing op vrouwen met een ruggenmergletsel. Hoewel zij dezelfde verlangens en behoeften hebben naar seksualiteit en intimiteit als vrouwen met een (tijdelijk) perfect functionerend lichaam, wordt hun 'seksuele subjectiviteit' minder (h)erkend. Als hun lichamen deel uitmaken binnen onderzoek, dan is dat vooral om het neurologisch functioneren te gebruiken als quasi-experimentele casussen om de link tussen seksueel functioneren en welzijn en het zenuwstelsel beter te begrijpen. In de context van dergelijk onderzoek hebben studies aangetoond dat vrouwen met een ruggenmergletsel een significant lager lichaamsbeeld neigen te hebben alsook een lager seksueel zelfvertrouwen en lagere seksuele voldoening (Beckwith & Yau, 2013; Moin, Duvdevany, & Mazor, 2009).

Voor dit lager lichaamsbeeld, seksueel zelfvertrouwen en voldoening kunnen enerzijds verklaringen worden gezocht in onderzoek met een focus op neurologisch functioneren, dat kijkt naar de obstakels die worden veroorzaakt door fysieke beperkingen. Dit soort onderzoek versterkt echter een gemedicaliseerde en performance-georiënteerde kijk op seksualiteit en voedt zorgverleningspraktijken die—van zodra revalidatie en medische interventies hun limieten hebben bereikt in het repareren en modificeren van het lichaam—niet meer kunnen bijdragen aan (de her-verkenning van) seksuele expressie en plezier (Tepper, 2000). Anderzijds is er onderzoek, vooral aangestuurd door Disability Studies en andere studies in social justice, dat kijkt naar de beperkende impact van sociale, culturele, en andere omgevingsfactoren op de ontwikkeling van seksuele identiteit en mogelijkheden voor seksuele expressie. Dit soort onderzoek loopt het risico omgekeerd essentialistisch te zijn. Dit door enerzijds het verwaarlozen van de mogelijke impact van leven met fysieke beperkingen en ongemakken op seksualiteit. Anderzijds door het gebruiken van het brede concept "beperking" of "disability" om mensen te groeperen (vanuit de veronderstelling dat deze mensen onderling dezelfde visies, ervaringen en prioriteiten hebben) en het vergelijken met een al even gegeneraliseerde groep mensen zonder beperkingen, met binaire data en conclusies tot gevolg. Beide onderzoekstendenzen geven aanleiding tot een essentialistische en deterministische kijk op leven met een lichaam dat vaak wordt beschouwd als onbegeerbaar op het vlak van "fysiek, cultureel en sociaal kapitaal" (vertaling van Hughes, Russell, & Patterson, 2005; Houston, 2019); een kijk waarin geen andere rol mogelijk is dan die van "slachtoffer van slecht-functionerende lichamen" of "slachtoffer van een onderdrukkende maatschappij" (Shakespeare, 2000, p. 162).

Onderzoek dat de doorleefde seksuele ervaringen en verlangens van vrouwen met een ruggenmergletsel laat horen en hun verhalen plaatst op het kruispunt van materie en normatieve praktijken (betreffende gender, seksualiteit, lichamelijk plezier, beperking, etc.) blijft beperkt (Kafer, 2003). Deze leegte binnen kwalitatief onderzoek rond seksueel welzijn bij vrouwen met een chronische aandoening in het algemeen—en bovendien in de context van groeiende aandacht voor plezier in onderzoek naar seksualiteit en lichamelijkheid—is onaanvaardbaar, aangezien er voor hen vele barrières zijn om intimiteit en hun lichaam als bron van plezier te kunnen beleven.

Dit doctoraatsproject omhelst een diepgaande verkenning van hoe vrouwen met een ruggenmergletsel zich verhouden tot hun lichaam en de manoeuvreerruimte die ze ervaren om via hun lichaam te kunnen komen tot voldoening gevende intimiteit met zichzelf en anderen. Het is een kwalitatief onderzoeksproject dat niet enkel aandacht besteedt aan wat het "betekent" voor participanten om met een veranderd lichaam te leven, maar vooral focust op hoe de her-ont-moeting en verkenning van hun lichaam als plezier kan openen of afremmen in samenspel met de mensen rondom, de materialiteit van hun lichaam, en de verschillende materieel-discursieve praktijken waaraan ze worden blootgesteld en waarmee ze aan de slag gaan (o.a. betekenisgevingen rond lichamelijk plezier, begeerlijkheid, intimiteit, aanraking, beperking, zorg, etc. overgedragen in taal en handelingen).

Twee onderzoeksvragen lopen doorheen alle hoofdstukken:

> (1) Hoe beleven vrouwen de evolutie van hun seksuele ervaringen en welzijn (i.e., hun doorleefde ervaring van hun lichaam en intieme relaties in het verleden, het heden, en de toekomst) als veranderd sinds het verkrijgen van hun ruggenmergletsel?
>
> (2) Hoe hangen hun belevingen samen met materieel-discursieve praktijken rond seksualiteit en het lichaam—praktijken uitgevoerd door henzelf en hun omgeving?

Op basis van doorleefde verhalen van vrouwen met een ruggenmergletsel brengt dit onderzoek inzicht in materiële en discursieve uitdagingen om zich seksueel te kunnen voelen en uitdrukken, alsook om het lichaam te kunnen beleven als (bron van) plezier. Het is niet de bedoeling om een universeel toepasbaar sjabloon te creëren over "wat het betekent om te leven als een vrouw met een ruggenmergletsel" of over een ver verwijderde "ander" te spreken. Dit proefschrift draagt bij tot kennis over potentiële obstakels en openingen in de zoektocht van vrouwen met een ruggenmergletsel naar intiem en lichamelijk plezier, en dient als een “potentiële site voor collectieve her-verbeelding” (vertaling van Kafer, 2013, p. 9).

De methode van kennis verzamelen in dit project was auto/etnografisch. Het proefschrift traceert een proces van continu zigzaggen tussen de verhalen van participanten en mijn eigen ervaringen op het continuüm van etnografie naar auto-etnografie (Denzin, 1997). De verschillende ontmoetingsrondes met participanten hadden als doel hen verschillende routes of gelegenheden aan de bieden om te reflecteren over het lichaam waarin en waarmee ze leven en over hun intieme relaties in het verleden, het heden, en (wat ze denken en hopen voor) de toekomst. Soms resulteerde dit in een transformatie van hoe ze zichzelf en lichamelijkheidsbeleving benaderden.

