(Un)Limited Pleasure: The negotiation of a (sexual) identity by wheelchair users in the Netherlands

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Citation

Voorend, L. (2021). *(Un)Limited Pleasure: The negotiation of a (sexual) identity by wheelchair users in the Netherlands*.

(UN)LIMITED PLEASURE.

The negotiation of a (sexual) identity by wheelchair users in the Netherlands.

Linde Voorend

Interviewing Menko in the field. Photograph by: Myrthe van Herk (2021)

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24 June 2021
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ABSTRACT

Although sexuality and partnership are crucial parts of every human's life, for wheelchair users the desire and need for these aspects of life are often overlooked, ignored, and complicated. This research explores how wheelchair users negotiate their (sexual) identity through sex, dating, and relationships against the background of Dutch society. By making a collaborative documentary, this research produces embodied knowledge about and broadens the view on their lived, multi-sensorial experiences. The collaborative nature of the research positions them as autonomous and sexual agents, contradictory to the paradigm of incapability and dependency performed in society. The research shows that the identities of people in a wheelchair are reduced to their disability which excludes them from the discourse around – and practices of – sexuality and partnership. Against this background, wheelchair users negotiate their (sexual) identity through sexual practices, dating, and relationships. In its goal to debunk assumptions around disability and sexuality, this research argues that the experiences of wheelchair users might help us think more openly about how sexuality and partnership can be defined.

[key words: disability, sexuality, the body, identity, intimacy, partnership, phenomenology, assemblage]

ACKNOWLEDGEMENTS

Without the conversations with Pien van der Veek, this research would not have taken place. I am thankful that, in these conversations, she has sparked my interest in the topic by confiding me with her personal experiences around sexuality and disability and for simply being my friend. Through his supervision, Koen Suidgeest has made sure that I am now able to present the best result I possibly could. His feedback and support have been very valuable to me. Moreover, I am grateful for the additional feedback and support from the other supervisors and the visual ethnography class of 2021. A special thanks to Christien van de Pavert. Our firing and study sessions have helped me to keep focus and motivation throughout the year as well as encouraged me to let go at certain moments.

By indulging myself in this topic, I have met so many wonderful people who led me to so many interesting, eye-opening and personal stories that together form the base of this research. The research would not have been possible without the openness and helpfulness of all these people. Joy Dekker, Ymke Kelders (Stichting Rutgers), and Monique Bijkerk (Stichting Snoezelzorg) have provided me with a starting point and the context for the research. By being incredibly open with me, Mira Thompson, Jacqueline Davis, Annika Mell, Vincent Olrichs, Nynke Koelma, and Menko Dijksterhuis have provided me with the information and stories that this thesis consists of. I am thankful for the willingness of René Tuinhof and Marie-Thérèse Roovers to cooperate with the participants on camera. I am most thankful to Vincent Olrichs, Nynke Koelma, and Menko Dijksterhuis for opening their homes to me and for letting me film (or film their own) most intimate moments. Thank you all for welcoming me with such warmth and trust and for making this research possible.

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1. INTRODUCTION

It was the first time I would speak to Vincent face-to-face. We had talked over Zoom, so I knew what he looked like. I remembered his eloquence, openness, and activist stance on the topic of my research. He had told me a little bit about his disability and the way he lives, but I was still curious to meet him in real life. It was also the first day I had brought my camera and the idea of having to manage both the camera and the conversation made me nervous. I was prepared to film only outside due to corona, and indeed Vincent was wearing a face mask. This is why I was surprised to hear him ask to come inside and have a look at his place. I was eager to see it, so I agreed. His room was not too big, with a small kitchen, bedroom, and bathroom. The first thing I noticed was the big wheelchair standing in the corner of the room, a different one than Vincent was in at the moment. The second things I noticed were his Ajax posters and numerous photographs of him and Trijntje Oosterhuis (a Dutch singer). When I asked him about this, he enthusiastically started to tell me about her and the concerts he had been to. He was a big fan. We decided to go outside and have a little walk. Unfortunately, Vincent's face mask kept sliding down and I had to help him keep it up. I felt a bit conflicted about doing this because of the corona, but Vincent seemed to have no problem asking it. I remember thinking how difficult it must be to not be able to do these things yourself. Exactly the kind of thought I was trying to avoid coming into the research. After our walk, we came back inside, and I took off my jacket only to realize Vincent could not do this by himself. He rang the staff of the building and waited for someone to come. We talked a bit more about his house and life. Ten minutes passed and I started to get impatient. When I asked Vincent if someone was still coming, he answered: 'yeah, they always do. I learned to be patient a long time ago.' This was the second time that day I got confronted with my thoughts. Not long after, someone arrived and helped Vincent out of his jacket and onto the toilet. The whole thing took about fifteen minutes and to me, it seemed like a lot of hassle. After he visited the toilet, Vincent got transferred into his other wheelchair, the one that had been standing in the corner. This, again, took about fifteen minutes. It was the third moment I caught myself thinking how relieved I felt that I was not dependent on someone else to help me with this. Someone brought lunch, and over a peanut butter sandwich, we started to talk about sexuality and mostly access to sexuality. I was prepared to ask the first question when Vincent caught me off guard by asking me 'what do you think about sexuality and disability? Do you think everyone should have access to sex or do you think it is weird?' Looking back on this moment, I now find this an excellent example of Vincent's personality, curiosity, and life spirit. Vincent's openness and visible personal attachment to the topic struck me a lot and the conversation was the start of a realization process of how multilayered the topic of disability, sexuality, and the body is.

In the research, I have found that wheelchair users are often looked at with pity. The vignette shows that I am no exception to this. Over the three months of fieldwork, every prejudice the participants voiced has gone through my head. Where do these prejudices come from? And what effect do they have on how wheelchair users experience their (sexual) body and identity? I know now that there is no easy answer to this. How the participants experience their body is – amongst other things – personal, social, political, emotional, sensorial, and institutional. This research reflects on the prejudices in society and how they become reified in infrastructure and policy. And most of all, it examines how wheelchair users negotiate their (sexual) identity within this background. The topic is important because society views sexuality as something that is not part of the identity of disabled individuals (Neufeld et al.: 859). Moreover, excluding a discourse of pleasure in talking about sex continuously reinforces negative prejudices around disabled people and their sexualities (Tepper 2000: 288). The output of the research consists of a written text and a 30-minute documentary. Its aim is to show the complexity of the multiple layers that together construct unique experiences of wheelchair users with sexuality and partnership. The two outputs together present the data that I collected with six participants, whom I will now introduce.