Na ethische goedkeuring werden er drie dataverzamelingsrondes georganiseerd tussen april 2015 en maart 2017. De eerste ronde omvatte individuele diepte-interviews met tien vrouwen met een traumatisch ruggenmergletsel, met aandacht voor seksualiteitsbeleving doorheen hun leven en hoe hun betekenisgeving evolueerde in relatie met hun omgeving. Deze levensverhalen begonnen vanuit één vraag: “Kan je me je levensverhaal vertellen met een focus op de ontwikkeling van relaties en seksualiteit?” Om de conversatie toegankelijker te maken werden de participanten gevraagd om een object mee te nemen dat voor hen “een belangrijke fase of moment in je relationele of seksuele ontwikkeling markeerde”. In de meeste interviews werd het verkrijgen van het ruggenmergletsel aangehaald als markeerpunt tussen een verleden van voldoening gevende seksualiteitsbeleving en een heden gedomineerd door een veranderd lichaam dat psychologisch en fysiek werk vereiste. Er werd vaak gemeanderd rond hoe de vrouwen hun lichamen zagen en beleefden en wat er niet meer is en nooit meer zou zijn. Schaarser waren recente ontmoetingen met lichamelijkheid in haar potentieel tot plezier.

Deze bevindingen leidden tot een tweede verzamelingsronde met als doel om contexten te creëren waarin vrouwen hun lichaam konden her-ont-moeten. Vier vrouwen met een ruggenmergletsel namen hieraan deel. Er werden lichaamsgecentreerde activiteiten georganiseerd met een zelfgekozen vriendin (“een persoon waarmee je kan praten over je lichaam en verlangens”), waaronder het zoeken naar kledij en accessoires juist buiten de comfortzone met een styliste, een make-up sessie, een fotoshoot met als opzet dynamische foto’s, en opvolgingsinterviews. Deze activiteiten leidden organisch tot het bespreken van belichaming van verschil, belichaming van vrouwelijkheid, worstelingen in het behouden of uitdrukken van eigenaarsschap van het lichaam, en hoe het ruggenmergletsel en lichaamswerk het potentieel hadden om hun relatie met hun lichaam te veranderen alsook de mogelijkheden die ze ervoeren om intimiteit en seksueel plezier te beleven.

De derde ronde van ontmoetingen omvatte een focusgroepdiscussie—met de vier vrouwen met een ruggenmergletsel van de tweede ronde—over de inductieve thematische analyse van alle verhalen die werden gedeeld tijdens het doctoraatsonderzoek. Het groepsgesprek centreerde zich rond seksualiteit als een ontdekkingstocht, een ruggenmergletsel als levensveranderend, onteigening van het lichaam en de kuisheidsgordel als metafoor voor het (seksueel) opgesloten voelen.

De auto-etnografische component van het onderzoek werd aangevuurd door twee gebeurtenissen naast ontmoetingen met onderzoeksparticipanten. In een eerste gebeurtenis werd ik een “kwetsbare observator” (vertaling van “vulnerable observer”; Behar, 1996) tijdens een stage van een maand in een Vlaams revalidatiecentrum. Wat in die stage begon als participerende observatie (zij) mondde uit in observerende participatie (wij). In een tweede gebeurtenis, zo halfweg mijn onderzoekstraject, bevond ik mezelf in een dansproject van vijf maanden dat me aanzette om met mijn lichaam te gaan werken als onderzoekssite en waarin ik reflecteerde over vrijer worden om te bewegen als vrouw.

Doorheen de verzameling, analyse en presentatie van doorleefde verhalen heb ik geprobeerd om een ontologie van “worden” eerder dan “zijn” te volgen (Deleuze & Guattari, 1987; geparafraseerd in Braidotti, 2010, p. 5-6). Ik probeerde de betekenisgeving en belichaamde ervaringen van de vrouwen omtrent intieme relaties en seksualiteit en hun lichaam steeds te benaderen als complex en nooit statisch, als altijd in wording en nooit allesomvattend. Fenomenologie—en meer specifiek interpretatieve fenomenologie (Smith, Flowers, & Larkin, 2009) en post-intentionele fenomenologie (Vagle, 2014)—werd gebruikt als analysemethode en als een manier om zowel mijn onderzoek te gronden in de belevingswereld van de vrouwen waarmee ik werkte als om op een breder niveau te kijken naar de materieel-discursieve praktijken die mee speelden.

Overzicht van de hoofdstukken

Het eerste hoofdstuk, *General introduction*, contextualiseert het onderzoeksproject. Het start met een pleidooi om te denken en te doen voorbij binariteiten in menselijke lichamelijkheid terwijl het ook de noodzaak onderstreept om het verleden-dat-doorleeft-in-het-heden te erkennen: een verleden van verwaarlozing van seksualiteit wanneer er werd gesproken over disability en van disability wanneer er werd gesproken over seksualiteit in onderzoek, zorgverlening, media, onderwijs. Het schetst onderzoekstendenzen over het 'technisch' seksuele lichaam (onderzoek dat focust op de impact van lichamelijke schade op seksueel functioneren) en het 'beleefde' seksuele lichaam (onderzoek dat focust op de sociaal-relationele context waarin seksualiteit wordt gevormd en uitgedrukt; hoe de ruimte waarin individuen zich vrij kunnen uitdrukken op seksueel vlak kan worden beperkt door processen van dis/ableisme). Het bespreekt ook kort enkele theoretische kaders (zoals seksuele scripts, de postmoderne richting in Disability Studies, New Materialism) en methodologische keuzes, en informatie over de vrouwen die hebben meegewerkt aan het onderzoek.

In het tweede hoofdstuk, *Encounters with the white coat: Confessions of a sexuality and disability researcher in a wheelchair in becoming*, reflecteer ik over mijn eigen worden van een kwetsbare observator tijdens mijn exploratief veldwerk in een Vlaams revalidatiecentrum: een context waarin ik werd omringd door mensen met zogenaamd "gebroken" lichamen (Shildrick & Price, 1996) en waarin impliciete attitudes van mezelf en anderen naar lichamelijk verschil zichtbaar en tastbaar werden. Centraal staat het ontdekken van een speelse onderzoekspraktijk die draait rond het op pad gaan met participanten als "peers in humanity", als medemensen. Het is een praktijk die ik volledig heb omarmd en waarmee ik ben blijven experimenteren doorheen volgende ontmoetingen met onderzoeksparticipanten.

Het derde hoofdstuk, *"So I made this click not to look at a guy that way ever again": About desexualisation, disownment, yet also rethinking possibilities of a young woman('s body)*, bespreekt hoe de aanwezigheid, hardnekkigheid, en doordringbaarheid van normen een invloed uitoefenen op seks- en lichaamsgerelateerde gedachten, gevoelens en motivaties om te ondernemen of niet, alsook de nood aan duidelijke alternatieven om iemands mogelijkheden tot manoeuvreren uit te breiden, en de breekbaarheid van verbeelding. Er wordt een exploratieve fenomenologische analyse weergegeven van het worden-in-de-wereld als een vrouw met een fysiek "gebroken" lichaam (Shildrick & Price, 1996). In drie diepte-interviews kadert de jonge vrouw op wiens verhalen dit hoofdstuk gebaseerd is haar seksualiteit aanvankelijk als niet praktisch, als niet vanzelfsprekend als vrouw met een ruggenmergletsel en als geen prioriteit. Daarnaast spreekt ze echter ook over het verlangen naar intieme connectie. Het hoofdstuk laat zien hoe een lichaam en de persoon die er in/mee leeft kan worden gevat en beheerst op fysiek, medisch, esthetisch, sociaal en psychologisch vlak in die mate dat het lichaam wordt gedeseksualiseerd en de persoon (seksueel) stemloos wordt. Het toont echter ook dat ontmoetingen met alternatieve manieren van leven genaturaliseerde grenzen kunnen doen wankelen en uitdagen en dus in zich het potentieel dragen voor weerstand tegen deseksualisering en seksueel stemloos worden. In dit hoofdstuk worden twee overkoepelende thema's geïllustreerd die het duidelijkst de dynamische en intra-actieve aard van de (zelf)(de)seksualisering van de betrokken participant betreffen: (1) (ab)normalisering van het lichaam, onteigening van lichaam en leven door medicalisering; en (2) de naturalisering en hardnekkigheid van normativiteiten in sociale ontmoetingen die voeding zijn voor de positionering van zichzelf als (a)seksueel en voor de (eigen) percepties van wat er mogelijk (of sociaal gepast en denkbaar) is op het vlak van seksueel plezier en intimiteit. Deze thema's komen ook terug in de ontmoetingen met andere participanten.

In het vierde hoofdstuk, *Retouching and revisiting the strangers within: An exploration journey on the waves of meaning and matter in dance*, ontwar ik mijn eigen wordingsproces van een vrouw die zich vrijer voelt om te bewegen en uit te drukken in en met haar lichaam. Hoe deze ervaringen voortdurend gemaakt en ont-maakt werden door de intra-actie van materie, beweging en de betekenissen die ik gaf aan mezelf en ontmoetingen met anderen. Dit auto-etnografisch hoofdstuk verkent de waarde van onderzoeksdata gebaseerd op werken met materialiteit bovenop en naast de waarde van taal in de zoektocht naar kennis over lichamen en lichamelijke relaties. Het verkent hoe (werken met) materie transformerend kan zijn voor leven in, met, en door een lichaam, alsook hoe lichamen affecteren en geaffecteerd worden. De tekst is gecentreerd rond "touchpoints" of aanrakingspunten, i.e., ontmoetingen door aanrakingen, ervaren door mezelf als een danser op wielen, en na diffractie verteld aan de hand van poëzie en foto's van bewegende beelden, verweven met theorie. Deze ontmoetingen worden benaderd als bewegingen en momenten in een assemblage die zowel gevaar als transformerend potentieel draagt.

Het vijfde hoofdstuk, *Flowing desires underneath the chastity belt: Sexual re-exploration journeys of women with changed bodies*, dompelt de lezer onder in een bad van verlangens en vragen—ooit of nog nooit verteld. Het is voornamelijk gebaseerd op individuele gesprekken, lichaamsgecentreerd veldwerk en een focusgroepdiscussie met vier vrouwen met een ruggenmergletsel. Deze momentopnames werden geanalyseerd aan de hand van post-intentionele fenomenologie en het inpluggen van concepten waaronder "containment" (in deze context misschien nog het best vertaald als "indamming") en seksueel en intiem plezier als processen "in wording". Het hoofdstuk benadert verlangen naar seksueel plezier als deel van een bredere zoektocht van de participanten naar een intieme (her)verkenning van hun veranderde en kwetsbare lichamen en de manoeuvreerruimte die ze daarin ervaren. Het suggereert hoe lichamen en materieel-discursieve praktijken omtrent seksualiteit, aanraking, en (gezondheids)zorg alsook de ‘eigen’ betekenisgeving van de vrouwen aan seksueel plezier en hun lichaam allemaal bijdragen (of niet) aan het kader en de beleving van lichamelijk en seksueel plezier en hun zoektocht ernaar. Het hoofdstuk is geschreven als een ‘monoloog in meerstemmigheid’ die de lezer vraagt om zich een vrouw voor te stellen, waarna een vermenging volgt van gefictionaliseerde autoethnografische stukken, geselecteerde woorden van participanten, en commentaren en vragen van een fictieve verteller gebaseerd op de analyse. Deze vorm is een bewust experiment in hoe over kwalitatief onderzoek kan worden gerapporteerd zonder dat het materiaal vastgezet wordt: ik zocht dus expliciet naar een manier die noch de onderzoeksparticipanten noch hun ervaringen noch de stromingen waardoor ze worden beïnvloed finaliseert. Met andere woorden: in dit hoofdstuk presenteer ik mensen en de assemblages van intimiteit waarvan ze deel uitmaken als voortdurend in beweging en wording. Elke vrouw heeft meerdere lijnen van denken over haar lichaam, plezier, en seksualiteit; de vrouwen in mijn onderzoek zijn tegelijkertijd divers op zichzelf en onder elkaar *en* ze worden beïnvloed door normativiteiten, verlangens naar erbij horen en verlangens naar verlangd worden die allemaal aanrakingspunten kunnen beroeren bij eender welke lezer.