The documentary covers the experience of three individuals. *Vincent* (49 years) lives in Blaricum. He is spastic and therefore needs a wheelchair and help with daily tasks like eating, showering, etc. Vincent cannot masturbate and he experiences intimacy and sexuality mostly together with a sex care worker. He is active at Stichting Tiresias and works for the LVS (Leerling Volg Systeem), which are both organizations that push for equal rights for disabled people. He is thus active in creating an open debate around sexuality and its accessibility. *Nynke* (33 years) lives together with her partner René in Wateringen. She has a progressive muscle disease which results in a decrease in her muscle strength. Because of the progressive nature of her disease, she is actively reinventing what sexuality means to her and her partner inside the scope of what is possible. On top of this, she is exploring polyamory and her queerness by dating women. *Menko* (28 years) lives in Amsterdam. He is single and experiences sex mostly together with his friends with benefits or through what he calls 'sexual dates'. He is gay and has helped me a lot in understanding how disability and beauty are constructed within the 'gay scene'. He is most active in trying to create a broader representation of bodies on social media. Besides these three individuals, I have talked to three other wheelchair users. *Mira, Annika,* and *Jacqueline* all have fairly different experiences with sex and their bodies. Annika and Jacqueline both have partners with whom they experience sexuality and partnership. Mira is single and (before corona) she explored sexuality through dating and flirts. Despite the uniqueness of their situations, I have found a lot of commonalities between all the lived experiences which I explore in the empirical chapters of this thesis. I have mostly found the participants by contacting them personally on Instagram or by contacting platforms like *feminists against ableism*. In the beginning, I was afraid this would give a slightly distorted picture since not all wheelchair users are as activist as the ones I collaborated with. However, the fact that they were all so engaged with the topic made it easy to talk to them and provided me with rich, extensive data. All the participants are native Dutch speakers. The quotes are translated by the author.

In this introduction, I have provided a context and the social relevance of the topic of this research. In the next chapter, I examine the anthropological debate around the most important concepts and the importance of the research stance within this debate.

2. A PHENOMENOLOGICAL FRAMEWORK

Phenomenology forms the basis of how this research is executed, providing the red thread in how I have approached the field, analyzed the data, and in how I have chosen the different outputs. After giving a short examination of how phenomenology is theorized within anthropological literature, I move to a phenomenological exploration of the concepts of the *body* and *identity*. Although they are theorized differently in anthropology, a phenomenological perspective can help overcome this separation of the mind and the body (Blume and Hiddinga 2010: 230). Afterward, I offer a phenomenological way of looking at the categories of disability and sexuality.

Phenomenology provides a way of looking at the emplacement of individuals in the world. Following a phenomenological perspective, this emplacement is temporal. Present experiences are influenced by past experiences as well as present opportunities for future experiences (Desjarlais and Throop 2011: 88). The main goal of phenomenology is to examine how these experiences and other cultural phenomena come into place. Humans live in a lifeworld that consists of a background in which they give meaning to their everyday situations. In this meaning-making process, individuals accept, interpret and redefine their surroundings and experiences (Appelrouth and Edles 2016: 605). This process is intersubjective. From a phenomenological viewpoint, academics argue that we cannot make a clear distinction between the meaning-making processes and the background these processes exist in. How individuals place themselves in the world is both constructed through their attitude as well as the 'background' that is inherent to this attitude (Desjarlais and Throop 2011: 89).

Through phenomenology, academics look at the body as a central entity through which we experience the world (ibid.). The concept of phenomenology can thus help me look at the body as such a central entity, as well as help, understand the fragmentary and temporary character of this emplacement. It combines – amongst other things - sensory, bodily, cultural, intersubjective, and political aspects. On the one hand, the process of mediation is an individual and bodily one. On the other hand, it is not just a matter of individual consciousness. People are selective in what they give attention to (Ram and Houston 2015: 2-4). Therefore, phenomenology allows me to grasp the universality as well as the particularity of the ways we give meaning to our bodies and identities (ibid: 1). In this research, I follow Van Wolputte's phenomenological point of view on the body. He argues that a sense of self and the body is constructed through multiple intersubjective social experiences (2004: 261).

REUNITING THE BODY AND MIND

Within medical anthropology, research on the body has long been dominated by the 'biological fallacy'. This fallacy follows a biomedicine paradigm in which the mind is separated from the body (Scheper-Hughes and Lock: 1987: 6). Within theory, the body has been looked at on three levels of analysis: the individual, social and political body. The individual body is seen as a psychological entity that exists outside of social order (ibid: 7). The social body is looked at from a symbolic point of view (ibid: 14). Theory on the social body looks at how the ways we give meaning to bodies reflect views in society and social relations. This way, the body becomes a symbol of societal views and values (ibid: 19). The political body looks at how ideas around the body are informed with power and control. Society creates the bodies they need through processes of socialization. It shows how 'culture' shapes the individual body to fit a social and political order (ibid: 23-26). A phenomenological approach to the body relies on the notion of Intercorporeality. Intercorporeality is based on the indeterminacy of bodies and their surroundings. The concept can help focus on the flexibility and fluidity of bodies and identities in different contexts and situations instead of looking at the body as something static (Van Wolputte 2004: 259).

How identity has been looked at within anthropology has shifted over time. It has moved from a bounded idea, in which identity is seen as something that can be achieved throughout life to a hybrid notion of identity. This postmodern approach looks at identity with a focus on performance and enactment (Luhrmann 2001: 532). An example of this contemporary idea of identity is to view it as a 'syndrome of ideas' (Barth 2002: 20). This 'syndrome of ideas' is constructed through diverse factors and experiences. It highlights the hybridity of identity formation as well as the power dynamics at play (East and Orchard 2014: 566). The hybrid view on identity has encouraged a shift to the concept of 'identification'. A focus on identification shifts the attention from the idea that we create a coherent identity to the idea that we construct ourselves through different processes of identification (Schachter 2003: 168). Constructing a sense of self and identity is an intermediate process, in which different aspects of the world get shape (Van Wolputte 2004: 261). We should thus not look at the question of what 'the self' is, but rather look at how individuals construct a sense of self (ibid).

The phenomenological approach on the body focuses on the construction of a sense of self and the indeterminacy of this process. In this research, the concept of the assemblage helps me examine this. I look at how wheelchair users – as existing in an assemblage of social, political, and individual aspects – give meaning to their (sexual) identity. The body is a part of this identity as well as a means to experience emplacement in the world.

THE CATEGORY OF DISABILITY

Categorizing ‘disabled’ bodies has its roots in a biomedicine paradigm in which the category of 'disability' is presented as purely biological (Shifrer and Frederick 2019: 3). Disability studies opposes this idea by shedding light on the social aspect of diseases and disorders (Ginsburg and Rapp 2013: 56). This social model of disability views the category of disability as a relational one which means that ‘disabled’ bodies are categorized in relation to other non-disabled bodies. It reflects ideologies about what society views as a ‘normal’ body (ibid: 61). Furthermore, through a process of stratification, society ascribes more value to one group than the other. The social model of disability looks at these processes of stratification and how it becomes a means for oppression (Shakespeare 2015: 195).

Although the discourse of the social model of disability can be fairly useful in making claims in disability activism, critical disability studies critics the social modal for viewing ‘disability’ as one, homogenous category. It tries to conceptualize diversity within a discourse of oppression and activism (Meekosha and Shuttleworth 2016: 182). This critical disability approach, which emphasizes the heterogeneity of people with a disability, moves away from the structural approach of earlier disability studies and highlights how individuals all have unique experiences that are shaped by the intersection of a lot of different aspects. The concept of intersectionality can be useful in moving away from simple binaries and instead look at the way different categories and the way we use them intersect in constructing a sense of the self and others (ibid: 185).

From a phenomenological viewpoint, following the idea that we construct multiple senses of self and the body in different contexts and situations, I look at the concept of disability as a category through which others try to make sense of the identity and body of wheelchair users as well as how wheelchair users themselves use the category of disability in the construction of a (sexual) identity. Although I stress the particularity of experiences, which seems to fit better with critical disability studies, I do not want to overlook the fact that it is unrealistic to think that we can totally move away from categorizing others as different (Vehmas and Watson 2014: 648). How we make sense of bodies and identities is inscribed by categories.