Het zesde hoofdstuk, *(In)Conclusions*, biedt enkele conclusies zonder de stemmen van de vrouwen die deelnamen aan het onderzoek of de bevindingen te finaliseren. Aan bod komen potentiële knopen en openingen in het her-ont-moeten van lichamen die anders zijn dan vroeger—en die als disfunctioneel worden gelabeld door Westerse geneeskunde— en wat deze processen kunnen vertellen over onze collectieve (ideeën over) chronische aandoeningen. Het biedt ook enkele richtingen aan waarin elke betrokkene kan handelen (en “respons-abiliteit” heeft), inclusief vrouwen (en mannen) met een ruggenmergletsel of andere lichamen dan voorheen, partners, onderzoekers, hulpverleners, en eigenlijk ook iedereen die buiten deze professionele domeinen handelt.

Manoeuvreren in het donker: Bevindingen

Het doctoraat is een project geworden over manoeuvreren in het samenspel van de materialiteit van het lichaam en materieel-discursieve praktijken rond seksualiteit, beperking, begeerlijkheid, plezier, etc. Met het concept *imaginative manoeuvrability* verwijs ik naar de bewegingsmogelijkheden die we ervaren om intimiteit en plezier te beleven met ons lichaam en/of er naar op zoek te gaan. Hoe vrij voelen we ons om te bewegen in en mee te bouwen aan de assemblages waarbinnen we lichamelijkheid beleven? We zouden kunnen spreken over de *imaginaire manoeuvreerruimte* die mensen ervaren op vlak van intimiteit en plezier in lichamelijkheid.

Terwijl het onderzoek voornamelijk gericht bleef op doorleefde ervaringen van beweging en vastzitten, verkende ik ook hoe de manoeuvreerruimte die de vrouwen ervoeren niet op zichzelf (be)staat maar wordt gecreëerd en uitgedaagd door de materiële en discursieve praktijken die hun zoektocht naar intimiteit en plezier door hun lichaam onderstromen. Het "donkere" in het manoeuvreren verwijst o.a. naar het niet-weten (voortvloeiend uit onbeantwoorde, ongehoorde, en/of ongevraagde vragen die vrouwen al dan niet hebben over hun lichaam) en de private aard van (de herontdekking van) seksualiteit en het lichaam als (bron van) plezier, vaak verstopt in gedachten of tussen slaapkamermuren.

De veranderde materialiteit van het lichaam door een ruggenmergletsel werd besproken als een keerpunt in de beleving van het lichaam als (bron van) plezier en van intieme voldoening. Seksualiteit was doorgaans minder expliciet aanwezig in het leven van participanten dan voor ze hun letsel verkregen. Ze evalueerden seksualiteitsbeleving heel duidelijk als 'anders' – anders als minder voldoening gevend voor zichzelf en/of hun partners. Daarnaast benadrukten de vrouwen ook dat ze nog steeds verlangen naar intimiteit, fysiek dicht bij hun partner zijn, emotionele verbinding, aanraking, samen slapen, zich aantrekkelijk voelen, etc. De kuisheidsgordel werd bedacht als metafoor voor de uitdagingen die ze ervoeren om intieme voldoening te ervaren met een lichaam dat anders aanvoelde dan voorheen (of niets meer kon voelen), een lichaam dat anders bewoog (of niet meer bewoog, of oncontroleerbaar bewoog), en een lichaam dat er anders uitzag (of met minder gepercipieerde mogelijkheden om het voorkomen te manipuleren). Het gevoel van een kuisheidsgordel dragen werd vooral geassocieerd met een lichaam dat emotioneel en fysiek werk vereiste in hun levens en dus alomtegenwoordig was, maar desondanks niet volledig van hen voelde doordat het verschilde van wat ze gewoon waren geraakt voor hun letsel en door noodzakelijke dagelijkse assistentie. Intimiteit werd beschreven als iets berekends en gepland en minder spontaan, en minder als een proces of ruimte om plezier te herontdekken.

Zowel de herontdekking van plezier door het lichaam als het aanvuren van seksueel verlangen worden uitgedaagd door materiële en discursieve praktijken die een invloed uitoefenen op de relatie die de vrouwen hebben met (leven met) hun lichaam. Het zijn praktijken die mogelijk de ‘kuisheidsgordel’ nauwer maken, i.e., de ervaring van vastzitten versterken. Drie van deze praktijken of stromingen worden besproken maar niet strikt gedefinieerd aangezien ze samenwerken: herstel- en zorgpraktijken, gestandaardiseerd seksueel en lichamelijk plezier, en doorkruisende genderrollen.

De *herstel- en zorgpraktijken* worden gekenmerkt door een nadruk op bescherming, voorkoming van verdere lichamelijke achteruitgang, beperking van schade, en zorgen voor. Terwijl dit perspectief op het lichaam niet inherent schadelijk is, minimaliseert het mogelijk wel het gevoel dat vrouwen hebben om seksueel te (kunnen) zijn en de mate waarin ze hun lichaam (kunnen) zien als een potentiële bron van plezier en creatie. De herstel- en zorgpraktijken worden uitgevoerd door zorgverleners, nabije anderen en de vrouwen zelf. Geleidelijk aan doordringen deze praktijken ontmoetingen met het lichaam en worden ze zo natuurlijk dat de impact op iemands relatie met haar lichaam, seksuele zelf, en romantische/seksuele partners zelden in vraag wordt gesteld. Het medische en gemedicaliseerde lichaam is niet enkel aanwezig in de taal die participanten en hun omgeving gebruiken, maar ook in de materialiteit van hun leven. Voorbeelden hiervan zijn de klinisch ingerichte en steriele badkamers en slaapkamers, de nauwgezet getimede lichaamsverzorging door zorgverleners met slechts beperkte flexibiliteit, kledij die wordt gekozen om haar functionaliteit eerder dan esthetiek, sofa's die te hoog zijn om te kunnen gebruiken zonder hulp van een partner, etc.