PHENOMENOLOGY AND SEXUALITY

Defining sexuality is difficult. Sexuality can be looked at from different standpoints such as a biological, personal, and phenomenological one (Heinämaa 2003: 53). Sartre describes sexual desire as an act in which all the meaning we ascribe to the body is stripped. In the act of sex, the body becomes purely an instrument to reach sexual pleasure (ibid: 64). Feminist theorists reject this biological view on sex and rather focus on the way sexualities are constructed. This is done on different levels (Rupp and Thomson 2016: 1-4). Sexualities and sexual identities are a manifestation of how to be in the world. People are constantly performing their sexual identity through, amongst other things, gestures, posture, and body movement (Heinämaa 2003: 67).

Besides individual, social and political, sexuality is a cognitive, emotional, psychological, and physical experience. Sex is not just intercourse, it contains issues such as trust, acceptance, and intimacy (Neufeld et al 2002: 858). It relates to issues of confidence, self-image, and attractiveness. In the end, we are all sexual human beings. Although progress has been made on understanding disability in a practical way and from a medical point of view, the understanding of psychosocial aspects such as sexuality within disability studies stays behind (ibid: 859.). Looking at sexuality as something that is performed individually as well as constructed socially helps to focus on the ways that wheelchair users give meaning to their (sexual) identity and how this is interdependent with how society constructs the sexuality of wheelchair users. I thus look at the combination of these processes and how they intersect with each other. On the one hand, how does society ignore or overlook the sexuality of wheelchair users? On the other hand, how can sexuality become central in processes of empowerment (Dekker 2020: 18)? The phenomenological focus on the body as an entity through which this mediation happens helps me to grasp the multi-sensorial aspects of sexuality.

The participants define sexuality in this research in diverse ways. This is influenced by the possibilities of and unique intersections with their surroundings. However, for all the participants, intimacy is an inherent part of sexual practices and the construction of a (sexual) identity. When I mention sexuality in this research, I thus do not simply refer to the act of sex. I refer to what the participants describe as sexual moments in which they create an intimate, erotic connection with someone else or with their own body. I have now determined the position of the research within anthropological theory by discussing the phenomenological approach to the most important concepts. The next aim is to reflect on the ethics of the research and my positionality within it by presenting the collaborative nature of the research.

3. ETHICS AND POSITIONALITY: COLLABORATION

In their book *Visual Research,* Marion and Crowder state that building good rapport with participants is the most important aspect of social research. Therewith, they state that in the end, it also provides the best research (2013: 3). Although this might be true for all ethnographic research, I have experienced this to be important in this research for several reasons. First, the topic of sexuality and partnership is an intimate one. The research revolves around conversations and images that are still seen as too intimate to talk about. Talking openly about the topic and even allowing me –as a researcher – to film intimate moments, requires a level of trust that cannot be broken. This trust is only achieved through building rapport. In line with Marion and Crowder's argument, building rapport has allowed me to talk about and film these intimate moments. This is shown in this quote of one of the participants:

'If you would not have taken it seriously, I would not have participated in the research.' [1] - Nynke

Having good rapport has thus been crucial in this research and, in the end, has also facilitated the best output. An aspect of building rapport is that of informed consent. Although most ethnographic fieldwork requires an informed consent form, the starting point for consent in this research is that it has to be communicated at every stage of the research. The AAA (American Anthropological Association) statement on ethics (2012) appoints this as being open and honest about your work.[2] I have done this by making sure that the participants felt comfortable with the topics, conversations, and images throughout the whole fieldwork period as well as in the editing and writing stage. This has been an ongoing process. However, participants do not have the same (academic) background (ibid.). Therefore, I have experienced that communicating about informed consent has been easier for the documentary than for the written part of the thesis. Another part of good rapport is the communication on possible perceptions and responses of viewers to the output. Although participants feel comfortable with the images used in the documentary, viewers can still have negative reactions to them (ibid: 6). I have struggled with this throughout the fieldwork period, as some scenes were perceived differently by peers than intended. As said, this research contains conversations and images that are viewed as too intimate or confrontational in society. However, the participants have voiced that, although the output could raise some critical voices or discomfort, this strengthens the social relevance of the topic and the importance to normalize talking about the need for sexuality and partnership of wheelchair users.

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[1] Excerpt from a conversation with Nynke at 05-05-2021.

[2] http://ethics.americananthro.org/category/statement/, consulted at 31-05-2021.

Besides good rapport, the ethical issue of representational authority is key. Images are often perceived as ‘the truth’ overlooking the fact that they reflect a particular viewpoint (ibid: 3). It is important to be aware of who’s viewpoint this is. The issue of representational authority receives larger importance in the argument of this research. I found that one aspect of being categorized as ‘disabled’ comes with the prejudice that wheelchair users are childlike, dependent, or not capable of doing things. People talk about them instead of with them. In this research, I have tried to avoid this by trying to make the research collaborative. However, collaboration does not necessarily mean that the power relations between participant and researcher are balanced (Lawrence 2020: 19). Although participants can never have full representational authority, through the collaborative approach, I have tried to involve them in the research process and the way they are represented as much as possible. Within this approach, I have tried to position myself as a layman who represents all the people with prejudices within Dutch society. Someone whom I see as an example of this is *Jurre Geluk*. He is the presenter of *Je zal het maar hebben*[3]*,* a Dutch TV show in which he portrays individuals with a rare handicap. In the program, Jurre is not afraid to ask 'bold' questions, but respectfully, placing the individuals as the (experience) experts.

This chapter, together with the theoretical framework, has explored the two most important pillars in this research: phenomenology and collaboration. I now turn to the research methods and explain how they suit these two pillars.

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[3] https://www.bnnvara.nl/jzhmh, consulted at 31-05-2021.

4. METHODOLOGY AND OUTPUTS

RESEARCH METHODS

Visual ethnography can provide a way to understand the interrelatedness of different aspects of experience, including the sensory and the invisible (Pink 2013: 47). Film offers a way to present ‘everything’ at once and therefore produces knowledge that is complex and intersubjective (Marion and Crowder 2013: 3). This composite character of visual images allows the viewer to grasp events in their totality which presents a way of looking at connections that are not achieved in a text (MacDougall 2005: 38). Therefore, film is inherently phenomenological, as it presents an intersubjective, multilayered image of how individuals give meaning to their experiences. The camera produces knowledge that uses not only speech but also the body to explore and thus produces an embodied type of knowledge (Pink 2013: 113-114). This research uses film to explore these sensory and embodied aspects of experiencing sexuality and partnership. Sensory knowledge is not only produced through the visual, but also through sound. Acoustemology refers to a sonic way of knowing and being in the world. It challenges the prioritization of visual epistemology by emphasizing the importance of sound in making sense of experiences (Rice 2018: 1-3). I have experimented with this by recording the sounds of masturbation and by looking at the knowledge it produces.