De her-ont-moeting met seksualiteit en herontdekking van lichamelijk plezier worden ook beïnvloed door de betekenisgeving van voldoening gevend seksueel en lichamelijk plezier en de daaraan gekoppelde verwachtingen (over waar, wanneer, hoe en met welk doel seks te hebben) die participanten hebben opgebouwd doorheen hun levensgeschiedenis. Deze *gestandaardiseerde* betekenisgevingen en verwachtingen weerspiegelen de prestatie-georiënteerde en genitaliën-benadrukkende benadering van seks die wijdverspreid is in het Westen, namelijk: de beperking van seks tot penetratie met explosieve sensaties die liefst leiden naar simultane en meervoudige orgasmes, met een climax als noodzakelijk voor voldoening en de beste seks als spontaan, gedreven door initiatief van onafhankelijke partners met een perfect functionerend lichaam (Tepper, 2000; Dune & Shuttleworth, 2009). Dit zou ook kunnen omschreven worden als *de chronische aandoening van seksueel zijn en worden in een wereld waar seks diepgaand maar vaak onzichtbaar wordt genormeerd en gereguleerd*. De confrontatie met de onmogelijkheid om deze normatieve vereisten van seksuele prestaties en sensaties te bereiken (en die ooit wel bereikbaar waren of leken) voeden gevoelens van te abnormaal of niet genoeg te zijn om (h)erkend te worden als een seksueel wezen en mogelijke seksuele partner, alsook gevoelens van verloren zijn, van niet weten hoe te manoeuvreren in bestaande intieme ruimtes en hoe nieuwe, niet-normatieve wegen te creëren.

Doorheen deze praktijken of stromen-die-mogelijk-bindend-worden, zien we ook het *intiem werk* dat dagelijks wordt verricht door de vrouwen en *waarin gender een sturende factor* is. Dit intiem werk is emotioneel (e.g., focussen op welk plezier ze nog kunnen geven veeleer dan ontvangen, zorg ondergaan in een lagere positie in zowel romantisch/seksuele relaties als in interacties met zorgverleners), mentaal (e.g., time management, prioriteiten onderhandelen), en fysiek (e.g., spieratrofie verbergen, bepaalde acties ondernemen om er vrouwelijker en/of minder beperkt uit te zien—categorieën die door sommigen worden gezien als onverenigbaar). Veel van dit soort werk wordt gevormd door of vindt haar "oorsprong in de sociale en politieke positionering van personen met een beperking en—net zoals de drijfveren van heteroseksuele vrouwen zonder beperking—in normatieve conceptualiseringen van vrouw zijn, vrouwelijkheid, en (hetero)seksualiteit" (vertaling van Liddiard, 2014, p. 125).

De verwevenheid van deze lijnen van gedachten en aanrakingen alsook de manieren waarop de vrouwen en hun nabije anderen ermee omgaan, sturen (de)seksualisering van het lichaam en geven of onttrekken ruimte en zuurstof voor de ontwikkeling en de groei van verlangen—of het nu specifiek seksueel verlangen is of een breder verlangen naar het verkennen van het lichaam gewoon voor het plezier of als bron van plezier. Het risico situeert zich in het feit dat deze stromen-die-mogelijk-bindend-worden elke dag, minuut, seconde aanwezig (kunnen) zijn in iemands leven en toch nauwelijks worden opgemerkt omdat ze zo natuurlijk zijn geworden, tenzij expliciet bevraagd. Hoe meer beïnvloed door deze praktijken, hoe verder weg en hoe ongewoner dat (de zoektocht naar) uitdrukking van seksualiteit en de beleving van het lichaam als (bron van) plezier wordt voor de vrouwen en de mensen die hen omringen (inclusief romantische/seksuele partners en mensen die bewegen en werken met de vrouwen buiten de context van romantiek en seks). Hoe meer beïnvloed door deze praktijken, hoe moeilijker het ook wordt om te manoeuvreren in intieme ruimtes—ruimtes die intiem zijn en toch gevormd door externe stromingen die intern worden en die niet uitnodigen om te experimenteren, te verlangen, en anders te verbeelden.

De herontdekking van het lichaam als (bron van) plezier en intimiteit omvat het onder de loep nemen van de verlangens die stromen onder 'de mogelijkheden van het lichaam' waar iemand naar snakt en het benaderen van de randen van iemands denkkader over wat seksueel en lichamelijk bevredigende ontmoetingen kunnen zijn. De herontdekking omvat bewegingen van 'ont-moeten', waarbij wordt losgelaten wat er niet meer kan en wat er 'moet' in het spanningsveld van normativiteiten. Bij de participanten werd de herontdekking van potentieel voor lichamelijke en seksuele voldoening voornamelijk aangespoord door ontmoetingen met mensen waarmee ze zich konden identificeren en die intimiteit en plezier anders benaderden, alsook door het benaderen van zowel verdriet als verlangen als legitieme gespreksonderwerpen met partners en zorgverleners, door het creëren van fysieke contexten die de beleving van intimiteit en lichaam als plezier faciliteerden, door het bevragen van waar schaamte en ongemak vandaan kwam, door meer vertrouwen en vaardigheden op te bouwen om eigenaarsschap van hun lichaam op te nemen, etc. Opmerkelijk is dat (beleefde) mogelijkheden om te manoeuvreren zich uitbreidden door kleine maar krachtige fysieke acties of denkoefeningen die direct of minder expliciet gelinkt worden aan seksualiteit, uitgevoerd door de vrouwen zelf en in relatie met hun omgeving.

Her-creëren van verhalen: Praktijken van onderzoek en ondersteuning

Voor verder(e) onderzoek(ers) wil ik graag pleiten voor het toelaten van multipliciteit. Multipliciteit in wie participanten (mogen en kunnen) zijn. Multipliciteit in hoe een onderzoeker zich kan verhouden tot participanten. Multipliciteit in wat kan tellen als "data". Hoe kan bijvoorbeeld lichaamswerk—elke activiteit die gebruik maakt van lichamelijkheid om tot inzichten te komen—ingezet worden, naast taal, als een instrument en toegangspoort voor onderzoek en her-ont-moeting? Multipliciteit in analyse en delen van bevindingen. Hoe kunnen verhalen worden benaderd en doorverteld op manieren die de fluïditeit, tijdelijkheid, en gelaagdheid van de ervaringen van de verhalenvertellers en dus de dynamiek van het menszijn respecteren? Hoe kan lichamelijkheid benaderd worden vanuit het materiële én het sociale?

In herstel- en zorgcontexten is er meer bewustzijn nodig over de macht van de praktijken die er plaatsvinden, zowel in het bijdragen tot betekenisgeving van het "beperkte" lichaam als in het openen van wat er nog kan wanneer veel verloren lijkt. Seksualiteit en het lichaam als plezier worden te gemakkelijk doorverwezen naar de verantwoordelijkheid en mogelijkheden tot beantwoorden van een collega. De gevolgen van dit opsplitsen van "respons-abiliteit" in de zorg moet in vraag gesteld worden. Bovendien is het niet zozeer de vraag *of* maar *hoe* mensen met een ruggenmergletsel voldoening kunnen beleven in hun intieme levens. Nog te vaak worden mensen alleen gelaten met de opdracht om te ontdekken wat seksualiteit en lichamelijk plezier kan zijn en worden. De onderzoeksbevindingen suggereren dat er meer manoeuvreerruimte kan worden gecreëerd. Ten eerste door het benaderen van intimiteit als een assemblage die verder reikt dan neurologisch (dis)functioneren. Ten tweede door meer bewustzijn van genaturaliseerde routines in herstel- en zorgpraktijken (die naast het verlenen van zorg ook betrekking hebben op privacy, schaamte, (niet) toestaan van vrouwelijkheid (of mannelijkheid), blootstelling, kwetsbaarheid, weerloosheid, onzekerheid, etc.). Ten derde door het hertekenen van revalidatie als rehab(il)itatie. Er moet ingezet worden op rehab(il)itatie als een proces dat stuurt naar het herwinnen van eigenaarsschap van een veranderd lichaam en naar het verkennen van nieuwe lichamelijke ontmoetingen binnenin en verder dan seksualiteit en relaties. Een proces van her-ont-moeten, waar de klemtoon niet ligt op prestatie maar op het bevragen van (geïnternaliseerde) sociale conditionering en het herschrijven van definities van seksualiteit, lichamelijkheid en intimiteit. Dit kan door o.a. het toegankelijker maken van seksualiteit en lichamelijk plezier als een gespreksonderwerp (niet in het minst met andere mensen met een ruggenmergletsel) en in activiteiten.

Verschillen van normatieve lichamelijkheid dragen het potentieel in zich om te destabiliseren van wat er als normaal wordt gezien. Verschillen sporen ons aan om te (her)denken wat we verlangen en hoe we het verlangen. Dit proefschrift was voor alle betrokkenen een voorzichtig geconstrueerd en tegelijk kwetsbaar project van stotteren en dwalen en verwondering, gedreven door de intentie om ruimte te creëren voor het bespreken van en leren uit ontmoetingen met en door het lichaam.

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Appendix 3

Data Storage Management

Data Storage Fact Sheet 1

Name/identifier dataset: Ethnographic field notes

Author: Inge Griet Emy Blockmans

Date: 12/06/2019

1. Contact details

1a. Main researcher

- name: Inge Griet Emy Blockmans
- address: Ghent University, Department of Special Needs Education, Henri Dunantlaan 2, 9000 Gent
- e-mail: Inge.Blockmans@UGent.be

1b. Responsible Staff Member (ZAP)

- name: Geert Van Hove
- address: Ghent University, Department of Special Needs Education, Henri Dunantlaan 2, 9000 Gent
- e-mail: Geert.Vanhove@UGent.be

If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies

* Reference of the publication in which the datasets are reported:

Blockmans, I. G. E. (2019). Encounters with the white coat: Confessions of a sexuality and disability researcher in a wheelchair in becoming. *Qualitative Inquiry, 25*(2), 170–179. https://doi.org/10.1177/1077800417750181

* Which datasets in that publication does this sheet apply to?:
Field notes and notes from participatory observations during fieldwork in

rehabilitation centre (13/01/2015-13/02/2015) and reflection notes after encounters with research participants throughout PhD.

3. Information about the files that have been stored

3a. Raw data

* Have the raw data been stored by the main researcher? [X] YES / [ ] NO

If NO, please justify: /

* On which platform are the raw data stored?
  - [X] researcher PC
  - [ ] research group file server
  - [X] other (specify): back-up on an external hard drive; notes in notebook

* Who has direct access to the raw data (i.e., without intervention of another person)?
  - [X] main researcher
  - [ ] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [ ] other (specify): ...

3b. Other files

* Which other files have been stored?
  - [ ] file(s) describing the transition from raw data to reported results. Specify: ...
  - [ ] file(s) containing processed data. Specify: ...
  - [X] file(s) containing analyses. Specify: Word document with annotated fieldnotes and interpretations; see publication.
  - [ ] files(s) containing information about informed consent
  - [X] a file specifying legal and ethical provisions: Pdf files of approval from Commissie Medische Ethiek UZ KU Leuven (local committee): S57094; Commissie Medische Ethiek UZ Gent (central committee): EC/2014/0809; Ethische Commissie UGent Faculteit Psychologie en Pedagogische Wetenschappen: 2014/40. The documents that were submitted for ethical approval are kept on the individual pc of the main researcher.
  - [ ] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: ...
  - [ ] other files. Specify: ...

* On which platform are these other files stored?
  - [X] individual PC
  - [ ] research group file server
  - [X] other: back-up on an external hard drive

* Who has direct access to these other files (i.e., without intervention of another person)?
  - [X] main researcher
  - [ ] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [ ] other (specify): ...

4. Reproduction

* Have the results been reproduced independently?: [ ] YES / [X] NO

* If yes, by whom (add if multiple):
  - name:
  - address:
  - affiliation:
  - e-mail:

Data Storage Fact Sheet 2

Name/identifier dataset: S1 (Study 1): Audio-recordings and transcripts of qualitative in-depth interviews with 9 women with SCI (21 interviews of 45-90 minutes, 18 of which were transcribed, between April 2015-March 2017).