Besides offering a way to grasp the complexity and multiple layers of making sense of experiences, in this research, filming has functioned as a collaborative route to producing knowledge. In the field, I have decided to film mostly handheld, This emphasizes the relationship between the filmmaker and protagonist because it makes the viewer aware of the person behind the camera and thus the intersubjective nature of the filmmaking process (Lawrence 2020: 92). This is important in this research because it puts attention to the collaborative character of the filming process. Besides handheld filming, I have handed over the camera to Nynke for two weeks. Handing over the camera is a technique that has been used in many different disciplines to give participants a chance to show the aspects of their life they think are important (Pink 2013: 114). The practice, therefore, shifts the focus from the output to the collaborative process through which it produces new levels of self-awareness and reflection (ibid: 118). For example, in *When the Dogs talked* (2014), Povinelli together with the Karrabing Film Collective reenacts the lifeworlds of indigenous people, which they try to understand through this reenactment (Lea and Povinelli 2018: 41). In this research the technique allowed for Nynke to reflect on her sexuality and intimacy within her relationship, presenting me with footage that helped me discover a deeper layer of reflection. The feeling of empowerment is something that is visible in the video footage and adds to the representation of the participants as agents in the research process. Moreover, having participants use the camera helps to position the viewer at the center of events. Handing over the camera thus enforces both the collaborative and phenomenological nature of the project. Another use of video is the possibility to view the video data together with participants. This presents an opportunity for the participants to reflect on how their experiences es are represented in the data (ibid: 119). I have used this at several moments during the fieldwork as well as after the editing of the rough cut of the documentary, which has led to new insights on how to improve the representation of the participants.

Besides audiovisual methods, interviewing and conversation have played a big part in this research. It has helped to outline the field and to define the aspects of the topic that the participants gave most attention to. The interviews and conversations I had in the field were all semi-structured or unstructured to minimize steering the conversations in a certain direction. However, this can never be completely out-ruled. Although it can be argued that interviews and conversations do not suit a phenomenological approach per se, they have provided me with a rich context around the topic and have enforced the importance of the phenomenological approach in the sense that they have shown the complexity of the different aspects influencing meaning-making processes. Besides, during the fieldwork period, on-camera conversations and speech have become a way to present the participants as agents. In the film, a lot of the speech is spoken directly to the viewer which enhances this feeling of agency and authority. Positioning myself as a layman in these conversations has strengthened this.

OUTPUTS

The pillars of phenomenology and collaboration also remain the most important motives for choosing the outputs of a written text and 30-minute documentary. As discussed, film provides embodied knowledge using the audiovisual to grasp the different layers of how individuals make sense of their experiences including sensorial aspects that are hard to convey via written text. The documentary uses the individual level as the starting point of analysis, giving in-depth focus to the particularity of experiences with sexuality, partnership, and the ways participants give meaning to their bodies. The written text on the other hand has space to elaborate on overlapping aspects that affect these experiences. You could state that the documentary focuses on the individual aspects of giving meaning to the body, while the written output covers structural aspects like the social or political. However, following Van Wolputte's idea that these aspects cannot be treated separately and that processes of meaning-making are highly fragmented (2004: 261) this is something I try to avoid in the empirical chapters and documentary. Although the two outputs have different starting points, the complex nature and the indeterminacy of meaning-making processes are key in both. In the documentary, societal views on the body are reflected through the individual experience. For example, I have included the ‘Tinder scene’, in which Menko and I are swiping on Tinder together. The scene shows how Menko’s individual experience with dating is influenced by the prejudices around disability in society. In the written part of the thesis, the concept of the assemblage helps grasp the complexity of the meaning-making process and therefore ties the structural and individual together. The empirical chapters follow the structure of the assemblage by making an argument through anecdotes and quotes that show how different aspects interrelate on different levels in the way wheelchair users give meaning to their body through sexual practices, dating, and relationships.

Prologue. The assemblage

‘Assemblages are open-ended gatherings. They allow us to ask about communal effects without assuming them. (…) Assemblages don’t just gather lifeways, they make them. Thinking through assemblages urges us to ask: How do gatherings sometimes become “happenings”?’ (Tsing 2015: 22-23)

Anna Tsing uses the concept of the assemblage to look at the hybrid way in which different species influence each other and together create new histories or realities (2015: 22). In this thesis, I look at the different aspects of meaning-making processes regarding sexuality, partnership, and a sense of self through this concept of the assemblage. I examine how different conceptualizations of the body, disability, sexuality, and partnership come together and influence each other on different levels, in different situations through different groups of people. I move from a fixed idea of looking at the body and identity to a hybrid space in which wheelchair users, together with their surroundings, construct a notion of their (sexual) identity. This fragmented approach to the topic has resulted in seven short chapters that all describe situations in which different groups of people, aspects, and levels of analysis intersect with each other. In some chapters, what is described as a structural perspective on meaning-making processes is in the foreground. In others, the individual and sensorial level are the starting point. In some chapters, sexuality is the main focus. In others, partnership is more present. Although in different situations, different aspects might seem more present, together they create unique, embodied experiences or ‘happenings’. I now turn to these experiences.

5. CHAPTER I: THE DISCOURSE OF DEPENDENCY, GOOD PARTNERSHIP, AND ASEXUALITY

'...I think that, in general, people think that you are not capable to. To have friends, to be intelligent, to have an opinion. I think people project a lot of things on me and people like me.' [4]

\- Mira

I have spoken to wheelchair users with various sexual orientations, disabilities, and relationship statuses. Despite these unique situations, I have found multiple commonalities in the prejudices the participants experience in the interaction with other people. The prejudices they expressed most were those of incapability, childlikeness, and dependency. Physically disabled people are seen as childlike and in need of protection (Neufeld et al 2002: 858). Nynke, for example, addresses that some people are being protective or treat her as a child. Likewise, Mira states:

*'What I hear very often – and this is something you have probably heard from others – is that I am so *blank* for someone in a wheelchair. So intelligent, so eloquent, so whatever.'* [5] – Mira

The slight surprise of people inherent to the comment Mira describes shows the assumption of incapability. Although the prejudice might not seem to be directly related to sexuality and partnership, I discovered that it affects how the ability of wheelchair users to be a sexual or good partner is perceived.

One effect related to the discourse of incapability and childlikeness is the assumption that disabled people are incapable of being good, equal partners (ibid.). This is reflected in the stories of the participants. For example, Mira expresses:

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[4] Excerpt from interview with Mira on 03-03-2021.

[5] Ibid.

‘I am not allowed to demand. When someone likes me and I don’t like them back, people sometimes say to me: “wow, you have high standards.” I always answer: “yeah, I better have that!”’ [6]

In line with this, Jacqueline told me that people tell her that she should be feeling lucky to have a partner. One practical aspect that enhances the assumptions around dependency and good partnership is receiving physical care. Receiving care is associated with a lack of competence as a social actor, disempowerment, and exclusion (Hughes *et al*.: 2005: 261). This idea of receiving care as something that is disempowering is a result of the way society conceptualizes care and the discourse in which it is placed (Beckett 2007: 363). Caring for a disabled husband is viewed differently than caring for a husband in general (ibid: 373). However, a conversation between Nynke and her partner René shows how everyone depends on their partner in a certain way:

‘R: It is a bit harsh if I would ask you the question: “Am I dependent on you? If yes, in what ways?”
N: Well, maybe you are also dependent on me.
R: Yes, that could be.
N: Like, you could not live on your own right?
R: Well, I could but…
N: …you have never done it. You wouldn’t cook for yourself for example.
R: No. I think in that case, I would be forty kilos heavier.’ [7]

René and Nynke are thus dependent on each other in different ways. This way, care becomes a relational act, one of interdependence rather than a practical, medical one (Hughes *et al.:* 270). How dependency and caring for disabled persons in a relationship are viewed, says something about how disability is categorized (Beckett 2007: 373) and what society sees as a good partnership.