Author: Inge Griet Emy Blockmans

Date: 12/06/2019

1. Contact details

1a. Main researcher

- name: Inge Griet Emy Blockmans
- address: Ghent University, Department of Special Needs Education, Henri Dunantlaan 2, 9000 Gent
- e-mail: Inge.Blockmans@UGent.be

1b. Responsible Staff Member (ZAP)

- name: Geert Van Hove
- address: Ghent University, Department of Special Needs Education, Henri Dunantlaan 2, 9000 Gent
- e-mail: Geert.Vanhove@UGent.be

If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies

* References of the publications in which the datasets are reported:

Blockmans, I., Van Hove, G., & Enzlin, P. (2017). "So I made this click not to look at a guy that way ever again": About desexualisation, disownment, and rethinking the possibilities of a young woman('s body). *DiGeSt. Journal of Diversity and Gender Studies, 4*(2), 11-31. doi:10.11116/digest.4.2.1

Blockmans, I.G.E., De Schauwer, E., Van Hove, G., & Enzlin, P. (under review). Flowing desires underneath the chastity belt: Sexual re-exploration journeys of women with changed bodies. In Shuttleworth, R., & Mona, L. (Eds.), *Routledge Handbook of Disability and Sexuality*. Routledge.

* Which datasets in these publications does this sheet apply to?:
- audio-recordings of individual interviews (21)
- anonymised transcripts of individual interviews (18)
- informed consent forms

3. Information about the files that have been stored

3a. Raw data

* Have the raw data been stored by the main researcher? [X] YES / [ ] NO

If NO, please justify: /

* On which platform are the raw data stored?
- [X] researcher PC
- [ ] research group file server
- [X] other (specify): back-up on an external hard drive; (the informed consent forms on paper:) locked cabinet at main researcher's office

* Who has direct access to the raw data (i.e., without intervention of another person)?
- [X] main researcher
- [ ] responsible ZAP
- [ ] all members of the research group
- [ ] all members of UGent
- [ ] other (specify): ...

As agreed in the informed consent forms, all recorded conversations can only be shared for the purposes of research and quality evaluation amongst the main researcher, supervisors Prof. dr. Geert Van Hove and Prof. dr. Paul Enzlin, Doctoral Advisory Committee members Prof. dr. Russell Shuttleworth and Prof. dr. Marcalee Sipski Alexander, and the ethical committees, up until the defence of the PhD. After the defence, this information cannot be passed on without the participants' explicit agreement.

3b. Other files

* Which other files have been stored?
- [ ] file(s) describing the transition from raw data to reported results. Specify: ...
- [X] file(s) containing processed data. Specify: transcripts with names/places replaced by participant number/description of person (e.g., "partner") or place (e.g., city, rehabilitation centre).
- [X] file(s) containing analyses. Specify: Word documents with annotated transcripts, with themes and supporting quotes, drafts of papers; see findings sections of publications.
- [X] files(s) containing information about informed consent: The completed informed consent forms of all participants are kept on paper in a locked cabinet of the main researcher's office and will be destroyed five years after the defence of the PhD.
- [X] a file specifying legal and ethical provisions: Pdf files of approval from Commissie Medische Ethiek UZ KU Leuven (local committee): S57094; Commissie Medische Ethiek UZ Gent (central committee): EC/2014/0809; Ethische Commissie UGent Faculteit Psychologie en Pedagogische Wetenschappen: 2014/40. The documents that were submitted for ethical approval are kept on the individual pc of the main researcher.
- [ ] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: ...
- [ ] other files. Specify: ...

* On which platform are these other files stored?
- [X] individual PC
- [ ] research group file server
- [X] other: back-up on an external hard drive; on paper in locked cabinet of main researcher's office.

* Who has direct access to these other files (i.e., without intervention of another person)?
- [X] main researcher
- [X] responsible ZAP
- [ ] all members of the research group
- [ ] all members of UGent
- [ ] other (specify): ...

As agreed in the informed consent forms, anonymised parts of the transcripts as presented in the publications can be used for the purposes of research and social awareness-raising about sexuality and disability. Full transcripts, however, can only be shared amongst the main researcher, supervisors Prof. dr. Geert Van Hove and Prof. dr. Paul Enzlin, Doctoral Advisory Committee members Prof. dr. Russell Shuttleworth and Prof. dr. Marcalee Sipski Alexander, and the ethical committees, up until the defence of the PhD. After the defence, this information cannot be passed on without the participants' explicit agreement.

4. Reproduction

* Have the results been reproduced independently?: [ ] YES / [X] NO

* If yes, by whom (add if multiple):
  - name:
  - address:
  - affiliation:
  - e-mail:

Data Storage Fact Sheet 3

Name/identifier dataset: S2 (Study 2)

Author: Inge Griet Emy Blockmans

Date: 12/06/2019

1. Contact details

1a. Main researcher

- name: Inge Griet Emy Blockmans
- address: Ghent University, Department of Special Needs Education, Henri Dunantlaan 2, 9000 Gent
- e-mail: Inge.Blockmans@UGent.be

1b. Responsible Staff Member (ZAP)

- name: Geert Van Hove
- address: Ghent University, Department of Special Needs Education, Henri Dunantlaan 2, 9000 Gent
- e-mail: Geert.Vanhove@UGent.be

If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies

* Reference of the publication in which the datasets are reported:

Blockmans, I.G.E., De Schauwer, E., Van Hove, G., & Enzlin, P. (under review). Flowing desires underneath the chastity belt: Sexual re-exploration journeys of women with changed bodies. In Shuttleworth, R., & Mona, L. (Eds.), *Routledge Handbook of Disability and Sexuality.* Routledge.