A second effect related to the discourse of incapability, dependency, and childlikeness is the assumption that wheelchair users are asexual. Viewing disabled persons as children excludes them from being sexual or having sexual desires (Neufeld *et al*.: 858). This assumption is mostly expressed through an extreme curiosity around the sexuality of the participants. For example, Menko states:

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[6] Ibid.

[7] Excerpt from video footage shot on 02-02-2021.

‘Sometimes they ask about what I can do. Often it gets very sexual, like “Does everything work? do you have dates?”, things like that. And I think: It does not matter because you would not ask that to someone else.’ [8] - Menko

Inherent to this quote is the idea that it is unusual or special for wheelchair users to have sex or dates. This prejudice of asexuality is performed and (re)produced in many different ways. Moreover, both the prejudice of asexuality and the incapability of being equal partners affect how wheelchair users perceive their sexuality. One of the ways in which the prejudices are performed and (re)produced is through(online) dating. The next chapter explores this.

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[8] Excerpt from video footage shot on 20-02-2021.

6. CHAPTER II: THE CONFRONTATION ZONE THAT IS (ONLINE) DATING

The last quote of chapter one shows the extreme curiosity around the sexuality of wheelchair users that a lot of the participants expressed. It is a quote from a conversation I had with Menko about (online) dating. The context of (online) dating is one in which the participants are confronted with prejudices around disability and sexuality. For example, Vincent voices:

'…I have tried [dating] via a website and when you just start with a message like: "Hi, I am Vincent, what kind of music do you like and what hobbies do you have?" people already don't answer. So, I always have the idea that they can see through the computer screen that I am in a wheelchair and not interesting to somebody.' [9]

Likewise, Menko expresses:

'L: Are you sometimes afraid to say [that you are in a wheelchair]?
M: Every time it is like, okay, am I still going to get a message afterward or does it stop? Sometimes it stops indeed or it is an unmatch and then I am like okay, clear.' [10]

Although it is hard to make an argument on the reason that people unmatch or stop talking after the moment the wheelchair is brought up, it is clear that the participants experience a rejection based on that specific fact. I want to argue that, in (online) dating, the identity of wheelchair users is reduced to their disability and the assumptions that come with it. Because of this, wheelchair users are excluded from the discourse around sexuality and partnership. Through both curiosity and rejection, the participants are constantly confronted with the fact that their bodies are different. Furthermore, the idea that wheelchair users are not suitable 'candidates' for dating and relationships gets confirmed. On the one hand, the participants internalize this. Nynke, for example, expresses:

'New people that I meet find it admirable of my husband that he is with me, or that I have a relationship in general. And when I started dating before corona, I also got that idea in my head. Like, are people even interested in me?' [11]

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[9] Excerpt from a conversation with Vincent on 18-01-2021.
[10] Excerpt from video footage shot on 20-02-2021.
[11] Excerpt from video fragment filmed on 17-03-2021.

On the other hand, participants find it annoying.

‘I really don’t mind being open about it [my disability], but I also sometimes think: there is more than just my handicap. It becomes such a hot topic while it is not a hot topic for me.’ [12] - Menko

Having to talk and answer questions about disability leaves little room for other parts of the participants’ identities. This chapter shows how the context of (online) dating becomes a zone of confrontation in which the assumptions and prejudices revolving around disability and sexuality in society are performed. I discuss the empowering effect of dating that I have also found in this research in the epilogue.

In this chapter, I discussed how prejudices are performed and (re)produced in (online) dating. In the next chapter, I turn to the issue of representation and how representation becomes a way of (re)producing the same discourses.

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[12] Ibid.

Interlude. Hyper sexualization

'I mean, the whole situation with dating apps…everyone is on them at some point and me too. One time I just stopped because it made me so sad. People say everything on the internet. I would literally get like very objectifying shit, but also that they hypersexualized me. Like "oh my god, you sexy, small thing in a wheelchair", that kind of shit. Or [they asked] if they could try me some time because they had never slept with a handicapped person. As if I am something for a list. I always answer things like "I am not something to check off your to-do list or bucket list."[13] – Mira

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[13] Excerpt from interview with Mira on 03-03-2021.

7. CHAPTER III: (RE)PRODUCING PREJUDICES THROUGH REPRESENTATION AND PULLING OUT THE BANANA IN SEX EDUCATION

'You don't see yourself anywhere. You don't see yourself represented anywhere.'[14]

– Menko

The representation of disabled individuals in the media is problematic (East and Orchard 2013: 569). The image of disabled people produced in this media reinforces the idea of dependency and childlikeness. For example, Annika tells me that the representation of wheelchair users in films is tragic. Although there are numerous examples of this, a striking one is that of the character of Artie Abrams in the TV series *Glee* (Brennan 2009). The series spends multiple episodes on how the character – who is in a wheelchair – feels miserable and wants to be able to walk again. On top of this, he is struggling to find someone who likes him.

The quote at the beginning of this chapter shows that there is in general just a lack of representation of wheelchair users. The participants don't see themselves represented in romantic plotlines, films, or porn for example. When represented in the media, the 'tragic view' only emphasizes the feeling of abnormality and the reduction of the personality of wheelchair users to the prejudices around being in a wheelchair. Society creates an idea of 'normal' bodies and 'normal' sexuality which is related to the idea of being healthy, independent, and fit (Bahner 2019: 28). This is the opposite of how disability is depicted in the media. Nynke states:

'There is a very one-sided image in the media: that you are vital and white. It is something that I am noticing more and more.'[15]

Another situation in which the participants expressed feeling mis- or underrepresented was that of sex education. Mira tells me:

'The moment I got sex education, and they pulled that banana out. I just felt people looking at me and thinking "Oh my god, how should she feel", or something like that. I hated that. I thought the

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[14] Excerpt from interview with Menko on 06-02-2021.

[15] Excerpt from interview with Nynke on 03-03-2021.

whole thing was just uncomfortable. I think every teenager finds that uncomfortable but for me, it was even worse because I didn't feel connected to it in any way."[16]

When looking at sex education, the participants voiced to either not have had proper sex education or to have had sex education that was mostly focused on the practicalities of the physical act of intercourse. Practicalities that are often not possible when you are in a wheelchair. The lack of representation, as well as the way that wheelchair users are depicted in the media, porn, and sex education again (re), produces the prejudices that exist around disability, excluding them from the discourse of sexuality and partnership. As I have discussed, the way wheelchair users are depicted is the opposite of a 'normal', sexy body (Bahner 2019: 28). What is this image of a 'normal', sexy body? In the next chapter, I turn to how the attractiveness of bodies is constructed in society as well as how the participants construct their notion of beauty and sexiness.

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[16] Excerpt from an interview with Mira on 03-03-2021.

8. CHAPTER IV: BEAUTY STANDARDS AND FEELING SEXY

'In the gay scene, it is important to live up to the masculine image or beauty standard that exists. That is, for example, broad shoulders, a six-pack, muscular, a low voice. Those are all stupid characteristics that are praised. Well, I know that I will never get a very muscular body, a six-pack, or broad shoulders. And if so, you don't meet the requirements which means you are lower on the social ladder when it comes to attractiveness. And besides that, I am disabled, which means I am lower on the ladder as well, because of all the prejudices it comes with.'

– Menko

Menko and I have talked a lot about our bodies and what we like and did not like about them. The quote shows how he experiences the way other people look at his body within the gay scene. Moreover, it shows how Menko experiences a strong standard in the gay scene that bodies have to live up to, which he cannot achieve. One aspect of the masculine body ideal, for example, is broad muscular shoulders. This is something that Menko cannot achieve because of his muscle disease. Another example is that the characteristic of being able to take care of or protect others is ascribed to masculinity. This clashes with the prejudice of dependency that wheelchair users are associated with.

The existence of certain beauty standards in society is something almost all participants voiced. However, when I asked to describe these standards, the participants were ambiguous. Although beauty standards are quite elusive, it is clear that the participants experience the feeling that they do, in any case, not meet these standards and as an effect have the experience that they are not attractive or sexy. Issues with self-image and insecurity are not solely bound to wheelchair users. Although body-related issues are something everyone experiences, some are specific to wheelchair users. Mira states:

'I think that there are beauty standards in society. Most people don't fit these standards of course, but I am so far away from it that I won't even come close with plastic surgery.' – Mira

In line with East and Orchard's case study (2014), the participants experience a disconnection between the representation of physically disabled people and an image of a desirable body.

However, sex and dating can enhance the feeling of being desirable. The participants expressed feeling sexy in moments with others during sexual and intimate practices. In line with this, the participants did not only mention aspects of sexiness and attractiveness that were purely related to the exterior of the body. The aspects are also influenced by the way the participants feel. Especially Annika, Mira, and Jacqueline voiced that their fatigue and physical wellbeing has an impact on how they look at their body.

'I think, feeling sexy is related to feeling physically well for me. Feeling well, dressing up, that kind of stuff.' – Mira

This chapter has shown that representation not only (re)produces discourses of dependency, incapability, asexuality, and partnership. It also contributes to a notion of beauty and sexiness. However, feeling sexy is a personal thing. In the next chapter, I examine how feeling sexy relates to a medical approach to the 'disabled' body.

Interlude. Passing

'In the gay scene, there is a term, like if you are 'passing'. It means that if you look like a straight guy, you will be more accepted within the heterosexual society which implies that you have less chance of being discriminated against because of your sexual preference or orientation. And because it is kind of accepted or has a preference ion society, it is also important in the gay scene.'[17]

– Menko

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[17] Excerpt from an interview with Menko on 06-02-2021.

9. CHAPTER V: THE DISABLED BODY AS A MEDICAL OBJECT

'If you are touched by others a lot, for example by caregivers, doctors or whatever, your body becomes less your own body and more that of someone else. Or a medical thing. Or an object or Instrument or something.'[18]

– Menko

In the last chapter, I showed that feeling sexy is related to the mindset with which both the participants and society look at the bodies of wheelchair users. One mindset follows the medical approach to the body. An aspect of this is the tension between receiving care or being touched in a 'medical' way and the way the participants feel about their bodies. Menko's quote shows how a medical mindset can affect how participants perceive their bodies. For example, Mira told me an anecdote about a time she went to the doctor. When she walked in, the doctor said 'wow, your body is really misshapen'. In this example, the doctor emphasizes Mira's 'misshapen' body, reducing her to her disability. She says about this:

"…It is often a very medicalized thing, a handicapped body.'[19]

I have found that this medical mindset is something the participants use as well. In the video footage of Nynke explaining a sex position within the mobile hoist she says:

"…and again, it is not that when we did it last night, having sex in the mobile hoist, that the next morning when I receive care, I have the same association. (…) I switch a button in my head that makes me think differently about it. I don't get aroused by being naked or getting undressed."[20]

Menko expresses something similar:

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[18] Excerpt from an interview with Menko on 06-02-2021.

[19] Excerpt from an interview with Mira on 03-03-2021.

[20] Excerpt from video footage shot by Nynke on 29-01-2021.

“Yes, it is mostly the mentality or mindset that you have, that you are in a different setting. While, when you are getting dressed and you need help you don’t look through, let’s say, glasses of intimacy, but rather through glasses of care.”[21]

To some extent, this is the case for everyone in society. Non-wheelchair users neither have their 'intimacy glasses' on all the time. However, the body of wheelchair users is more frequently looked at with a medical mindset and this influences the way the participants perceive their body and the sexual value of their body. Sexual practices, dating, and relationships can help shift back to a mindset of sexuality and can validate the needs for these aspects of life. In the next chapter, I discuss how the medical mindset described in this chapter becomes reified in infrastructure and institutions and how this influences access to sex.

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[21] Excerpt from an interview with Menko on 06-02-2021.

10. CHAPTER VI: THE MEDICAL APPROACH AND ACCESS TO SEX

'V: I did not get it [sex education] at all.

L: No?

V: No. Because here we go again; they think disabled people don't do it [sex], so why tell them?'[22]

- Vincent

This quote is part of a conversation I had with Vincent at the beginning of the fieldwork. In the previous chapters, I have already talked about the underrepresentation of wheelchair users in sex education as well as the medical mindset with which the participants are approached. This chapter covers how these two aspects get reified in institutions and infrastructure and how this excludes wheelchair users from experiencing sexuality and partnership. In addition to the quote at the beginning of the chapter Vincent says:

'I think it has to do with the way you are raised and with if you are at a school that talks about these things [sex and relationships] normally. (…) At my school, they didn't discuss these things at all, they only talked about me in medical terms. (…) I think it is important to talk less about the medical side and more about the other side of life and about the person you can become.' – Vincent

The quote shows how a medical approach to the disabled body is institutionalized at school through, for example, (the lack of) sex education. Something that is also present in Vincent's experiences with sexuality and partnership is the struggle with access. This is something that, on the one hand, resonated with other participants, mostly related to COVID-19. On the other hand, it is specific for Vincent's situation, because he is the only participant mostly dependent on sex care workers to experience sexuality with.

The WHO (World Health Organization) acknowledges sex as a human right[23]. Sex can improve intimate relationships and create a feeling of connectedness with the world (Tepper 2000: 288). However, the reality is that politics around access were very present in my conversations with

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[22] Excerpt from a conversation with Vincent on 18-01-2021.

[23] https://www.who.int/health-topics/sexual-health#tab=tab_2, consulted at 31-05-2021.

Vincent. Money, for example, can play an issue in access to sex care. Sex care is not subsided by the municipality, and for many people, it is hard to pay for. Besides, corona creates an extra obstacle for Vincent.

"…that is why it sucks that it [sex care] can't go on because of the lockdown. (…) Right now it is only on medical indication, but how do you get that!? They say: you have to have an indication, so they make it medical."[24]

Vincent's medical need for sex is thus not seen as immediate enough, which excludes him from experiencing sexuality. The lack of access to sex or sexual information becomes institutionalized through a lack of attention to sexual needs within care. Seeing sex only as a way of reproduction excludes disabled people from sexuality (Tepper 2000: 285). All the participants voiced that their sex education revolved mostly around reproduction and the dangers of sex.

Within this background of limited access to sex, all the participants find ways to make their sexuality their own, despite a lack of knowledge, representation, and access. Vincent states:

"And, by the way, I did some research myself. Like, what is it and that kind of stuff. I messed around with a girl in the toilet once, so yeah. You get curious you know. And those feelings also develop. To say it a bit vulgar; you get horny. I mean, you want to know and try stuff and see what it looks like."[25]

In the empirical chapters, I have tried to describe the assemblage in which wheelchair users negotiate their (sexual) identity. The documentary that accompanies this written text goes into more detail about how wheelchair users construct a (sexual) identity through sexual practices, dating, and relationships. I have tried to show how different aspects within the assemblage affect how wheelchair users experience their (sexual) bodies and identities and how these aspects operate on different levels and together construct a complex network in which prejudices around disability and sexuality are performed, (re)produced and reified.

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[24] Ibid.

[25] Excerpt from a conversation with Vincent on 18-01-2021.

Epilogue. Feeling human

'…because intimacy is nice to experience. Also, because it makes you experience a kind of humanity. Like, I am normal, I have intimacy, I want sex. That makes it nice. And because of that, you are more into your own body.'[26]

– Menko

The empirical chapters have shown that the way wheelchair users experience sex, dating, and relationships is influenced by a lot of factors that are among other things social, individual, political, emotional, and institutional. All these aspects influence the way wheelchair users give meaning to their (sexual) bodies and identity. Within this assemblage, wheelchair users experiment, experience, and negotiate their (sexual) identity through sexual practices, dating, and relationships. Nynke says about this:

"…I can have sex. It demands some adjustment, it is different. But that makes it even more special or beautiful. We really take the time to have sex with each other and it is just figuring out what is still possible, what is nice, what my body can do. And yes, René has to work a bit harder, that is true. But we do reach a climax together."[27]

Sexual pleasure can boost individual confidence and satisfaction (Jolly 2010: 230). Although the experiences with sex, dating, and relationships are different for every participant, I have found that having sex or being in a relationship works empowering, relaxing and most of all makes the participants feel human. This is mentioned by Menko in the quote at the beginning of this chapter.

Annika tells me that sex allows her to experience her body positively. This is in line with the results of Bowman's research that women with sex-positive attitudes experience masturbation as an act of sexual empowerment (2014: 373). When I ask Nynke about the nice aspects of sex, she says:

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[26] Excerpt from interview with Menko on 06-02-2021.

[27] Excerpt from video footage shot by Nynke on 29-01-2021.

'…it takes away all the worries of the day and you can really experience that moment. Maybe also that I forget the muscle disease or all the things I have to do and, well, that you just enjoy the moment. That it overpowers everything else.'[28]

Sex can thus function as a way to relax and experience the body in a positive and pleasurable way. For example, experiencing sex and intimacy can have positive physical effects like pain release or relaxation like this quote of Vincent shows:

'You become two meters taller. Or two centimeters because it has a gigantic effect on my body.'[29]

Sex not only influences the way wheelchair users look at their bodies. It allows for a different way of being in connection with others or being touched differently by others. This is a connection that is fundamentally different from the connection made with for example care workers, family, or friends.

The pleasure of sexual practices makes everyone feel completely human (Tepper 2000: 2880). In line with this, all the participants expressed that same feeling of validation in sex and relationships.

'There is an intrinsic value, a human value, that I feel if I feel sexy or attractive that you can't feel if you have never experienced it [sex].'[30] - Mira

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[28] Excerpt from interview with Nynke on 25-02-2021.
[29] Excerpt from a conversation with Vincent on 18-01-2021.
[30] Excerpt from interview with Mira on 03-03-2021.

11. CONCLUSION AND DISCUSSION

All the different aspects of the experience with sexuality and partnership of wheelchair users discussed in the empirical chapters confirm how multilayered and complex the topic of disability and sexuality is. How wheelchair users experience sexuality, partnership, and their body is affected by prejudices in society that are performed in different situations in different ways. It is affected by infrastructure that excludes wheelchair users physically from places. It is affected by the politics around who has access to sex and sex care. It is affected by existing ideas of sex and beauty standards and the feeling of not fitting in those boxes. The other way around, sexual practices, dating, and relationships shape the experience of wheelchair users with their (sexual) identity. Having sex or being intimate with someone allows for the establishment of a different connection than a medical one and a different kind of touch. It takes away the attention from being categorized as disabled and gives the participants a feeling of being 'normal' or 'human'. In this way, it empowers wheelchair users and validates that their sexual needs and desires are valid. Although the ways in which wheelchair users give meaning to their (sexual) identity in these contexts is so diverse, I have shown that the bodies and identities of wheelchair users are in many situations reduced to their disability and the prejudices associated with them. This is mostly done in society and not by the participants themselves.

'What do I think about it [being in a wheelchair]? I don't mind. I mean, the wheelchair is very freeing for me. (…) It's just a shame the world does not see it like that.' [31] - Mira

The individual has a central role in negotiating a sexual identity (Sakelleriou 2011: 168). In this text, I have presented a complex assemblage of – amongst other things – political, social, emotional, discursive, and institutional actors and aspects, in which wheelchair users experience sexuality and partnerships in their way and on their terms. The research foremost states that assuming wheelchair users do not have desires and needs for sexuality and partnership is wrong and that wheelchair users should be included in the discourse around sexuality and partnership. It does this without overlooking the unique struggles that the participants experience in sexual practices, dating, or relationships. Not only should sexuality and partnership be seen as inherent to the identity of disabled individuals, but we should also think about the way sex, partnership, and disability are defined in society and how an inclusive image can benefit all of us in experiencing sex, dating, and relationships. This is the starting point of the documentary that accompanies this written text.

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[31] Excerpt from interview with Mira on 03-03-2021.

Over the last year, I have noticed that people label this research as an activist one. Although activism and anthropology can go hand in hand, I find this an interesting observation. The approach and research methods of this research are no different than in other ethnographies. Still, I have noticed that people looked at the research and the openness of the participants with slight admiration and awe. The reason that I want to include this observation in the conclusion is that I find it exemplary of the stigmas and prejudices that revolve around disability and sexuality. In my first conversation with Mira, I used the term 'taboo breaking'. She answered:

'I don't like the term 'taboo breaking' because it shows that this topic is something we actually should not be talking about.'

Labeling talking about sexuality and sharing sexual, intimate moments as activist indirectly emphasizes the abnormality of it, or at least, it emphasizes the lack of spaces in which it is done.

One aspect this research has covered is the aspect of access to sex care, which is prominent in Vincent's experience with sexuality and partnership. During the fieldwork period, I had one interview with the director of Stichting Snoezelzorg, who stressed the importance of sex care within general care. It opened up a whole new focus for research. Unfortunately, in this research, I could not grasp the totality of the topic of sex care and the politics around it. Therefore, I propose this as a field for further analysis within disability studies. A new film about the topic of sex care has just been released, in the hope to break the taboo around sex care. Ada (2021), played and directed by Fabuch Social Cinema sheds light on the importance of sex care and the unique struggles and opportunities it comes with. Besides this documentary and a short film about the sex care worker *Tika Stardust* (2017), not a lot is written or made about the topic. It thus presents a field that is still unexplored and in need of further research.

12. REFERENCE LIST

American Anthropological Association

2012 AAA statement on ethics. http://ethics.americananthro.org/category/statement/.

Appelrouth, Scott and Laura D. Edens

2016 Classical and Contemporary Sociological Theory. London: SAGE.

Bahner, Julia

2019 Mapping the terrain of disability and sexuality: from policy to practice. Ars Vivendi Journal 11:27-47.

Barth, Frederik

2000 Boundaries and Connections. In: Anthony P. Cohen (ed.), Signifying Identities: Anthropological perspectives on Boundaries and Contested Values. New York: Routledge. Pp. 17-36.

Beckett, Clare

2007 Women, disability, care: Good neighbours or uneasy bedfellows? Critical Social Policy 27(3): 360-380.

Blume, Stuart and Hiddinga, Anja

2010 Disability Studies as an Academic Field: Reflections on its development. Medical Anthropology 22(2): 225-236.

BNN VARA

2001-2021 Je zal het maar hebben (JZHMH). https://www.bnnvara.nl/jzhmh.

Boer, Tracy de

2015 Disability and Sexual Inclusion. Hypatia 30(1): 66-81.

Bowman, Christin P.

2014 Women’s Masturbation: Experiences of Sexual Empowerment in a Primarily Sex-Positive Sample. Psychology of Woman Quarterly 38(3): 363-378.

Brennan, Ian., Murphy, Ryan. and Falchuk, Brad.

2009 Glee (45 min). Los Angeles, Paramount Studios.

Danette Crawford BA and Joan M. Ostrove PhD

2003 Representations of Disability and the Interpersonal Relationships of Women with Disabilities, Women and Therapy, 26:3-4, 179-194.

Crowder, Jerome W. and Jonathan S. Marion

2013 Visual Research, A concise introduction to thinking visually. New York. Routledge.

Dekker, Joy

2020 Woman and Sexual Pleasure. Search for and experience of sex, intimacy and pleasure of adult women with a physical disability in the Netherlands. Medical Anthropology and Sociology Graduate school of social sciences: 1-70.

Desjarlais, Robert and C. Jason. Throop

2011 Phenomenological Approaches in Anthropology. Annual Review of Anthropology 40: 87 - 102.

East, Laura J. and Treena R. Orchard

2014 Why can't I?': an exploration of sexuality and identity among Canadian youth living with physical disabilities. Journal of Youth Studies 17(5): 559-576.

Ellington, Tameka N. and Lim, Stacey R.

2017 Rendered Powerless: Disability versus Westernized beauty Standards. A Journal in GLBTQ Worldmaking 4(3): 170-176.

Friedland, Michelle T.

1999 Not Disabled Enough: The ADA's "Major Life Activity" Definition of Disability. Stanford Law Review 52 (1): 171-203.

Ginsburg, Faye and Rayna Rapp

2013 Disability Worlds. Annual Review of Anthropology 42: 53-68.

Heinämaa, Sara

2003 Sexual and Erotic Bodies. In: Toward a phenomenology of sexual difference: Husserl, Merleau-Ponty, Beauvoir. Lanham: Rowman and Littlefield Publishers. Pp. 53-79.

Hughes, Bill, et al.

2005 Love's Labours Lost? Feminism, the Disabled People's Movement and an Ethic of Care. Sociology 39(2): 259-275. London, New Delhi. SAGE publications.

Jansen, Fabian.

2021 Ada (30 min). Fabuch Social Cinema.

Jolly, Susie.

2010 Pleasure and Empowerment: Connections and disconnections. Development 53(2): 227–231.

Karrabing Film Collective

2014 When the dogs talked (34 min).

Kok, Nienke. Et al.

2017 Tika Stardust (15 min). Ottforce productions.

Lawrence, Andy

2020 Filmmaking for Fieldwork: A Practical Handbook. Manchester: Manchester University Press.

Lea, Tess. and Povinelli, Elizabeth. A.

2018 Karrabing: An Essay in Keywords. Visual Anthropology Review 34(1): 36-46.

Lightman, Ernie

2009 'Not disabled enough': Episodic disabilities and the Ontario Disability Support Program. Disability Studies Quarterly 29(3).

Luhrmann, Tanya M.

2001 Identity in Anthropology. Elsevier 11: 7154-7159.

MacDougall, David

2005 Voice and Vision. In the Corporeal Image: Film, Ethnography, and the Senses Princeton University Press. Pp. 32–63

Meekosha, Helen and Russell Shuttleworth

2016 What is so “Critical” about Critical Disability Studies? Australian Journal of Human Rights 15(1): 47-76.

Neufeld, Jacob A. et al.

2002 Adolescent Sexuality and Disability. Physical Medicine and Rehabilitation Clinics of North America 13: 857-873.

Pink, Sarah

2013 Doing Visual Ethnography. London: SAGE publications.

Pintilie, Adina

2018 Touch me not (123 min). Bucharest: Manekino Film.

Ram, Kalpana and Houston, Chris

2015 Introduction: Phenomenology’s Methodological Invitation, in: Phenomenology in Anthropology: A Sense of Perspective. Bloomington: Indiana University Press.

Rice, Tom

2018 Acoustemology. In: Callan, Hilary (ed.), *The International Encyclopedia of Anthropology.* John Wiley and Sons: 1-7.

Rupp, Leila. J. and Thomsen, Carly.

2016 Sexualities. In: Lisa Disch and Mary Hawkesworth (eds.), *The Oxford Handbook of Feminist Theory.* Oxford: Oxford University Press. Pp. 1-24.

Schachter, Elli P.

2004 Identity Configurations: A New Perspective on Identity Formation in Contemporary Society. Journal of Personality 72(1): 167-200.

Scheper-Hughes, Nancy and Margaret M. Lock

1987 The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology. Medical Anthropology Quarterly 1(1): 6-41.

Shakespeare, Tom.

2010 The Social Model of Disability. In: L.J. Davis (ed) The Disability Studies Reader. New York. Routledge. Pp. 195-203.

Shifrer, Dara and Angela Frederick

2019 Disability at the Intersections. Sociology Compass 13: 1-16.

Suhr, Christian and Rane Willerslev, eds.

2013 Transcultural Montage. New York: Berghahn Books.

Taleperos, George and Marita P. McCabe

2002 The Impact of Sexual Esteem, Body Esteem, and Sexual Satisfaction on Psychological Well-being in People with Physical Disability. Sexuality and Disability 20(3): 177-183.

Tepper, Mitchell. S.

2000 Sexuality and Disability: The Missing Discourse of Pleasure. Sexuality and Disability 18(4): 283-290.

Tsing, Anna Lowenhaupt

2015 The Mushroom at the End of the World: Life in Capitalist Ruins. Princeton: Princeton University Press.

Van Wolputte, Steven

2004 HANG ON TO YOUR SELF: Of Bodies, Embodiment, and Selves. Annual Review of Anthropology 33: 251-269.

Vehmas, Simo and Watson, Nick

2014 Moral wrongs, disadvantages, and disability: a critique of critical disability studies. Disability and Society 29(4): 638-650.

World Health Organization

2010 Sexual Health. https://www.who.int/health-topics/sexual-health#tab=tab_1, consulted at 31-05-2021.