* Which datasets in these publication does this sheet apply to?:
- audio-recordings of conversations during shopping (4 x 90-120 min)/make-up

(4 x 120 min)/photoshoot (4 x 120 min)
- audio-recordings of joint interviews (4 x 120 min)
- anonymised transcripts of conversations during shopping/make-up/photoshoot
- anonymised transcripts of joint interviews
- photographs
- audio-recording of focus group discussion (120 min)
- anonymised transcript of focus group discussion
- informed consent forms

3. Information about the files that have been stored

3a. Raw data

* Have the raw data been stored by the main researcher? [X] YES / [ ] NO

If NO, please justify:

* On which platform are the raw data stored?
  - [X] researcher PC
  - [ ] research group file server
  - [X] other (specify): back-up on an external hard drive; (the informed consent forms on paper:) locked cabinet at main researcher's office; co-researcher Maaike Boonstra (degree of Master in sexology, KU Leuven)

* Who has direct access to the raw data (i.e., without intervention of another person)?
  - [X] main researcher
  - [ ] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [X] other (specify): photographer Cheyenne Dekeyser (photographs); co-researcher Maaike Boonstra (degree of Master in sexology, KU Leuven) (recordings)

As agreed in the informed consent forms, all recorded conversations and photographs can only be shared for the purposes of research and quality evaluation amongst the main researcher, supervisors Prof. dr. Geert Van Hove and Prof. dr. Paul Enzlin, Doctoral Advisory Committee members Prof. dr. Russell Shuttleworth and Prof. dr. Marcalee Sipski Alexander, the ethical committees, Maaike Boonstra, and the photographer, up until the defence of the

PhD. After the defence, this information cannot be passed on without the participants' explicit agreement.

3b. Other files

* Which other files have been stored?

- [ ] file(s) describing the transition from raw data to reported results. Specify: ...
- [X] file(s) containing processed data. Specify: transcripts with names/places replaced by participant number/description of person (e.g., "partner") or place (e.g., city, rehabilitation centre).
- [X] file(s) containing analyses. Specify: Word documents with annotated transcripts, with themes and supporting quotes, drafts of papers; see findings sections of publications.
- [X] files(s) containing information about informed consent: The completed informed consent forms of all participants are kept on paper in a locked cabinet of the main researcher's office and will be destroyed five years after the defence of the PhD.
- [X] a file specifying legal and ethical provisions: Pdf files of approval from Commissie Medische Ethiek UZ KU Leuven (local committee): S57094; Commissie Medische Ethiek UZ Gent (central committee): EC/2014/0809; Ethische Commissie UGent Faculteit Psychologie en Pedagogische Wetenschappen: 2014/40. The documents that were submitted for ethical approval are kept on the individual pc of the main researcher.
- [ ] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: ...
- [ ] other files. Specify: ...

* On which platform are these other files stored?

- [X] individual PC
- [ ] research group file server
- [X] other: back-up on an external hard drive; on paper in locked cabinet of main researcher's office.

* Who has direct access to these other files (i.e., without intervention of another person)?

- [X] main researcher
- [ ] responsible ZAP
- [ ] all members of the research group
- [ ] all members of UGent
- [ ] other (specify): ...

As agreed in the informed consent forms, anonymised parts of the transcripts as presented in the publications can be used for the purposes of research and social awareness-raising about sexuality and disability. Full transcripts, however, can only be shared amongst the main researcher, supervisors Prof. dr. Geert Van Hove and Prof. dr. Paul Enzlin, Doctoral Advisory Committee members Prof. dr. Russell Shuttleworth and Prof. dr. Marcalee Sipski Alexander, and the ethical committees, up until the defence of the PhD. After the defence, this information cannot be passed on without the participants' explicit agreement.

4. Reproduction

* Have the results been reproduced independently?: [ ] YES / [X] NO

* If yes, by whom (add if multiple):
  - name:
  - address:
  - affiliation:
  - e-mail:

Data Storage Fact Sheet 4

Name/identifier dataset: Autoethnographic dance project

Author: Inge Griet Emy Blockmans

Date: 12/06/2019

1. Contact details

1a. Main researcher

- name: Inge Griet Emy Blockmans
- address: Ghent University, Department of Special Needs Education, Henri Dunantlaan 2, 9000 Gent
- e-mail: Inge.Blockmans@UGent.be

1b. Responsible Staff Member (ZAP)

- name: Geert Van Hove
- address: Ghent University, Department of Special Needs Education, Henri Dunantlaan 2, 9000 Gent
- e-mail: Geert.Vanhove@UGent.be

If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies

* Reference of the publication in which the datasets are reported:

Blockmans, I. G. E., De Schauwer, E., Van Hove, G., & Enzlin, P. (2018). Retouching and Revisiting the Strangers Within: An Exploration Journey on the Waves of Meaning and Matter in Dance. Qualitative Inquiry. https://doi.org/10.1177/1077800418809731

* Which datasets in these publications does this sheet apply to?:
- personal observations and interpretations written in personal notebook

- visual footage of training and performance (mp4; compressed and sent to me by the Lecter Media production manager of "Over Winnaars", partly available on youtube as posted by broadcasting company VTM: https://youtu.be/S0DQtOoeLTE)

3. Information about the files that have been stored

3a. Raw data

* Have the raw data been stored by the main researcher? [ ] YES / [X] NO

If NO, please justify:

* On which platform are the raw data stored?
  - [ ] researcher PC
  - [ ] research group file server
  - [X] other (specify): (visual footage:) Lecter Media, VTM

* Who has direct access to the raw data (i.e., without intervention of another person)?
  - [ ] main researcher
  - [ ] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [X] other (specify): (visual footage:) Lecter Media, VTM.

3b. Other files

* Which other files have been stored?
  - [ ] file(s) describing the transition from raw data to reported results. Specify: ...
  - [X] file(s) containing processed data.
  - [X] file(s) containing analyses. Specify: Word documents with annotated stills of the broadcasted dance edition of "Over Winnaars" (partly available on youtube as posted by broadcasting company VTM: https://youtu.be/S0DQtOoeLTE); drafts of papers; see findings section of publication.
  - [ ] files(s) containing information about informed consent.
  - [ ] a file specifying legal and ethical provisions:
  - [ ] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: ...
  - [ ] other files. Specify: ...

* On which platform are these other files stored?
  - [X] individual PC
  - [ ] research group file server
  - [X] other: back-up on an external hard drive.

* Who has direct access to these other files (i.e., without intervention of another person)?
  - [X] main researcher
  - [X] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [X] other (specify): co-authors Prof. dr. Elisabeth De Schauwer, Prof. dr. Geert Van Hove, Prof. dr. Paul Enzlin.

4. Reproduction

* Have the results been reproduced independently?: [ ] YES / [X] NO

* If yes, by whom (add if multiple):
  - name:
  - address:
  - affiliation:
  - e-mail: