

# **Becoming the ‘Other’**

A qualitative study of power, masculinities and disabilities in the lives  
of young drivers after road traffic accidents

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## 2 Abstract

This study is qualitative, positioned in the interdisciplinary research field of disability studies, and draws on the theoretical insights of critical feminist studies. The fieldwork consisted of qualitative interviews with and participant observation of 14 young adults who had sustained injuries in road traffic accidents in which they had been drivers. The thesis investigates three hegemonic discourses that this group encountered after their accidents.

The first article identifies and investigates a discourse that we have termed ‘the language of percentages’. This term refers to the use of numbers and percentages in measurements and tests that are part of standard rehabilitation procedures. We find that this discourse might be understood to construct disability as a percentage of a ‘complete’ normative ideal, or one hundred per cent. The reality of this construct leaked into the social lives of the study participants who felt that they ‘became’ incomplete.

The second article examines one hegemonic cultural repertoire that non-disabled people draw on in encounters with unusual bodies. We find that when a biomedical framing is the main or only reference for non-disabled people in encounters with disabled people, ‘ableism’ is produced and maintained by ignorance. In this thesis, I term the discourse that constitutes that which is culturally known and not known about disability ‘non-disabled ignorance’.

The third article describes and analyses young men’s driving practices, views on safety and construction of their identities as (disabled) men in relation to masculinity ideals. We find that, overall, the male participants rely heavily on hegemonic masculinity ideals. While they tend to continue their deviant driving practices, the accident represents a turning point in which they tend to reformulate their ideals towards an increased care for others and an

incorporation of safety assessments that we term their ‘traffic safety agency’. We suggest that recognising and stimulating young men’s caring capacity holds the potential for change towards safe(er) driving. We argue that there might be a platform for dialogue and a potential for successful integration of traffic injury prevention practices if young men’s internal logic is recognised and their caring capacity is taken into account as resources and understood on emic terms by traffic injury prevention experts.

I argue that the discourses explored in the articles (i.e. ‘the language of percentages’, ‘non-disabled ignorance’ and the tendency of traffic injury prevention experts to conceptualise young, male drivers as problems) may all be recognised as processes in which the study participants are constructed, and sometimes construct themselves, as ‘Other’ in relation to the ‘Self’. As a consequence of this discursive ‘Othering’, ‘ableistic’ notions about unusual bodies are reproduced culturally, and the safety agency of young, male drivers remains (relatively) unrecognised by traffic injury prevention experts.

In conclusion, I argue that strategies of resistance, interpreting the world view of the ‘Other’ on their own terms and introducing alternative conceptual frameworks might work to destabilise the ‘Othering’ that occurs in these hegemonic discourses. Thus, such measures might influence our social realities in terms of challenging ‘ableism’, acknowledging young men’s ongoing negotiations of safety in their driving practices, and potentially joining them in this transformative work.

### 3 List of articles

I

Status: Published

Svendby, R., Romsland, G.I., and Moen, K. 2017. The language of percentages: ranking bodies, shaping realities, and limiting opportunities. *Journal of Disability and Rehabilitation*. doi: 10.1080/09638288.2017.1390789

II

Status: Published

Svendby, R., Romsland, G.I., and Moen, K. 2018. Non-disabled ableism: An autoethnography of cultural encounters between a non-disabled researcher and disabled people in the field. *Scandinavian Journal of Disability Research* 20(1): 219-227. doi: <http://doi.org/10.16993/sjdr.6>

III

Status: Submitted

Svendby, R., Lilleaas, U-B. 2018. Recognising young men's care and 'traffic safety agency': masculinity, driving and safety among 'young problem drivers' in the aftermath of severe road traffic accidents. *NORA – Nordic Journal of Feminist and Gender Research*.

## 4 List of figures

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## 5 Introduction

### 5.1 The study and research focus

*In the initial phase of this qualitative study, I attended a seminar about young, male drivers and what to do about their high accident involvement – which is thoroughly documented through decades of injury and fatality statistics. The lecturer was an authority in the field in Norway: Dagfinn Moe, who had researched traffic injury prevention strategies for years. Moe painted a clear picture of the situation. In spite of continuous efforts to introduce road traffic safety measures, there is a sub-set of young men who seems impossible to ‘tame’. Targeted as the greatest road traffic challenge due to their ‘maniac’ driving practices, they continue to pose a threat to the well-being of all road users, including themselves. After the lecture, a question was posed from the audience: ‘But... is it possible to get these young, thrill-seeking men to stop their reckless driving behaviour?’ The question was directed at Dagfinn Moe. ‘I’ve asked myself that question many times,’ he answered. He stroked his chin. Sighed. Said: ‘We’ve tried everything. That group of young men that we haven’t been able to reach... I wonder whether we will just have to give up on them.’ Moe’s response stirred my curiosity. Before giving up, it would be interesting to talk to young drivers and explore their own views on these matters, I thought. For example, how do young men who drive like ‘maniacs’ relate to cultural masculinity ideals? Moreover – what happens to young drivers after an accident? Do they change their perceptions of road traffic safety? Do they drive differently? How do they relate to their bodies after the accident? How do they experience the rehabilitation culture? Do they face prejudice from non-disabled people? This study digs into these questions. It explores the experiences of young people – 12 men and 2 women – who have been drivers in severe road traffic accidents in which they*

*became disabled. In the course of the study, I have engaged in conversations with and participant observation of these young, disabled individuals. This explorative study is about their broader lives and the culture they encountered as disabled, as gendered and as rehabilitees – and the discourses that constructed them as such.*

This qualitative study is situated within the interdisciplinary field of disability research and investigates the social realities of young drivers in the aftermath of severe road traffic accidents in which they sustained injuries. Initially, the aim was to explore their everyday life after the accidents, including their experience of the rehabilitation process, of living with their bodies, and of their social encounters with medical professionals and other people in their surroundings. Moreover, I aimed to explore their emic view of driving and safety after the accidents and their driving practices in relation to notions of masculinity.

I followed 14 Norwegian study participants between 20 and 36 years of age, who contributed to the production of qualitative data through interviews and participant observation. Most were in their twenties at the time of the fieldwork, and the accidents had happened between 2 and 15 years previously, when they were between 16 and 24 years of age. They had sustained a variety of injuries in the accidents, including traumatic brain injury (TBI) and spinal cord injuries (SCI).

The study period lasted from 1 January 2013 until 15 July 2018. The main fieldwork took place in 2013 and 2014, but I was in contact with several of the study participants until November 2016. The study participants lived in different parts of Norway, and I often travelled to meet them. The study approach was inductive and explorative, and the research direction developed over the course of the fieldwork to focus on hegemonic discourses<sup>1</sup> that

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<sup>1</sup> I outline the study's use of the term 'discourse' in the chapter 'Theoretical framework'.

surrounded the study participants and in which, I argue, they were ‘Othered’<sup>2</sup> – as rehabilitees, disabled people, and young, male drivers. To give an overview of the study, I will now briefly outline the research focus in each of the articles and in the final discussion of the thesis. This is followed by two graphic overviews, one of the three articles and one of the whole study. The aim of these figures is to make the findings and main arguments in the dissertation easily accessible to the reader.

The first article explores the study participants’ encounters with the culture of rehabilitation and medical professionals, and asks, How is disability constructed in rehabilitation practice, and how do normative ideas about bodies and functionalities in the rehabilitation process matter for the rehabilitees’ conceptualisations of themselves and their bodies? In this article, we identify and examine a discourse that we have termed ‘the language of percentages’. This term points to the use of numbers and percentages in measurements and tests that are commonly used in rehabilitation practice. We argue that in this discourse, the study participants, as rehabilitees, were positioned, and positioned themselves, as incomplete in relation to the normative ideal of one hundred per cent, which represented the complete (non-disabled) body.

The second article explores the non-disabled researcher’s encounters with the study participants as ‘disabled people’, and asks, How is disability constructed through what is known and not known about impaired bodies in mainstream cultural notions? What are the social effects of this knowledge and ignorance? The article explores the hegemonic cultural repertoire that ‘non-disabled’ people rely on in encounters with unusual bodies. We argue that ‘ableism’<sup>3</sup> is produced and maintained when a biomedical discourse is the main or only

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<sup>2</sup> The concept of ‘Othering’ is outlined in the chapter ‘Theoretical framework’.

<sup>3</sup> See the chapter ‘Theoretical framework’ for a definition of how ‘ableism’ (Campbell 2001) is to be understood in this dissertation.

reference available to non-disabled people in encounters with unusual bodies. In this thesis, I term this discourse ‘non-disabled ignorance’<sup>4</sup>.

The third article explores the emic perspectives of young, male drivers in relation to their driving practices in a masculinity perspective and asks, What masculinity discourses do the men relate to; what masculine characteristics do they idealise before and after the accident? How do they construct their identities as disabled men? Did the accident have an impact on their understanding of driving and safety? Have their driving practices changed after the accident? How might findings in this study inform work with safety measures directed at the target group? This article problematises the tendency of traffic injury prevention experts to – largely – conceptualise and discuss young, male drivers in pathological terms. We argue that this discourse might overshadow the internal logic that young, male drivers relate to. We highlight that the men’s capacity to care is lost in the current discourse and make visible young men’s situated knowledge, which we term their ‘traffic safety agency’. We argue that acknowledging this agency as a resource might create a platform for dialogue about injury prevention between traffic injury prevention experts and young, male drivers.

In the final discussion, I use the strategy of following a thread (Moran-Ellis et al. 2006) that cuts across the overall empirical data and analytical work in the three articles, and thereby document the coherence of the thesis. I do this by examining one particular aspect of the discourses the study participants encountered, namely the aspect of ‘Othering’ (Beauvoir (2000 [1949]; Ramazanoğlu and Holland 2002; Brons 2015). By ‘Othering’, I mean processes that negatively differentiate the study participants from those who inhabit normative standards of health, appearance and ‘performance’ (Goffman 1990 [1959]). I seek

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<sup>4</sup> The concept ‘non-disabled ignorance’ is explicitly introduced for the first time in this thesis. However, it is derived from the discussion in article 2. Therefore, it will be closely connected to article 2 in this thesis.



to further present, compare and analyse the three articles' overall findings in a holistic perspective by addressing the following questions: What are the mechanisms behind the processes of discursive 'Othering' that the study participants encountered as rehabilitees, disabled people and young, male drivers? What are the consequences of this 'Othering', and is there a potential to alter the study participants' position as the 'Other' in these discourses? How do the findings in this study relate to neoliberal discourses, particularly in terms of the cultural construction of useful citizens – and how do disability, masculinity and age intersect in this context?

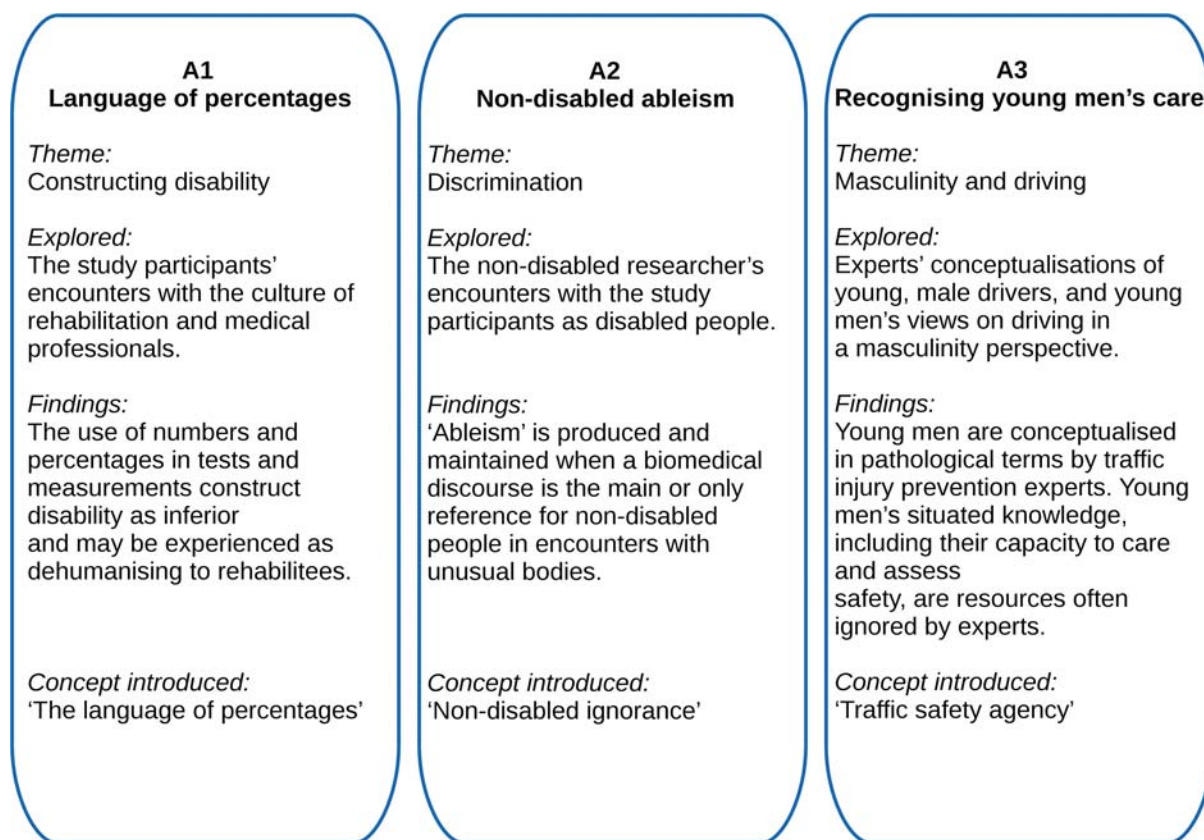
## **5.2 Teamwork and my independent contributions**

This thesis has been written in collaboration with several researchers who have contributed in different ways and at different stages of the research process, and this needs special recognition. The first two articles in this study were developed and written in collaboration with the two supervisors, Kåre Moen and Grace Inga Romsland, who also supervised the fieldwork period of the study. The third article was developed and written in collaboration with Ulla-Britt Lilleaas, and the writing of this very thesis was supervised by Stine Helena Bang Svendsen. This teamwork entails ongoing, extensive academic and analytical discussions that embrace the potential for exploration and intense consideration of data (Stewart 1998).

Because this study includes teamwork, I will switch between 'I' and 'we' in the writing of this thesis according to what I find most appropriate in a given context, in order to separate my independent work from the teamwork. Also, given that the formal criteria of working with a Ph.D. thesis is to produce a scientific product where independence is highlighted, I will outline my independent contributions to the study:

First, I planned and developed the design of the study, and applied for external funding (which was granted by the Norwegian Extra Foundation for Health and Rehabilitation). Second, I conducted the fieldwork, interacted with the study participants and generated (in collaboration with the study participants) all the data that have been produced during the course of study. Third, I coded the data. Fourth, I introduced and developed the main ideas and findings that became the topic of discussions in meetings concerning the study. Fifth, I produced the first drafts of all the texts that have been written and was the first author of the articles. This entails that I have crafted the main parts of the written products in this study. Sixth, I chose and developed the main theoretical, analytical, methodological and ethical directions of the study. Seventh, the introduction (this thesis) is my independent contribution to the study. Eighth, I was the corresponding author in the process of submitting and revising the articles, which includes crafting the replies to the peer reviewers. Ninth, I applied for approval to conduct the study from the ethical boards. Tenth, I administered formalities in the study such as writing reports on the study progress to the collaboration partners (the funder and the Norwegian Council for Road Safety through which I applied for funding). In sum, I assess my independent contribution to this study as significant while simultaneously crediting the invaluable contributions from the co-authors and others who have shared and discussed my work and their own work during the process of conducting this study.

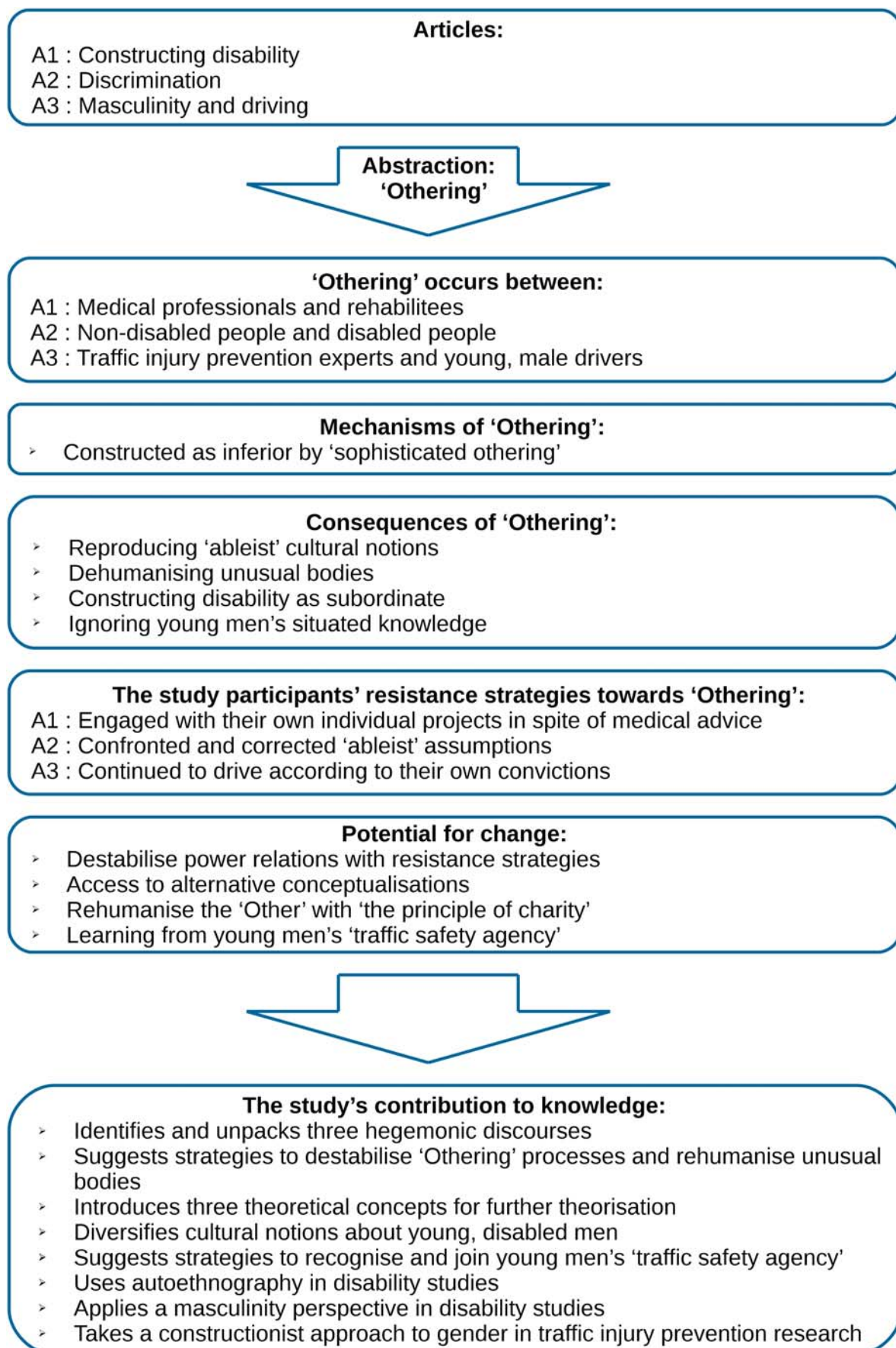
## 5.3 Graphic overview of the articles \*



\* **Figure 1:** The figure above is an overview of the articles in the study. Each of the three boxes represents one of the study's three articles. A1 refers to article 1, A2 to article 2, and A3 to article 3. Each box sums up the respective article's research focus, main findings and the concept derived from each article. (The concepts in A1 and A3 are introduced in the articles. The concept in A2 is introduced in this thesis.)

\* **Figure 2:** The figure on the next page is an overview of the whole study. The first box sums up the themes in each of the three articles in the study. The next five boxes show the process of the main argument and the findings in the final discussion of the thesis. The last box sums up the study's overall contribution to knowledge.

## 5.4 Graphic overview of the study \*



## **5.5 Structure of the thesis**

In the following, I first present the background of the study. I position the study in the field of disability studies and give an overview of the contexts and research literature on which the study relies. Second, I outline the theoretical framework. Third, I present the methods used in the study. Fourth, I address ethical considerations. Fifth, I briefly present each of the three articles. Sixth, in the discussion of the findings, I outline the thesis' coherence, overall findings, and contribution to knowledge with 'Othering' as the point of departure. Here, I explore the mechanisms, consequences, resistance strategies and potential for change to the discursive processes of 'Othering' that the study participants experienced as rehabilitees, disabled people and young, male drivers. Also, I position the study in relation to global neoliberal discourses. Finally, in the conclusion, I sum up the study's overall contribution to knowledge. The three articles are attached in the appendix.



# 6 Background

## 6.1 Introduction

The participants in this study had been injured in road traffic accidents, and their experience of living in their bodies and the disabling barriers they face in society are explored in light of theories and perspectives developed in the field of disability studies. Through these investigations, the study also seeks to contribute original knowledge to this research field. In addition to the study's overall focus on disability, which examines the study participants' life situations and experiences *as* disabled people, article 3 explores young men's driving practices in a masculinity perspective. This latter article is positioned in the intersection of disabled masculinity. Taken as a whole, this study thus combines disability studies with a gender perspective and offers a 'thick description' (Geertz 1973) of cultural encounters experienced by the study participants in the aftermath of severe road traffic accidents in which they were injured.

In this chapter, I will introduce the contextual and academic background that the study relies on. I start with a presentation of disability research and situate the study within it. This includes a brief overview of the political turn to discourses of accessibility and disabling barriers in Norway. Then, I outline literature that frames the thesis' discussion of taken-for-granted ideas that contribute to the construction of disability (article 1). Next, I outline research on normalcy, which provides background for the thesis' discussion on 'non-disabled ignorance' (article 2). Then, I introduce the academic field of men and masculinity research with emphasis on the intersection between masculinity and disability. Finally, I contextualise road traffic accidents and outline literature that frames the thesis' discussion on masculinity

and driving practices (article 3). I address the study's contribution to the research literature along the way.

## **6.2 Disability research**

The study is situated in the field of disability studies, which is a multidisciplinary field of research that includes (among other disciplines) anthropology, sociology, philosophy, history, political science and gender studies. It consists of a diverse range of methodologies and topics concerning disability (Grue 2014), such as health, education, employment and social care (Shakespeare 2015). In general, disability studies is concerned with exploration of the experiences of disabled people and societal responses to disabilities, such as discourses and cultural representations of disability, or social, legal and political management of disability at different times and places (see e.g. Goffman 1990 [1963]; Stiker 1997; Garland-Thomson 1997; 2009; Romsland 2009; Grue 2014, Campbell 2009; Shakespeare 2014; 2015). The point of departure for disability studies is that disability is multidimensional and needs to be explored as its own independent field of research. The reason for this approach is that traditional, established disciplines such as medicine and psychology do not sufficiently embrace and explain the complexities of the phenomenon (Grue 2014; Shakespeare 2015). Rather, in these traditions, disability is often constituted as a biomedical problem. Disability studies seeks to diversify such reductionism (Grue 2014) by examining and explaining disability from medical, social, psychological, cultural and political perspectives (Shakespeare 2015).

Disability studies is closely linked to political activism and balances the urge to both fill knowledge gaps and support political change (Shakespeare 2015, p. 1). Thus, taken together, the work done by disability scholars ranges from approaches that are explicitly political, such



as the work by Oliver<sup>5</sup> (1983; 2004; 2013) who aims to unite disabled people in a struggle for political change that will be beneficial on a group level, to more theoretically oriented work, such as investigations of cultural representations of disability.<sup>6</sup> This study shares the political ambition of improving the lives of disabled people and joins the quest for justice, equality and human rights. It has a constructionist<sup>7</sup> approach and as such belongs to the more theoretical strand of disability studies (Shakespeare 2014). The constructionist approach views knowledge as something that is made in a historical and societal context rather than discovered by humans: ‘We do not construct our interpretations in isolation but against a backdrop of shared understandings, practices, language, and so forth’ (Schwandt 2000, p. 197). Before I move on with the presentation of disability studies, for the sake of contextualisation I will briefly address the political situation concerning disability in Norway.

### **6.2.1 The political turn to accessibility and disabling barriers**

Discrimination against disabled people is a critical issue in the political terrain in Norway, and the approach to it has changed over the years. Nordic political discourses about disability have traditionally been welfare oriented. Until 2000, the main focus was on providing economic support to compensate for lost income and supplying different sorts of services for disabled people, such as rehabilitation or educational facilitation. Since the millennium, political attention has been directed more at regulations to make society less disabling (Tøssebro 2010). This discursive shift has entailed a change in focus towards increased accessibility for disabled people, for example, by including universal design (UD) as a mandatory element in built and planned architecture and attention to human rights, such as

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<sup>5</sup> I present his politically oriented work with the social model of disability as the point of departure in the chapter ‘Theoretical framework’.

<sup>6</sup> One example of the latter is Garland-Thomson’s (2009) theorisation of cultural objectification and staring with illustrations and photographs (and more) of unusual bodies as empirical cases.

<sup>7</sup> In the chapter ‘Theoretical framework’, I outline the study’s constructionist approach in more detail.

introducing laws preventing discrimination against disabled people<sup>8</sup> (Tøssebro 2010). A part of this discursive change was the proposition *Ansvar og meistring* [Responsibilities and Coping Strategies<sup>9</sup>] (Ministry of Health and Care Services, 1998) that for the first time in Norway approached rehabilitation from a holistic perspective, and the Norwegian Official Report (NOU) *Fra bruker til borger* [From Patient to Citizen<sup>10</sup>] (NOU 2001:22), emphasising disabling barriers, which was followed up with the proposition *Nedbygging av funksjonshemmede barrierer* [Dismantling of Disabling Barriers]<sup>11</sup> (Ministry of Labour and Social Affairs, 2003). The turn to disabling barriers in Norwegian society brings attention to taken-for-granted notions about what is seen as ‘normal’ or ‘deviant’ by looking at the surroundings and questioning the unspoken privilege of accessibility. Accessibility is understood here as ‘equal opportunity, or capability, to make use of goods and benefits, and to participate in ordinary, common life as one is, and according to one’s preferences. Accessibility is thereby for all people a prerequisite of participation’ (Lid 2010, p. 23). Tøssebro (2010) argues that this is the most acute problem in relation to disability policies in Norway; the welfare system works relatively well, but there are still major challenges in terms of accessibility for disabled people, while in the United States, for example, the situation is the opposite.

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<sup>8</sup> In 2007, Norway signed the United Nations Association (UN) Convention on the Rights of Persons with Disabilities, which was ratified in 2013. The Anti-discrimination and Accessibility Act came in 2008. Recent Norwegian legislation ‘treats accessibility as a basic right and lack of accessibility as discrimination’ (Lid 2010, p. 22), which is promising in a social justice perspective.

<sup>9</sup> Translated from Norwegian.

<sup>10</sup> Translated from Norwegian.

<sup>11</sup> Translated from Norwegian.

## 6.2.2 Feminist disability studies

The study draws on feminist theory,<sup>12</sup> and in disability studies an independent strand of interdisciplinary feminist research has evolved under the name ‘feminist disability studies’ (see e.g. Fine and Asch 1988; Garland-Thomson 2005; Hall 2011; Kafer 2013). Here, disability is understood as ‘a system of exclusion that stigmatises human differences’ (Garland-Thomson 2005, p. 1557). Where feminist studies traditionally investigates issues related to gender, feminist disability studies investigates issues related to disabilities in similar ways: ‘Feminist disability studies questions the dominant premises that cast disability as a bodily problem to be addressed by normalisation procedures rather than as a socially constructed identity and a representational system similar to gender’ (Garland-Thomson 2005, p. 1559). Inspired by feminist thinking, the body of work in feminist disability studies includes theorisation that challenges stereotypes related to disabled bodies, that embraces the marginalised voices of disabled people, that questions discriminatory notions about disabilities, that critiques practices in which disabled people are placed as subordinate beings, that explores relations between bodies and identities, and that addresses human rights in a disability perspective (see Garland-Thomson 2005 for an overview). This scholarship links research on gender and disability in a number of ways and contributes to gender research and vice versa. For example, it broadens the scope of critical feminist theorisation on gender when disability is brought into intersectional analysis and research on the politics of appearances, reproductive rights and femininity (ibid.). Feminist concepts, such as the male gaze that is cast upon the female body and objectifies it, have been adopted by disability scholars and turned into theorisation of the non-disabled stare that is cast upon the disabled body and turns it into a spectacle of the grotesque (Garland-Thomson 2009). While there are many similarities, tension emerges concerning certain issues of interest in both feminist

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<sup>12</sup> In the chapter ‘Theoretical framework’, I outline the study’s relationship to feminist theory in more detail and locate the study’s approach to gender.

studies and disability studies. For example, while non-disabled feminists critique the compulsory obligation of motherhood, disability scholars emphasise ways in which disabled women are constructed as unfit for womanhood. Also, the issue of abortion is one in which tensions have arisen. Feminists have a long history of defending abortion rights, while ‘feminist abortion rationale seldom questions the prejudicial assumption that “defective” foetuses destined to become disabled people should be eliminated’ (Garland-Thomson 1997, p. 26). This study connects with feminist disability studies in particular by emphasising asymmetrical power relations and with discrimination by exploring the feminist concept of ‘Othering’ in relation to disability and normalisation practices (Wendell 1996). ‘Normal’, Garland-Thomson states, and I agree: ‘grounds the oppressive system of representation that makes cripples and freaks from the raw material of human variation’ (2005, p. 1577).

### **6.2.3 Constructing disability**

In article 1 about the study participants’ encounters with the culture of rehabilitation, we examine the discursive construction of disability through tests and measurements and the experience of being positioned as ‘disabled’ as a result of these evaluations. This critical investigation relies on the work done by disability scholars to identify classificatory construction processes and their outcomes. This body of work has shown that many categories that are taken for granted as ‘truths’ are cultural creations that are localisable in time and space and shape the realities of individuals (Lakoff 2003; Bowker and Star 2000; Foucault 1975; Goffman 1990 [1963]; Stiker 1997; Stone 1984). Scholars have criticised the epistemological point of departure from which the disabled body is constructed as a neutral, objective phenomenon ready to be measured in rehabilitation practices and the like (e.g. Rapley 2003; Hammell 2004; Rosengarten 2005; Abrams 2014; Gibson 2014). This critical strand questions taken-for-granted concepts and how discourses and practices, such as measuring health and bodies, construct disability. This epistemological critique and

deconstruction of universalist values includes, for example, a thorough problematisation of the widely used concept ‘quality of life’ (QOL) which, according to Rapley (2003), loses its purpose because it is used to ‘describe everything from the state of nations’ bank balances to the happiness of individuals with the contents of theirs. QOL describes outcomes of political projects, as well as how pleasant (or otherwise) it is to live in Brisbane, Berlin or Beijing’ (p. 11). Gibson explores both QOL (2016) and the unintentional consequences of another much used and taken-for-granted concept, namely ‘universal design’ (UD), and remarks that ‘(e)ven as UD admits for bodily variations and strives to maximise accessibility for as many people as possible, it will always need to rely on some version of sameness, of some fixed assumption regarding what kinds of bodies and mobilities orient design’ (2014, p. 1329). Along the same line of argument, Hammel (2004) questions the use of the International Classification of Functioning, Disability, and Health (ICF) by occupational therapists ‘as if it were somehow “correct”’ (p. 408). She points to the ICF as a human-created discourse that functions as a tool that not only creates the norm, but also constructs deviance. To my knowledge, the use of numbers and percentages has not been critically examined in disability studies previously, and only a few studies have explored the experience of being tested. For instance, Bjorbækmo and Engelsrud (2011) have explored disabled children’s lived experience of extensive professional testing and argue that it might become an ordeal for the tested and possibly result in their lacking confidence in their bodies. Krohne, Slettebø and Bergland (2011) have explored older patients’ experience of cognitive screening and found that they experienced it as strenuous due to a perceived pressure to perform. In article 1, we seek to contribute to the research literature with a critical investigation of the very idea that percentages are a ‘natural’ way of measuring and talking about disabilities in rehabilitation practice and explore how that which is considered ‘normal’ (and ‘deviant’) is experienced from the perspective of those who ‘become’ disabled through testing.

#### **6.2.4 Normalcy - difference**

In article 2, I seek to contribute to the dialogue on ideas of normalcy and difference and their consequences by problematising ‘non-disabled ignorance’. I do it from a position that has not often been the point of departure in disability research, namely that of a non-disabled representative of the majority society (myself) who is acting out the ‘ableism’ which is under scrutiny. Since the ideas of normalcy and difference and the consequences of such conceptualisations have been key issues both in disability studies and in this thesis, I will give a brief overview of relevant research on these issues in this section. Also, I consider how the processes of hierarchisation and separation may affect the view of what is considered ‘normal’ and ‘different’.

#### **Hierarchy**

In disability studies, studies have shown that to be defined outside of the idea of what it means to be normal at a given point in time may lead to social, cultural and economic exclusion, neglect, and oppression, while being categorised within the bounds of what is considered normal may lead to acknowledgement, privileges and social inclusion (Foucault 1975; Goffman 1990 [1963]; Stiker 1997; Stone 1984; Oliver and Barnes 2012; Grue 2014; Ahlvik-Harju 2016). As early as 1963, Erving Goffman discussed the boundaries between what is socially perceived as normal and abnormal in his famous work *Stigma* (1990 [1963]). He theorised how these boundaries led to the systematic exclusion of those who were classified as different physically or psychologically. Goffman proposed that some individuals are positioned as inferior and not quite human in encounters with ‘the normals’, and thus subjected to stigmatisation (p. 15). Since this work was published, issues pertaining to normality and difference and to discrimination against disabled people have been continuously addressed in disability research, and this scholarship now makes up a large, heterogeneous body of work (e.g. Hacking 1986; Davis 1995; Davis 1997; Garland-Thomson 1997; 2009; Evans 1999; Solvang 2000; Grue 2015).

Feminist disability studies has contributed in particular to the discussion on normalcy and deviance by theorising disability as an effect of power relations and uncovering discriminatory attitudes and actions towards bodies that are considered 'abnormal' (Garland-Thomson 2005). For instance, Garland-Thomson (1997) coined the analytical concept 'the normate' for the ideal human body, against which disabled bodies are constantly contrasted and constructed. Feminist disability studies emphasises how the cultural discourse of disability is encapsulated in systems of oppression similar to that which other groups that are considered different are subjected to. For example, 'people of colour', 'women' and 'queers' are each grouped together in subordinate discourses in ways that are similar to the grouping and subordination of subjects with a variety of characteristics, experiences and identities who are reduced to 'disabled' in social categorisation and stigmatised through cultural notions of inferiority (Garland-Thomson 2005). This critique include textual representations as well:

Just as critics have come to recognize that the blackness of an Othello or the madness of an Ophelia, for example, goes beyond metaphor to do the cultural work of racism and sexism, so feminist disability studies understands that textual figures of disability both register and materialize social patterns of bias and exclusion based on ability norms that operate similarly to the gender and racial systems (Garland-Thomson 2005, p. 1564-1565).

Although representations of disabled people might be considered discriminatory by some, others might disagree. Solvang (2000) gives an interesting illustration of this point when he discusses a debate in the Norwegian media that followed in the aftermath of an art exhibition in 1998. Here, the Norwegian painter Nerdrum presented his painting 'Pissing Woman' of a naked, limbless woman urinating. The reactions from Norwegian disability organisations

were contradictory. On one hand, the special organisation for the physically disabled (NHK) reacted negatively to the painting, which they found to represent disabled people in a degrading way. On the other hand, the umbrella organisation for the disabled (FFO) reacted positively to the painting, which they found to celebrate bodily diversity. Solvang locates the first reaction in a normality/deviance discourse in which disabled people are to be treated 'as normal'. He locates the second reaction in an us/them discourse in which difference is celebrated. This example illustrates that different discourses are at play simultaneously in relation to disability (Solvang 2000). This study does not escape the tension and ambiguity of the discursive terrain related to disability. It is critical to cultural constructions and representations in which disabled people are treated or portrayed in ways that might be considered oppressive, and it simultaneously embraces the celebration of bodily variation. In line with the feminist framework this study relies on, I accept that there are no absolutes and I embrace contradiction (Tracy 2010; Lahman et al. 2010); what counts as discriminatory or liberating depends on the approach; the same thing – such as Nerdrum's painting – may be both at the same time. Also, the potential to reduce oppression may lie both in a discourse of normalisation and in a discourse that celebrates diversity. In this case, however, the study is positioned in the latter discourse and embraces the celebration of difference as will become increasingly clear in the next section.

### **Separation**

In the section above, I have illustrated that the process of hierarchisation and subordination is of the essence in conceptualisations of 'the normal' and 'the deviant'. However, another mechanism is also at play, that of separation. Inspired by feminist disability studies, I will continue to use examples that connect disability studies and gender studies, including queer studies.



The production of difference between women and men is not only produced vertically by the subordination of women in relation to men, but also horizontally by the separation between women and men. It is one of the most fundamental divisions in society and includes the division of labour into women's work and men's work (West and Zimmerman 1991).

Disabled people share with women a history of both subordination and separation (from non-disabled people), the latter exemplified by specialised institutions, schools and so forth (Oliver and Barnes 2012). Such segregation clearly marks the boundary between what is considered 'normal' and 'different'. Also, these examples show that processes of hierarchisation and separation may both be at play in the construction of difference. While these processes may occur simultaneously, some argue that separation does not need to entail hierarchisation. I partly support this view although I find the issue too complex to provide absolute answers, as I will exemplify.

Separation may entail the creation of subgroups in which rules, standards and normative ideals different from those existing in majority society may take shape. One example is organisations created by marginalised groups. For example, organised sports for disabled people may provide views of disability that resist 'ableism' and in which disabled people may take part in social networks where they share experiences and acceptance of their condition is communicated within the environment in ways that they do not encounter in majority culture (Lindemann and Cherney 2008). This illustrates the *potential* for separation without hierarchisation into subcultures. However, becoming part of a subculture does not necessarily entail a lack of hierarchy or liberation from hegemonic ideals. For example, Lindemann and Cherney (2008) found in their study of disabled masculinity in a group of wheelchair rugby players that although the culture they encountered was empowering for disabled people and challenged 'ableist' notions of disabled people as 'weak' or 'sick', the athletes related to hypermasculine ideals that reinforced 'ableist' values of mental and

physical strength in order to become more 'normal'. Hierarchisation was still very much at play, which illustrates the complexity and ambiguity of the terrain. I will further elaborate on this matter.

Separation of that which is perceived of as 'different' or 'deviant' (e.g. women, disabled people or 'queers') from that which is considered 'usual' or 'normal' (e.g. men, non-disabled people and heterosexuals) may under certain circumstances lead to new normative conceptualisations in which it is possible to argue that the ruling hierarchy at a given time is dissolved. Political liberation movements illustrate such potential effects. I will exemplify with the successful political work of the LGTB movement as my point of departure:

The LGBT movement has a long tradition of arranging pride parades in which people celebrate a wide spectrum of gender identities, sexualities and bodily expressions that differ from 'heteronormative'<sup>13</sup> ideals. This way of highlighting diversity might not only work to empower 'unusual' people and create a greater cultural acceptance of diversity. It may also work to challenge, and over time change, cultural notions of that which is viewed as 'normal'. The substantial, enduring political work of LGTB communities (including projects to make diversity visible, such as in the parades) has increased the acceptance of gay relationships both socially and legally (Solvang 2000) and thus illustrates such an effect. It is now possible to imagine that sometime in the near future, gay relationships will have status equal to that of heterosexual relationships. One way to look at this is that two groups that previously were positioned as opposites in a hierarchy are now facing the prospect of melding together and thus this particular hierarchy is collapsing. However, there is not

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<sup>13</sup> Berlant and Warner (1998) outline 'heteronormativity' as 'the institutions, structures of understanding, and practical orientations that make heterosexuality seem not only coherent – that is, organized as a sexuality – but also privileged. Its coherence is always provisional, and its privilege can take several (sometimes contradictory) forms: unmarked, as the basic idiom of the personal and the social; or marked as a natural state; or projected as an ideal or moral accomplishment' (p. 548).

political (or academic) consensus on whether such a union is possible – or indeed desirable. While some position themselves in a normalisation discourse and argue in favour of sameness and equal rights, others position themselves in an us-them discourse and work for the prospect of equal rights *and* the right to be different. These conflicting perspectives continue to highlight different solutions on how to increase social equality and justice.

In terms of the increasing equity between discourses on homosexuality and heterosexuality in Norway, one might complicate the issue by asking: Is it really a process of separation without hierarchy that is currently taking place? Who does it embrace and exclude? Does this process challenge the hierarchy or does it in fact strengthen it by playing by the rules of hegemonic notions of gender and sexuality? I suggest that the latter is what is going on; while some (new) groups are included in this process, others will still be excluded – for the same reasons as before the process of inclusion took place. The perspective of ‘homonormativity’, i.e. a politic that supports instead of challenges ‘heteronormative’ ideals (Duggan 2003), highlights the complexity of the issue. While ‘homonormativity’ might be considered increasingly acceptable, this might not be the case when people express a more radical difference that challenges ‘heteronormative’ discourses (Svendsen, Stubberud and Djupedal 2018). This study is first and foremost positioned within an us-them discourse, thereby resisting the notion that normalisation is the most useful approach to equality. Instead, I emphasise the right to be different *and* equal, and support the continuous effort to achieve this aim through political work and problematisation of social injustice in which difference is degraded.

Inspired by the political work of LGTB communities, the disability movement has also arranged pride parades in which the goal is to fight against prejudice, empower disabled people and make visible positive aspects of living with ‘unusual’ bodies (Grue 2014). This challenges the dominant perceptions of disability as subordinate and might over time, in combination with other political and academic work, lead to a greater cultural acceptance of

bodies in all its amazing variations. The question remains, however, to which degree social acceptance of diversity is realistic and on what terms acceptance might occur. These are questions to which I have no definite answers.

Taken together, the work on normalcy and deviance in disability studies (and gender studies) is complex. Studies have located disability in hierarchical systems in which disabled people are subordinated in a variety of ways. Also, studies have deconstructed the idea of ‘disability’ and investigated resistance strategies used by disabled people who face discrimination (Solvang 2000). Disability studies continues to contribute concepts and theorisation that work to reimagine bodily variation in ways that escape reduction and discrimination.

### **6.3 Masculinity research and disability**

Traditionally in science, men have had the status of ‘human beings’, the ‘normal’, ‘universal’ and ‘neutral’ point of entry. However, feminist theory<sup>14</sup> and the study of women’s experiences, practices and places in the gender system have led to a recognition of men as gendered beings. In the 1990s, the study of men as gendered beings – which today is commonly known as the critical study of men and masculinities – was established as a small but independent, international field of research<sup>15</sup> (Lorentzen 2006). Studies on men and masculinities often draw on feminist theory and use the same theories and analytical tools that have been developed in feminist research in addition to concepts developed by masculinity researchers (as I will soon get back to).<sup>16</sup>

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<sup>14</sup> I elaborate on feminist theory and what it entails in the chapter ‘Theoretical framework’.

<sup>15</sup> However, books and studies on men, especially concerning fatherhood, have been published since at least the 1960s (Lorentzen 2006).

<sup>16</sup> However, not all masculinity research is feminist, but most of it is, and it is feminist and/or pro-feminist masculinity research I address in this thesis.

This research field of men and masculinity studies is interdisciplinary and consists of a range of topics and approaches. Lorentzen (2006) separates the research on men and masculinities into three main (overlapping) categories. First, research oriented towards gender equality which evolves around topics such as fatherhood, work, families, distribution of power, ethnicity and sexualities. Second, research oriented towards gender-related problems which includes violence, sexual abuse, alcoholism, suicide and criminality. Third, historic accounts which include the history of masculinity, art and literature, stereotypes and theories on the patriarchy. Research on disabled masculinities cuts across all three categories.

The shift from role theory to more constructionist-oriented research (which elsewhere in this thesis I describe in relation to the development of feminist theory and studies on women as gendered beings) took place in the field that studied men as gendered beings as well. The critique of role theory highlighted that role theory did not account for power and heterogeneity and that it blurred norms and behaviour (Pleck 1981; Kimmel 1987; Connell and Messerschmidt 2005). Masculinity scholars embraced the constructionist approach of ‘doing’ gender (West & Zimmerman 1991). This offered an alternative to more biologically based understandings of men’s characteristics and practices. Over time, masculinity was used in the plural (masculinities) to capture the internal variations among men. Today the frameworks of multiple forms of masculinity and ‘hegemony’<sup>17</sup> have replaced role theory and contributed to, for example, the revelation of the mechanisms of ‘hegemony’ and its costs and expanded the scope of what men are and can do. (See Connell and Messerschmidt 2005 for an overview of relevant studies.) Connell’s theoretical contribution has been particularly influential in this respect.

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<sup>17</sup> The term ‘hegemony’ draws on the work of Gramsci, who used it to understand class relations (Connell 1977). I outline the concept of ‘hegemony’ in the chapter ‘Theoretical framework’.

Connell outlines four types of masculinity that are constituted in relation to each other and that form a hierarchy among men. The top position, that of ‘hegemonic masculinity’ (Carrigan, Connell and Lee 1985; Connell 1987; Connell 1995; Connell and Messerschmidt 2005), constitutes the idealised form of masculinity at a given time and place. It is part of an oppressive gender system shaped by unequal power positioning in relation to subordinate masculinity (e.g. homosexual men who have lower status in the system), complicit masculinity (the majority of men who supports the system although they do not inhabit the idealised position) and marginalised masculinity (which refers to men positioned in a social category related to, for example, class or ethnicity that has negative status in the hierarchy). The masculinity theory developed by Connell was among the first theoretical contributions<sup>18</sup> in this field of research, and it has been well received by scholars and widely used in a range of academic work (Connell and Messerschmidt 2005). However, it has also reviled critique, especially related to its somewhat static and universal conceptualisation of masculinities, lack of specificity as to who represents hegemonic masculinity, whether it reduces in practice to a reification of power, and its less sufficient theory of the masculine subject (Connell and Messerschmidt 2005; Lorentzen 2006; Messerschmidt 2012). Connell and Messerschmidt (2005) and Messerschmidt (2012) have responded to this critique by reformulating the concept and suggesting that what must be retained from the original concept is the relational aspect – that it is constituted in relation to femininity and non-hegemonic masculinities and that it is not a pattern of domination but one of hegemony. The researchers promote the theorisation of hegemonic masculinity on different levels, local, regional and global. Also, they emphasise that the agency of subordinated groups should be recognised, intersectionality

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<sup>18</sup> Other significant theoretical contributions in the field of men and masculinities include the work of Mosse (1996), who theorised how the masculine stereotype was constructed and maintained in relation to countertypes in Europa from the 18<sup>th</sup> century, and the work of Kimmel (1994), who suggested that in the search for idealised masculinity, power and conquest, men are (in an American context) driven by the fear of falling into demasculinisation rather than from the drive to dominate.

valued and that a more sophisticated treatment of its embodiment is needed as well as conceptualisations of how it might be challenged and changed. Also, the theory has been criticised for not sufficiently taking into account the power dynamics between men and women and for using a conceptualisation in which women are excluded from the notion of masculinity. Drawing on this critique, I will address the absence of theorisation on female masculinity in this study.

Article 3, which does have a gender perspective and addresses driving practices in a masculinity perspective, draws on the experience of the 12 men in the study while the two women are left out. It would be interesting, however, to include the experiences and understandings of the two women. It would have been possible to do so within the constructionist approach of the study, as masculinity is understood in terms of ‘doing’ gender, which allows for a theorisation of masculinity without men. Indeed, this potential has been embraced by some theorists (see e.g. Halberstam 1998; Bengtsson 2016). However, in this article I chose to focus solely on the young men since this group in particular is targeted as a ‘problem’ in traffic injury prevention research, and the limited space available in the article format made it necessary to narrow down the empirical focus.

Many researchers who work at the intersection of disability and masculinity have been inspired by the work of Connell, in particular the theorisation on ‘hegemonic masculinity’ (see e.g. Hahn 1989; Gerschick and Miller 1994; Shakespeare 1999; Sparkes and Smith 2002). One early contribution in this intersecting field of research is a study by Gerschick and Miller (1994), who theorised three typical responses from disabled men in relation to ‘hegemonic masculinity’, that of reliance, rejection and reformulation. The researchers argue that some disabled men internalise current understandings of ‘hegemonic masculinity’ and construct their identity in relation to this, while others reject it and/or reformulate alternatives.

Another significant contribution is that of Shakespeare, Gillespie-Sells and Davies (1999), who offer a rare account of disabled men and women's experiences of their sexual lives. Shakespeare (1999) argues in relation to this work that male sexuality is traditionally constructed as phallosentric and oppressive and that this constitutes a problem for men in general. However, what he sees as an obsessive focus on perceived impotence and lack of manhood in popular notions of disabled men 'reinforce the idea of disabled men being excluded from sexual activity because of erectile failure, and consequently of being less than men' (p. 57). Furthermore, disabled men are 'Othered'. They are denigrated and rejected by a masculine ideology that negates vulnerability, weakness and the body and projects it onto the 'Other'. According to Shakespeare, 'hegemonic masculinity' undermines not only disabled men's subjectivity, but also generates and maintains prejudice against disabled people in general.

Like the field of masculinity research in general, the early work of masculinity disability research has been criticised for static conceptualisations of masculinity and disability and for a lack of nuances in this respect. Shuttleworth, Wedgwood and Wilson (2012) argue that the main problems in this research field are, first, the minimal attention paid to differences in impairment and the body (in the flesh) and, second, the lack of research on intersecting identities. In sum, this paints a picture of disabled men as a homogenous, one-dimensional group. In addition, one misses out on the rich theoretical insight that might be revealed when the experiences of bodily variation and the impact of ethnicity, class, age and so on complicate the picture. However, the researchers emphasise that increased diversification and interdisciplinary approaches in the field of men and masculinities have led to more sophisticated analysis and complex understandings of disabled men's gendered experiences since the mid to late 1990s.



Internationally, the lack of research on disabled men in comparison with research on disabled women have been emphasised (Shakespeare, Gillespie-Sells and Davies 1996; Shakespeare 1999; Sparkes and Smith 2002). However, there has been an increase in research on disabled masculinities over the years that has evolved towards a nuanced perspective on both disability and masculinity and that contributes to intersectional analysis (Shuttleworth, Wedgwood and Wilson 2012). For example, Guter and Killacky (2004) contribute an anthology in which gay, disabled men share and discuss their experiences of living as queer men with spinal cord injuries (SCI), AIDS, mobility and neuromuscular disorders, amongst other conditions. The move towards a more dynamic understanding of disabled masculinities includes research that explicitly addresses the disabled male body. For example, Sparkes and Smith (2002) theorise the embodied experience of four men who experienced SCI through rugby football playing. This account thematises the experience of lost masculinity and self-identity *as men* in relation to the bodily experience of SCI.

In the Norwegian context, however, gender remains under-examined in the field of disability research (and vice versa), and there is, with a few exceptions (see e.g. Moser 2006; Sundstrøm 2015), a particular lack of studies of disabled men's experiences (Kittelsaa, Kristensen, and Wik 2016). Overall, according to Kittelsaa, Kristensen, and Wik (2016), a common feature of Norwegian disability studies which include gender is that they focus mainly on the lives and experiences of women (e.g. Kristiansen 2004; Olsvik 2006), they tend to essentialise gender, and they lack nuance, such as sensitivity towards variation within gender categories (e.g. Gundersen, Neuman and Egeland 2014).

Shuttleworth, Wedgwood and Wilson (2012) note that overall there is still minimal research on disability and masculinity in a non-Western context, as well as impairment-specific research, including 'men with sensory impairments, degenerative diseases, transient impairments such as mental illness and impairments that affect social functioning such as

Asperger's' (p. 187). They also emphasise the necessity to avoid presenting disability as if it were a 'generic category' in relation to masculinity rather than exploring how it intersects differently with various types of impairment. In response to this call, I emphasise the bodily variation of the study participants and its intersection with masculinity in article 3.<sup>19</sup> I have realised in the aftermath of publishing article 1 and article 2, however, that these texts would have benefited analytically from impairment-specific recognition as well. In these texts, disability is treated in a rather homogeneous manner. This is problematic since, first, treating disabled people as a single, uniform group may make it appear as though disabled people are more homogeneous than they are, and fails to acknowledge that 'disabled people' is a socially created category as diverse as the individuals it is meant to encompass (Couser 2005; Lid 2013; Kittelsaa, Kristensen and Wik 2016). Second, it misses out on the personal experience of impairment-specific embodiment and the important insight that, for example, the degree of impairment will produce different outcomes in similar situations (Shuttleworth, Wedgwood and Wilson 2012). For example, some study participants were visibly impaired while others were not, and the prospect of recovery varied. It would have been interesting to address the potential impact of such differences in the discussion of 'ableism' in article 2 or the different opportunities to attain employment in relation to the degree of impairment in article 1. These are insights that I count as part of the learning outcome in the process of conducting this study and maturing as a researcher.

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<sup>19</sup> Please note that in article 3 I do not suggest that caring aspects are related to 'hegemonic masculinity'. What I do suggest, however, is that in traffic injury prevention research responsible driving, i.e. driving according to traffic laws and regulations, is constructed as hegemonic; it is discursively produced as rational human behaviour. In contrast, deviating from normative driving ideals is constructed as irrational and pathological behaviour which is associated with 'young problem drivers'.

## 6.4 Road traffic accidents, masculinity and driving

The commonality shared by participants in this study is not only their experience of ‘becoming’ disabled, but also that they have been drivers in road traffic accidents. Thus, I will present the context and relevant research on road traffic accidents.

Worldwide, approximately 1.25 million people are killed in traffic accidents every year, and up to 50 million are injured as a result of road traffic accidents (WHO 2013; WHO 2015). This makes road traffic accidents the ninth leading cause of death globally and the leading cause of death for those who are 15–29 years old. Thus, road traffic accidents are a global health issue and one that concerns the health and well-being of young people in particular. In spite of extensive prevention efforts directed at young drivers, this group has continued to be over-represented in crash, fatality and injury statistics (Scott-Parker et al. 2013). In Norway, which ranks among the safest countries in the world to drive in (IRTAD 2014) and in which the road traffic fatality and injury statistics are relatively low (and decreasing), men and younger people are groups with relatively high representation in the accident statistics. With a population of 5,295,619 residents<sup>20</sup> (Statistics Norway), a yearly average of 138 people have been killed (103 men and 36 women), and 679 people (443 men and 236 women) have been severely injured, in road traffic accidents during the past five years. Out of the yearly average of 138 fatalities, 25 are between 16 and 24 years old (Statistics Norway). It is in this context that the Norwegian Council for Road Safety has requested more research about young adults who have been drivers in severe accidents, and the study was initially motivated by this call.

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<sup>20</sup> Population as of 1 January 2018.

Research on road traffic accidents is a vast field that consists of a variety of perspectives, which often are problem focused. For instance, studies have sought to, first, identify attitudes towards and the prevalence of driving while drunk and/or intoxicated, which is generally considered a severe problem in terms of reduced traffic safety (i.e. Fynbo 2014; Bogstrand et al. 2015); second, examine the risks and experiences of driving motorcycles, which has a high mortality rate in comparison with cars (Simpson, Wilson, and Currey 2015); and, third, look at the long-term consequences of injuries sustained in road traffic accidents, which are found to be severe not only in terms of physical but also social and psychological distress (Gopinath et al. 2015; Craig et al. 2016). This dissertation looks at young drivers' experiences and practices; therefore, I focus mainly on research on this group and ways to reduce road traffic accidents in which this group is involved. This is a topic that has received much attention in the field over the years (see e.g. Engström et al. 2003; Senserrick 2006; Moe 2012). Measures to reduce accidents among young drivers include social marketing campaigns, vehicle technologies, and programmes to make young men reflect on risky driving practices and their own attitudes towards driving (see e.g. Senserrick 2006; Falk and Montgomery 2007; Moe 2012; Lewis, Watson and White 2013). The role of peers and parents in shaping young drivers' behaviour has also been under scrutiny. The influence of peers in particular is highlighted as substantial (Gheorghiu 2015).

Men make up more than fully three-quarters of all road traffic fatalities (WHO 2013; WHO 2015) and young men in association with driving are often presented as dangerous, both in mainstream media and in academic literature (Redshaw 2008; Best 2008; Balkmar 2012). The construction of gender is therefore an obvious approach for critical analysis of road traffic accidents and driving practices. Nevertheless, the research literature in the field of road traffic injury prevention, which may benefit the most from such investigations, typically has an essentialised understanding of gender (see e.g. Jonah 1997; Iversen and Rundmo 2002;

Ulleberg 2001; Moe 2012). However, in previous studies gender researchers have explored constructions of gender by, for example, car racers, car modifiers, and greasers (Hatton 2007; Lumsden 2010; Balkmar 2012; 2014; Joelsson 2013) and addressed the stereotypical presentation of the ‘dangerous’, young, male driver, which constructs a strong binary between insiders and outsiders (Best 2008; Balkmar and Joelsson 2014). In these studies, racing, cruising, modifying cars and risky driving practices are understood as ways for young men to display and negotiate their masculine identities. Research on risk typically employs the taken-for-granted knowledge that risk is negative and dangerous (Douglas 1992; Austen 2009; Balkmar and Joelsson 2014), but instead these scholars explore the drivers’ actions as situated and context-dependent social practices that are meaningful to the individual or group within the universe in which they operate. For example, in her study of a group of young Swedish greasers, Joelsson (2013; 2014; 2015) explores the social context that the drivers rely on to understand the risk-taking driving practices they engage in. She argues that the greasers constructed a discourse of fun and control that was strictly regulated, and risky driving practices were the result. To become a legitimate greaser in this specific culture, the young, male driver had to display control – over the car, his emotions, and the (humorous) narrative in which he presented himself. Moreover, having fun, being fun, and creating fun were crucial for the legitimacy of the greaser. To the greasers, bored and boring people (mainly represented by ‘geeks’) functioned as a counter-image, against which the greasers constructed themselves as fun people. Having fun was associated with cruising, speeding and drifting, and thus risk-taking, was the social effect of the discourse. Joelsson argues that risk-taking practices with motor vehicles are to be understood as violations because dangerous driving practices created in the realms of ‘fun’ and control, in addition to their potentially harmful consequences, obscure aspects of the men’s care for themselves as well as their care for others (Joelsson 2014). In article 3, we take part in this critical research dialogue on young men and driving practices by exploring the world views of young men who have

*already* experienced the harmful consequences of severe traffic accidents. What our approach offers is an exploration of these young men's capacity for safe (rather than risky) driving and care (rather than carelessness). In addition, we seek to illustrate the potential for fruitful communication about injury prevention strategies between traffic injury prevention experts and young, male drivers when the situatedness of the men's actions is the point of departure. Furthermore, this article contributes a gender perspective to disability studies.

## **6.5 Summary**

In this chapter, I present the background of this interdisciplinary study. I introduce the research fields of disability studies (including feminist disability studies) and masculinity studies – with emphasis on research in the intersection of disability and masculinity. To contextualise the study, I present the political turn to discourses of accessibility and disabling barriers which are currently emphasised in national policies related to disabilities and give an overview of the contextual landscape concerning road traffic accidents internationally and nationally.

# **7 Theoretical framework**

## **7.1 Introduction**

As I am a social scientist myself, the reader might notice that I often speak of and from the field of the social sciences. However, I work in a radically interdisciplinary terrain which requires that different theoretical approaches are used and brought into dialogue with one another. In effect, this study is a hybrid inspired by a range of interdisciplinary theoretical approaches, including theories about disability, cultural encounters, Othering processes, discourses, constructions of cultural concepts and masculinity ideals (Oliver 2004; Shakespeare 2014; Hastrup 1992; Beauvoir 2000 [1949]; Campbell 2009; Brons 2015; Goffman 1990 [1963]; Bowker and Star 2000; Gibson 2014; Connell 1995; Elliott 2016). In this chapter I will present the overarching theoretical approaches that cut across the thesis and describe the road that the study follows. I start by introducing feminist theory and locate the study in this theoretical terrain, including its take on social constructionism. Then, I outline the study's understanding of discourses, power and hegemony. Lastly, I elaborate on two theoretical aspects of particular significance in this study. First, I discuss 'Otherness' as a theoretical tool, and second, I contextualise the study's use of the social model of disability.

## **7.2 Feminist theory**

### **7.2.1 The study's feminist approach**

The theoretical approach in this study is influenced by my background in gender studies and disability studies. The critical, feminist framework that has emerged and been developed in these academic fields informs the study. A feminist approach entails that the study openly commits to a social justice agenda and shares a solidarity approach to marginalised groups

which in the context of this study involves disabled people and a problematisation of ‘ableism’ in particular. Women and ethnic minorities are examples of other groups that have been subjected to marginalisation by majority society. Feminist theory has contributed perspectives that identify and confront sexism and racism, and promoted alternatives that aim to increase equality and social justice (Olesen 2018).

The overall feminist framework influences my way of writing in the sense that I situate myself in the text and seek to be reflexive and make explicit the impact of power in the research process and resist oppression (Finlay 2002; Ramazanoğlu and Holland 2002). By the latter I mean that the study embraces the challenge of a critical social science which ‘requires that the researcher reconstruct the purposes of inquiry to engage with the struggle for equity and justice, while at the same time examining (and countering) individual power created for the researcher within the context of inquiry’ (Cannella and Lincoln 2018, p. 84). Thus, the study seeks to critically investigate power asymmetry in both conduct and content. Gender studies and disability studies have been influential in this respect by offering theoretical concepts and departures that enable an awareness and examination of cultural conceptualisations in which some groups are positioned as ‘Other’ while some are positioned as ‘Self’, which is of primary concern in this thesis.

Since the 1970s, feminist activists and researchers have systematically investigated the gender system from a variety of angles. Their academic contributions include the development of pervasive critical analysis and ground-breaking theories that have challenged and changed the direction of the social and humanistic sciences in profound ways (Ramazanoğlu and Holland 2002; Davies 2006). In this chapter, I will introduce and discuss feminist theory in order to give the reader an overview of the theoretical landscape that has inspired this study. By putting feminist theory in dialogue with key issues in disability



studies, I will show how the study is situated in the intersection between disability studies and gender studies, which is also where it makes its scientific contribution. In this discussion, I will point out epistemological tensions in the terrain that this study operates within to clarify the kind of knowledge this study produces and to locate the study theoretically.

### **7.2.2 Feminist critique: uncovering bias and misrepresentation**

Feminist researchers have offered radical critique of research that traditionally has been presented as unbiased, universal and holistic. Specifically, feminist critiques of scientific practice and epistemology have pointed out how bias is produced by the methods and tools of research, the data selection process, and scientists' attempt to produce 'objective' presentations of social matters (Harding 1992; Haraway 1992; Ramazanoğlu and Holland 2002). For example, feminist researchers revealed that much ethnographic research which appeared to be unbiased was highly gendered in both conduct and content (Davies 2006). Often, and without acknowledging the fact, anthropological studies were conducted by men, had only male informants, and discussed the lives of men (ibid.). Thus, feminists revealed both male bias and the absence of women and their perspectives in ethnographic studies.

Critique raised by early feminist researchers and the political movement for women's rights that worked for social change and equity between the sexes had significant and long-term impact in academia. First, feminism encouraged more women to pursue academic careers and as a result the representation of women researchers increased. Also, and relatedly, since female researchers more often (but not necessarily) took an interest in issues related to women and gender, these became a topic of greater interest in anthropological studies (Davies 2006). For example, Rosaldo and Lamphere (1974) published an anthology in which 16 female anthropologists problematised the male bias in ethnographic research and explored the thus far under-investigated complex roles and agency of women in culture(s). A

significant contribution in this volume is the theorisation by Ortner (1974). She was among the first to challenge the positivist understanding of gender in anthropology in which sexual asymmetry (in which women are positioned as subordinate), segregation of the sexes, and differences between men and women had been perceived of as ‘natural’ and taken for granted. She aimed to offer an explanation for the universal subordinate status of women in comparison with men. Her main argument was that women are associated with nature due to childbearing and so forth while men are associated with culture. As nature is subordinated to culture, so women are considered inferior to men (ibid.). The theory received criticism for being too simplistic and for not taking into account that nature may not be as universally distinguished from culture as she assumed (Hylland-Eriksen 2010). Nevertheless, such perspectives have opened up the possibility to critically examine the power and legitimisation of gendered social structures and to investigate the constructed nature of gendered categories and their consequences in terms of social injustice. These are insights that this study draws on by investigating the construction of both masculinity and disability as social categories and social processes of ‘Othering’.

One of the results of the critique feminist academics launched against the practice and authority of science in the 1970s onwards, was the establishment of fields of study that resisted disciplinary rules in established university disciplines. This study is positioned at the intersection of gender studies and disability studies, which are both examples of such interdisciplinary fields. They are indebted to two different social movements, but also have theoretical affinities. Specifically, issues of gender and disability can be fruitfully explored in tandem with attention to how inequalities are written onto bodily functions. For example, in the field of psychoanalysis, feminists have recognised Freud’s theorisation, such as that of penis envy, as problematic given that it constructs the male body as normative at the expense of the integrity of the female body (see e.g. Kate Millett 1970; Shulamit Firestone 1970;

Betty Friedan 1974). Freud constructs women as disabled in terms of being ‘castrated’ male bodies that menstruate by ‘eternal wounds’ (Freud 1957). In the field of philosophy, Aristotle describes woman as a ‘deformed male’ (Aristotle 1944).<sup>21</sup> This is a conceptualisation in which the male is constituted as norm, which in turn produces the female body as abnormal. In line with feminist disability studies, I understand these conceptualisations of gender and bodily difference as key resources for understanding how gender and disability are conceptualised in our society.

Women’s bodies have not only been associated with a lack of physical bodily functions. Importantly, the female body has also been ascribed with a lack of mental functions, which in turn has been explained by their bodies (Laqueur 1990; Lloyd 1993). Genevieve Lloyd explores how rationality and truth are associated not with humanity, but with maleness, and argues that: ‘The obstacles to female cultivation of Reason spring to a large extent from the fact that our ideals of Reason have historically incorporated an exclusion of the feminine, and that femininity itself has been partly constituted through such processes of exclusion’ (Lloyd 1993, p. xix). As Thomas Laqueur and others have shown, a variety of theories about what exactly it is in female bodies that produces mental inferiority has been postulated in Western science over several decades (Laqueur 1990). Like disabled people, women have been denied access to the public sphere, including education, political participation and the labour market, due to ascribed bodily deterioration and lack of strength and capacity to manage the burden of reasoning, thinking and reading (Garland-Thomson 1997). Furthermore, the cultural tradition of drawing analogies between bodily and mental functions is very real and still a problem both for disabled people and for women’s struggle for equality and respect.

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<sup>21</sup> I borrow the examples of how female bodies are linked with disability in the theorisation of Freud and Aristotle from Garland-Thomson (1997).

### 7.2.3 The materiality of the body

As shown in the preceding section, studies on gender and disability can be productive elements in dialogue on the social production of bodily capability. While there are many similarities between discursive processes and their material effects in constructions of gender and disability, the disabled body has a materiality that should also be accounted for.

Shakespeare (2014) argues that the link between gender and disability may be very fruitful to explore in terms of, for example, addressing experiences of oppression and marginalisation, but that it also has important limitations:

Disability always has a biological dimension that usually entails limitation or incapacity, and sometimes frailty and pain. These aspects of disability can be modified or mitigated by environmental change or social intervention, but often cannot be entirely removed. They are not just a matter of culture and language (Shakespeare 2014, p. 49).

Shakespeare cautions against a simplified equation between gender and disability and an approach to disability in which disability is construed as a purely social construct, because this might lead to a production of stories about disabled people that do not account for their lived realities as impaired. For example, one might legitimately argue, he notes, that women are not really made less capable by their biology, while impairments may entail a complex and problematic biological situation for the subjects involved. Thus, the bodily experience of gender and of disability is radically different in this respect. And while problems faced due to gender might be solved by equality, the situation is more complex in terms of disability:

[E]ven in the absence of social barriers or oppression, it would still be problematic to have an impairment, because many impairments are limiting or difficult (...) disabled

people often experience major disadvantages as a result of their genetic endowment, whereas members of other historically oppressed communities experience either minimal or non-existent biological disadvantages (Shakespeare 2014, p. 29-31).

These insights on the materiality of the disabled body – and the difference between gendered bodies and disabled bodies in this respect – actualises potential limitations in the constructionist approach used in this study. I acknowledge that the materiality of disabled bodies is of significance to the study participants' lived realities, and by speaking from a constructionist position I also seek to take this insight into account in the study. Therefore, I have chosen to describe impairment-specific bodies in article 3. I do so in order to illustrate that the biological body may come to matter, for example, in terms of possibilities and the lack thereof as it is experienced by individuals due to their particular bodily situations.

#### **7.2.4 Feminist theories on objectivity and 'situated knowledges'**

The academic contributions on women and their lives by feminist researchers concern issues of epistemology because they raise questions about what knowledge is, who counts as knowledgeable, who speaks and who they speak to – or who they speak for. These are questions that touch upon the notion of objectivity and how it has been perceived of in science. One might argue that producing knowledge about women will make science more objective since it fills gaps in the knowledge about the world, about humans, about culture – which makes it more representative. However, feminist theorisation on objectivity went much further. Two of the most substantial contributions considering objectivity and epistemology are Harding's 'standpoint'<sup>22</sup> theory (1992) and Haraway's concept of 'the God trick' (1996),

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<sup>22</sup> Inherent in 'standpoint' theory is the implicit understanding that one views the world from a standing position. In response, feminist disability scholar Garland-Thomson (2005) has coined the term 'sit-point' theory to draw attention to this bias.

which have influenced feminist thinkers for decades and which inspire the conceptualisation of objectivity used in this study.

‘Standpoint’ theory is an attempt to reach a higher standard of objectivity than that which is accessible in older epistemologies and traditional scientific methods. Rather than attempting to eliminate bias such as androcentrism and sexism, which some feminists hold to be possible – standpoint theorists find that there are certain locations that are better than others as points of departure to produce knowledge. The main idea is that dominant groups are epistemologically disadvantaged when it comes to the ability to understand the world.

Marginalised groups, on the other hand, have a social position that potentially might generate better knowledge. According to the theory, this approach holds the potential to produce less distorted, partial accounts and therefore to reach a higher level of objectivity (Harding 1992).

‘Standpoint’ theory has been used by disability scholars to complicate issues of bodily configuration in terms of their impact on identity and subjectivity (Garland-Thomson 1997).

Disability ‘standpoint’ theory includes Grealy (1994), who discusses the gendered system of appearance and beauty from the position of having personal experience of facial disfigurement, and Wendell (1996), who discusses normalcy from the position of living with disabilities.

A voice in the same debate as Harding is Haraway, who uses ‘the God trick’ as a metaphor to capture ways in which (male-based) science has been presented as neutral and objective in the positivist sense, as ‘the gaze from nowhere’. However, she argues that this is an illusion; research is always ‘a gaze from somewhere’ despite how successful the strategies used to conceal that it is. Instead, Haraway argues in favour of ‘situated knowledges’ and suggests that it is by situating oneself – so that others may investigate the research from an informed position – that one may achieve objectivity (Haraway 1996).

I do not position myself as a ‘standpoint’ theorist – and I do make attempts to uncover and confront bias in the research process. However, I agree that marginalised groups speak from a position in which other, significant knowledge might arise and acknowledge the significance of letting voices from the margin be heard. This influences the emphasis in this study on emic perspectives and on collaborating with the study participants in the process of producing data. Moreover, the feminist debate on epistemology and objectivity influences the emphasis in the study on, first, situating the researcher in the texts to highlight the particular position from which this study is conducted; second, on using reflexive practices in order to make the research process transparent; and, third, on positioning the study not as objective in the positivist sense, but through the effort to produce ‘situated knowledges’ and thus position myself accountable for the study’s knowledge claims.

### **7.2.5 Feminist theorisation on gender**

Thus far, I have outlined two significant contributions to science by feminist researchers: the revelation of misrepresentation and male bias in research (followed by studies on women and substantial critique of androcentrism in science) and epistemological theorisation on issues of objectivity. Another significant feminist contribution is advanced theorisation of bodies and gender in terms of the sex/gender divide.<sup>23</sup> I will briefly address significant feminist contributions in this terrain, locate the study within it, and then in the next section use these contributions as a point of departure to discuss this study’s social constructionist epistemology.

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<sup>23</sup> This includes the revelation that men too are gendered beings, which I address in the chapter ‘Masculinity research and disability’.

Initially, gender was theorised in feminist studies in terms of gender roles. This entailed seeing gender not simply as biologically given, but also as shaped by socialisation processes both in the family and in society. Role theory researchers argued that due to their reproductive roles, women were socialised into positions in the home where they were responsible for domestic tasks and caregiving while men were socialised into positions outside the home to economically provide for their families (Dahlstrøm et al. 1962; Parsons 1942). The theory of gender roles inspired approaches in gender research that often fall under the category of ‘doing’ gender, which is the conceptualisation of gender used in this study. This approach offers more room to understand processes of change, resistance, internal variation within the gender categories, and how the notions of gender are constituted than when gender is framed in terms of roles (Lorentzen and Mühleisen 2006). I will use the work of West and Zimmerman (1991) to outline the ‘doing’ gender perspective.

West and Zimmerman positioned themselves in opposition to role theory, stating that ‘gender is not a set of traits, nor a variable, nor a role, but the product of social doings of some sort’ (p. 129). They argued that how one ought to present oneself as a gendered person is prescribed by cultural norms that one must follow in order to be acknowledged as a legitimate human being. Thus, gender is not optional or something one might ‘take on’ or not (as the role of a waitress for instance) as indicated by the term ‘role’. Gender is an obligatory master status by which we continuously judge others and are judged by others, and it is constructed by productions of difference between the sexes:

Doing gender means creating differences between girls and boys and women and men, differences that are not natural, essential, or biological. Once the differences have been constructed, they are used to reinforce the ‘essentialness’ of gender (West and Zimmerman 1991, p. 137).



As implied by this quote, the construction of gender makes gender appear as ‘natural’. Thus, by constructing gender, institutional gender arrangements are made legitimate. The construction of gender is so fundamental and successful that arrangements producing this very system are seen merely as a response to the actual (biological) differences – ‘the social order being merely an accomodation to the natural order’ (p. 146). However, ‘doing’ gender is labour. It is accomplished by a complex system that involves recruiting children into self-regulating processes that value particular ways to be and behave. Moreover, it involves the construction of gender identities that individuals strive to maintain. Gender is continuously ‘done’ in interactions with others. When gender is ‘done’ right, it reproduces and legitimates the gender system – including the subordination of women and segregation of the sexes – while when failing to ‘do’ it appropriately ‘we as individuals – not the institutional arrangements – may be called to account (for our character, motives, and predispositions)’ (West and Zimmerman 1991, p. 146). While it is by this approach gender is understood and used in this thesis, I will also outline Butler’s notion of gender. I do so both because it offers a comparative perspective by which my epistemological position emerges with more clarity and because it is a significant contribution to the research literature in gender studies that ought to be acknowledged.

Butler introduced the term ‘performativity’. She argued that femininity and masculinity are creations that are continuously shaped by cultural and historical processes in a complex system of performances by individuals who imitate (and resist) cultural norms through repeated acts in order to be recognised as ‘men’ or ‘women’ (Butler 1990; 1993; 2004). While it may appear similar, the theorisation of Butler is not framed in the same way as the ‘doing’ gender perspective. Butler acknowledged the feminist motivation behind work that emphasised the separation of sex from gender. After all, such a logic offers women the

prospect of liberation from discrimination because in such a framing it does not matter how fixed sex is; gender is culturally constructed and thus its content is negotiable. However, Butler took a critical position towards the theory itself and pointed to what she saw as a logical problem in its structure:

If gender is the cultural meanings that the sexed body assumes, then a gender cannot be said to follow from a sex in any one way. Taken to its logical limit, the sex/gender distinction suggests a radical discontinuity between sexed bodies and culturally constructed genders. (...) When the constructed status of gender is theorized as radically independent of sex, gender itself becomes a free-floating artifice, with the consequence that *man* and *masculine* might just as easily signify a female body as a male one, and *woman* and *feminine* a male body as easily as a female one (Butler 1990, p. 9).

Butler rejected the view that the sexed body is prediscursively produced as male and female. Instead, she argued that such a view is itself a discursive production. The sexed body is naturalised to support hegemonic gender systems. She suggested that in fact, both sex and gender are culturally constructed:

If the immutable character of sex is contested, perhaps this construct called 'sex' is as culturally constructed as gender; indeed, perhaps it was always already gender, with the consequence that the distinction between sex and gender turns out to be no distinction at all (Butler 1990, p. 9-10).

Clearly, the approach to gender framed by West and Zimmerman on the one hand, and Butler on the other hand, differ substantially. The reason for this is that they belong to different

paradigms of knowledge. The first relates to a constructionist epistemology and the second to a subjectivist one. This study is based on a constructionist epistemology which entails the view that male and female bodies exist as objects in the world, but they become gendered when they are constructed as such and filled with such meaning. This stands in contrast to the subjectivist view posed by Butler in which all meaning comes from the mind of human beings and thus male and female bodies do not exist as objects in the world. In the next section, I will elaborate on what these epistemological positions entail theoretically in order to make explicit the kind of knowledge this study produces and its analytical approach.

### **7.2.6 Social constructionism in the study**

The difference between a constructionist and a subjectivist epistemology emerges in the relation to the object of knowledge. In constructionism, meaning or ‘truth’ is generated by our engagement with realities in the world: ‘subject and object emerge as partners in the generation of meaning’ (Crotty 1998, p. 9). Thus, femininities and masculinities are constructions that emerge from the subject’s interpretation of the object (the body). In subjectivism, the object makes no such contribution in the generation of meaning. Instead, meaning (and thus gender) comes from somewhere else:

[In subjectivism, the] meaning we ascribe to the object may come from our dreams, or from primordial archetypes we locate within our collective unconscious, or from the conjunction and aspects of the planets, or from religious beliefs, or from... That is to say, meaning comes from anything *but* an interaction between the subject and the object to which it is ascribed (Crotty 1998, p. 9).

Thus, constructionism and subjectivism do not fit well together. Epistemologically, this study operates in a constructionist terrain. Constructionism stands in opposition not only to

subjectivism, but most definitely to objectivist epistemology which holds the notion that ‘truth and meaning reside in their objects independently of any consciousness’ (Crotty 1998, p. 42). Instead, constructionism holds that

all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context (Crotty 2008, p. 41).

In constructionism, meaning cannot be described as either objective or subjective (Crotty 1998, p. 43). Meaning is not *discovered* as in objectivism or *created* and imposed on the object of knowledge as in subjectivism (ibid., p. 48). Instead, it is always *constructed* in the interaction between the subject and the objects that are under interpretation: ‘We construct meaning. We have something to work with. What we have to work with is the world and objects in the world’ (ibid., p. 44). Thus, in this epistemology the object is central to the construction of meaning; it might be meaningless in itself, but it plays an important part in the process of meaning-making (ibid., p. 48). In the constructionist approach, there is no ‘true’ interpretation. However, some interpretations might be more useful than others (ibid., p. 47). Whereas some constructivists<sup>24</sup> are concerned with the individual mind and its meaning-making processes, this study is social constructionist. By this I mean that the study emphasises collective, shared processes of generating and transmitting meaning (Schwandt 1994; Crotty 1998). As Crotty (1998) emphasises – the ‘social’ in social constructionism is not about the object of knowledge being social. The object might be from the social or the natural world (e.g. a tree); the social element here relates to the way one perceives of

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<sup>24</sup> Crotty (1998) makes a distinction between constructivism and constructionism, which I follow. My use of the term ‘constructionism’ entails that I view all meaningful reality as socially constructed.

meaning-making *as* social. This study's epistemology assumes that all knowledge about both the natural and the social world is socially constructed. For example, a 'chair may exist as a phenomenal object regardless of whether any consciousness is aware of its existence. It exists *as a chair*, however, only if conscious beings construe it as a chair' (Crotty 1998, p. 55). To 'say that meaningful reality is socially constructed is not to say that it is not real' (ibid., p. 63). Social constructionism is thus both realist and relativist, the latter because the same phenomena may be interpreted differently depending of the context (ibid., p. 64). The critical tradition in which this study is positioned entails a critical gaze towards some of the meanings that are culturally constructed:

It emphasises that particular sets of meanings, because they have come into being in and out of the give-and-take of social existence, exist to serve hegemonic interests. Each set of meanings supports particular power structures, resists moves towards greater equity, and harbours oppression, manipulation and other modes of injustice and unfreedom (Crotty 1998, p. 59-60).

While I have now positioned the study in a social constructionist epistemology, I will add a clarification concerning the autoethnography since this is an approach that tends to be associated with subjectivism (Crotty 1998). The autoethnographic account in this study is conducted from a constructionist viewpoint. It concerns the subject's inner processes of meaning-making and relates to personal experiences, thoughts and feelings which might appear subjectivist. However, these processes occur in the interaction with objects in the world – bodies. Meaning is constructed in this interaction between the subject and objects.

## **7.3 Power and discourses**

### **7.3.1 Introduction**

Overall, this study is concerned with investigations of discourses – i.e. systems of meanings that are socially constructed (Jørgensen and Phillips 2010) – and the consequences that follow from the discourses under scrutiny. Hence, I conduct a form of discourse analysis, and in this section I will first explain what I mean by the term ‘discourse’ and then describe the study’s approach to discourse analysis. Then, I outline the study’s take on power, which is understood as relational and under continuous negotiation between groups and individuals. Thus, in relation to power I draw on the concept of ‘hegemony’. I introduce this concept and outline the understanding of hegemonic discourses in this thesis.

### **7.3.2 Critical discourse analysis**

The word ‘discourse’ is frequently used in academia, and its actual meaning might be confused when it is left unexplained. Often the term ‘discourse’ is attributed to Foucault and his highly influential body of work on ‘grand’ historical discourses<sup>25</sup> (2009 [1961]; 1975; 1970; 1977; 1990). However, the term has been understood in a variety of ways by different scholars, and different kinds of discourse analysis have been developed. Sometimes discourse analysis might be strictly linguistically oriented and refer to specific texts without contextualisation. Other times, discourse might refer to textual exchange in social contexts, and the analysis might concern the social and political meaning of a phenomenon (Alvesson and Kärreman 2000). In my use of the term ‘discourse’, I mainly refer to the latter of these

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<sup>25</sup> His work can be divided into an ‘archaeological’ period (2009 [1961]; 1975; 1970), in which he questioned emerging concepts from historical archives and demonstrated that the concepts were produced in social and ethical contexts that undermined the objectivity of science (Springer and Clinton 2015), and a ‘genealogical’ period (1977; 1990), in which he questioned the notions of progress, e.g. that schools and factories resembled prisons in the ways they constructed control mechanisms (Springer and Clinton 2015).

understandings. By discourse I mean the production of texts in a broad sense – i.e. practices of thinking, talking and writing – and the production and reception of particular understandings that make them come into being as understandable and ‘real’. Phillips and Hardy state that

social reality is produced and made real through discourses, and social interactions cannot be fully understood without reference to the discourses that give them meaning. As discourse analysts, then, our task is to explore the relationship between discourse and reality (Phillips and Hardy 2002).

In line with critical discourse analysis, I find that discourses both constitute and are constituted by the social world (Jørgensen and Phillips 2010). The ‘language of percentages’ that I explore in this thesis is an example of such a discourse. It is a discourse produced at the clinic through thoughts, speech and written texts. What is the relationship between this discourse and reality? I argue that the disabled body is constructed through ‘the language of percentages’. Moreover, the disabled body may not be conceptualised as equally valuable as the non-disabled body in this discourse, as the logic in this language ranks bodies and does not allow for an interpretation in which the disabled body is ‘as good’ as the non-disabled body. This discourse affects the lived realities of the study participants; it leaks into their understandings of themselves as less valuable and/or complete than non-disabled bodies. Consequently, the discourse produces a social reality in which disabled bodies are conceptualised as incomplete, as a fraction of a whole body, and by which (disabled) individuals understand themselves as such and are understood as such by others. By examining language as a technology that contributes to the construction of the disabled body, it is possible to clarify how the meaning of the disabled body is produced.

There are many, overlapping approaches on how to analyse discourses. Some provide rigid descriptions as to how it should be done while others are less authoritative (Phillips and Hardy 2002). My take on discourse analysis evolved from a point of entry in which I had used thematic analysis. By identifying themes, I noticed how themes were a part of patterns that could be described as discourses. When discourses that caught my interest emerged from the data set, I started to investigate them more closely. This process was inspired by the approach known as critical discourse analysis. Critical discourse analysis describes both a constructionist approach to discourse and a very specific method described by Norman Fairclough (1995). I have not conducted a critical discourse analysis according to Fairclough's model, and I use the term here to describe the broader project (see Jørgensen & Phillips).

The critical discourse analysis tradition has a Marxist heritage, and seeks to uncover the reproduction of unjust power relations and produce knowledge that may be used to promote social change (Jørgensen and Phillips 2010). As such, it is not politically neutral; critical approaches to discourse seek to unveil the ideological content of ways of speaking about a phenomenon (Fairclough 1995). Phillips and Hardy (2002) emphasise that the approach may help to reveal how taken-for-granted understandings serve to privilege some and disadvantage others. This study has sought to do so, for example, by exploring non-disabled 'ableism' and ways in which it reproduces the notion of non-disabled superiority. To clarify, I treat 'ableism' in this study as a manifestation of the opinion of the non-disabled majority. This discourse works to reinforce the status of the dominant group as 'neutral, normal, legitimate, and identifiable' (Garland-Thomson 1997, p. 31) by constructing disability as subordinate and alien: 'The process of stigmatization thus legitimates the status quo, naturalizes attributions of inferiority and superiority, and obscures the socially constructed



quality of both categories' (ibid.). In the next section, I clarify the understanding of power used in this thesis.

### **7.3.3 The understanding of power in this study**

This study is committed to the political ambition of social justice and equity, and as such it is concerned with power. Power is a central concept in the study in terms of both content and conduct.<sup>26</sup> The question remains, however – what do I mean when I use the term ‘power’? According to Engelstad (2016), it shapes the lives of every citizen and exists in all kinds of relations. In this study, power enters the discussion in several ways, including theoretical approaches and methodological choices. Analytically, I approach power through the concept of ‘Othering’, which concerns how something is positioned in an asymmetrical relationship with something else. In this theoretical perspective, power can be found in the discursive production of a centre of reference and meaning against which other positions are defined. This power of definition is imbricated in material processes. As Edward Said has shown, the discourse of orientalism provides a model for thinking and writing about the world that is crucial for the colonial project (Said 1978). The power of definition is inextricably linked to power relations between groups of people and individuals. This is also the case with the relationship between researcher and research participants, as I discuss in the chapter on methodology. In both of these examples, power is exerted through discourse. Discursive power was also my starting point for understanding what power is. Initially, I relied on Foucault’s understanding of power. His conceptualisation of power is broad; he states that

the exercise of power is not simply a relationship between partners, individual or collective; it is a way in which certain actions modify others. Which is to say, of

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<sup>26</sup> The chapter ‘Reflexivity’ offers an exploration of the understanding and impact of relevant power orders (class, age, gender and ethnicity) in the course of the study.

course, that something called Power, with or without a capital letter, which is assumed to exist universally in a concentrated or diffused form, does not exist. Power exists only when it is put into action, even if, of course, it is integrated into a disparate field of possibilities brought to bear upon permanent structures (Foucault 1983, p. 219).

In this understanding, power exists only ‘in action’ although its potential might be present in structures. Power, in this conceptualisation, is not a thing. It is an ability or a feature of a relation which has an affect (Engelsrud 2016). This notion of power as produced relationally and discursively – and the focus on its *effects* – resonates with the understanding and use of power in this thesis. However, it is central in Foucault’s understanding of power that it may not be *held* or *taken* by groups or people. Power is everywhere, and it is productive (Sandmo 1999); it is not distinguished into malign and benign power. These points do not merge frictionlessly with the use of power in this thesis and so clarification is needed. The study draws on feminist theory in which the interrogation of unjust *power relations* is paramount. Moreover, exploring the misuse of power held by groups or people as well as resistance strategies used to counter such dominance have been the focus of much attention in feminist theorisation (Ellingsæter 1999). Feminists have criticised the theorisation of Foucault for lacking the possibility to conceptualise change, agency and resistance strategies (Ramazanoğlu and Holland 2002), and these tensions are brought to life in this study which works at the intersection of these theorisations.

The understanding of power in this study draws on Foucault in the sense that power is seen as relationally and discursively produced. In opposition to Foucault, however, I conceptualise power as potentially benign/malign, as seen from the standpoint of particular social groups. Also, power may be used strategically, and thus I acknowledge agency in terms of both using

and resisting power. In this respect, I draw on an understanding of power as it is conceptualised by Gramsci; power is *negotiated* and people may act as agents who have the ability to resist in the face of power (Jørgensen and Phillips 2010).

#### **7.3.4 The concept of ‘hegemony’**

I will introduce the term ‘hegemony’, which is related to power, and then explain how it is used in this thesis. Initially, the concept of ‘hegemony’ was introduced by Gramsci (1973), who used it primarily to theorise about class differences. In his theorisation, ‘hegemony’ is managed and organised by groups and organisations such as schools and churches. They maintain power through rituals, myths, theologies, theories or cultural institutions.

‘Hegemony’ relates to the means that one group uses to establish power over another group (Engelstad 2016). The group has dominant status because the power is understood as legitimate. Thus, the concept of ‘hegemony’ assumes that a group gains and maintains power through traditions and culture in a particular society. This does not happen without resistance; there are ongoing ‘battles’ about ‘hegemony’ which are played out in the public sphere, such as in politics, the media, books, education and public debates (Engelstad 2016).

The theory of ‘hegemony’ has been used to understand various kinds of power systems and asymmetrical relations between groups. In gender studies, the concept of ‘hegemonic masculinity’ has been used to understand and analyse how men are a part of gendered systems in relation to power, as I outline in the section ‘Masculinity research and disability’. The concept refers in this context to the way in which men on a group level combine their access to resources with legitimating discourses that maintain the dominance of the group (Connell 1995). I also use hegemony as a key ingredient in a critical approach to discourse.

### **7.3.5 The understanding of hegemonic discourses in this study**

The term ‘hegemonic discourses’ is used to describe and term underlying notions, ideas, ‘truths’, knowledge and/or meanings that are socially and culturally dominant. By ‘underlying’ I mean that these constructions are seen as ‘natural’, they are taken for granted and their dominant status is rarely or never questioned. Hegemonic discourses are present in the language that people use to talk and think with. Hegemonic discourses might be governed by institutions, and their effects may be materialised in bodies. I will explain what I mean with two examples.

In this thesis, I describe the biomedical discourse (Oliver 1983) as hegemonic. In this discourse, disabled bodies are constructed as having something wrong with them that ought to be fixed (Svendby et al. 2018). This dominant ‘truth’ is institutionalised and has effects. For example, I argue that ‘the language of percentages’ (Svendby et al. 2017) draws on the biomedical discourse. ‘The language of percentages’ is produced in the context of the clinic and manifested in testing procedures. The power of this discourse to define bodies as ‘incomplete’ and ‘inferior’ is maintained through these procedures. The underlying notion of inferiority is usually not questioned because the discourse is hegemonic. The power and effect of the discourse is visible not only in the procedures, but also in people’s understandings of themselves and their bodies when they integrate the underlying ‘truth’, the discourse itself. Treatment related to the test results illustrates the power of this discourse because it is materialised not only in people’s mind, but also in their flesh. By calling the discourse into question and suggesting that it might not always serve the best interest of patients, I participate in and produce a form of resistance towards this hegemonic discourse. Hegemony is never fully stable and needs to continuously change in order to keep current power relations intact (Gramsci 1973).

In article 3, I use the concept of hegemonic discourse in relation to knowledge produced by traffic agency experts. The hegemonic discourse that they produce and maintain is one in which rational behaviour in relation to driving practices is normative and central, I argue. Analytically, it would be possible to argue that when young men are acting out deviant driving practices (speeding and so forth), they are not positioned in conflict with hegemonic notions of masculinity (and youth). Instead, one might argue that deviant driving practices fit well into a hegemonic cultural script in which young men are testing boundaries, doing certain things before they become ‘boring’ adults, conforming to masculine norms, etc. (Joelsson 2013). I might have followed such an analytical approach if the study had been about deviant driving practices and young men in general. In article 3, however, the focus of attention is directed at a particular sub-sample of drivers (so-called ‘problem drivers’). The behaviour of this particular group is not explained and understood mainly or only through masculinity norms by the experts (although it may draw on gendered discourses as well). Instead, the practices and behaviour of this group are constructed as pathological and understood as a result of biology. Thus, the discourse I critique in this analysis is mainly related to ir/rationality and the in/ability to care for others.

Perhaps the greatest challenge in the work of identifying and describing present hegemonic discourses is their taken-for-granted status. The researcher as well as the study participants are embedded in the taken-for-grantedness of ruling discourses of their own culture(s) and thus will probably be blind to them. Following Tuana (2006), some knowledge may be available to us only in hindsight and ‘we do not even know that we do not know’ (p. 6). However, confrontation and comparison are helpful tools which may cast new light on hegemonic discourses and what they *do*. For example, the turn from disability in bodies to structures may be seen as a consequence of the ‘battle’ over how disability should be understood. This turn, in which two competing discourses were articulated, highlighted what

they *did* in terms of positioning the body in networks of power. Notably, what the biomedical discourse *entailed* – its perspective on the body – had not been explicitly articulated before it was critiqued. (In order to critique the discourse, it was necessary to describe it.) While the biomedical discourse located disability in the biological body, and thus held the defining power in which unusual bodies were constructed as defective, the turn to structure had other effects. Instead of focusing on the body, the focus was directed at the environment and architecture. Although these are external to our bodies, they also *do* something in relation to our bodies. By their design, buildings can make people move or not move in particular ways and directions (Engelstad 2016); they may work to exclude or include particular bodies. In this thesis, I seek not only to identify and critically examine hegemonic discourses, but also to investigate what they do and do not do in the context of the culture under study.

## 7.4 ‘Othering’ as a theoretical tool

### 7.4.1 ‘Othering’

In the thesis’ final discussion, the three articles are put in dialogue using the concept of ‘Otherness’, and I will therefore present this concept. Simone de Beauvoir (2000 [1949]) introduced the idea of the ‘Other’ in relation to the ‘Self’ in her critical examination of women as ‘the second sex’.<sup>27</sup> She argued that women are constituted as the ‘Other’ (objects) in society in relation to men who are constituted as the ‘Self’ (subjects). This is a two-way relationship in which the woman ‘determines and differentiates herself in relation to man, and he does not in relation to her; she is the inessential in front of the essential. He is the subject; he is the Absolute. She is the Other’ (p. 6). Moreover, that which is associated with men and masculinity is implicitly constituted as neutral and *human*, whereas that which is associated

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<sup>27</sup> Here Beauvoir (2000 [1949]) draws on Hegel’s work (1967 [1807]), which influenced her theorisation of the Other. Her point of departure is Hegel’s theorisation of the ‘master–slave dialectic’ about the hierarchical relationship between feudal lords and serfs.

with women and femininity is constituted as sexed. In contrast to men, women are recognised as gendered. Although Beauvoir used gender as her empirical case, she emphasised that processes of 'Othering' are fundamental in human thought:

No group ever defines itself as One without immediately setting up the Other opposite itself. It only takes three travellers brought together by chance in the same train compartment for the rest of the travellers to become vaguely hostile 'others'. Village people view anyone not belonging to the village as suspicious 'others'. For the native of a country, inhabitants of other countries are viewed as 'foreigners'; Jews are the 'others' for anti-Semites, blacks for racist Americans, indigenous people for colonists, proletarians for the propertied classes (p. 6-7).

Indeed, since Beauvoir's contribution, the concept of 'Otherness' has been used in critical research traditions to problematise a range of asymmetrical power relations between groups and (some of) their consequences in terms of discrimination and exoticism. For example, in *Orientalism* (1978) Edward Said problematises the Western construction of the Orient as the exoticised Other. In disability studies, several scholars have criticised and theorised the Othering of the disabled body in relation to the normative (non-disabled) 'Self' (see e.g. Erevelles 2011; Michalko 2002; Goodley 2014; Mik-Meyer 2016). One substantial contribution is that of Campbell (2001), who has problematised constructions of disabled people as Other in relation to non-disabled people through the term 'ableism', which she defines as 'a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human' (p. 44). In her work, Campbell (2009) has examined the construction of normativity

and the cultural production and internalisation of ‘ableism’ and shifts the focus from the marginalised Other to the problem of the ‘Self’ (Goodley 2014, p. 22).

#### **7.4.2 ‘Sophisticated othering’**

In the analysis of the study’s findings, I am inspired by the conceptualisation of ‘sophisticated othering’, which is a specific kind of ‘Othering’ outlined by Brons in ‘Othering, an Analysis’ (2015), where he explores the logic of ‘Othering’. In ‘sophisticated othering’, ‘Otherness’ is not only constructed through ‘Self–Other’ distantiating, but also through ‘Self–Other’ identification; the ‘Self’ sees himself or herself in the ‘Other’: ‘It is the implicit, and largely unconscious, modeling of the other as self by assuming that what’s true for the self is true for the encountered other as well’ (Brons, p. 71). Thus, in the process of ‘Othering’, the ‘Self’ makes conclusions based on his or her own world view. Brons uses a conversation about religious beliefs to explain the reasoning and logic that underlie this form of ‘Othering’:

I had a conversation with a Dutch teenager of Turkish descent, who at some point remarked that I was a Christian (he was a Muslim himself). I denied, which led him to inquire into my religious beliefs. My explanation that I didn’t have any, that I was (and am) an atheist, led to strong disapproval. In his mind, being an atheist implied that I was completely amoral. His argument was roughly that right and wrong are determined by God, that moral rules are God’s commands, and therefore, that someone who doesn’t believe in God cannot believe in right and wrong or moral rules either. It wasn’t so much my atheism itself that made me a bad person, but what followed from it. (...) In most – if not all – cases, the underlying argument seems to be something like the following: (a) moral beliefs are religious beliefs; (b) the other has no religious beliefs; therefore (c) the other has no moral beliefs (Brons, p. 71).



This example illustrates that in the argument, the ‘Self’ (here, the Muslim), interprets his conversation partner in terms of his own world view. ‘Othering’ occurs when he concludes that atheists are amoral. Similar processes occurred in this study, such as in encounters between disabled study participants and myself, the non-disabled researcher (as described in article 2). I took for granted that a) to be mobile and sexually capable requires a non-disabled body; b) the other has a disabled body; therefore c) the other is immobile and sexually incapable.

Brons argues that ‘sophisticated othering’ generally appears to be reasonable and is therefore persuasive. Although the argument is flawed, it appears obvious, and the ‘Othering’ is mostly accepted. Also, ‘Othering’ tends to be implicit and justifies exclusion and discrimination. However, there is a potential for transcendence when the flaw in the argument is revealed:

[E]xposure of the fallacy turns the self towards herself, and at the same time, by rejecting the conclusion (that atheists are amoral), it liberates the other from her inferiority and/or radical alienness (i.e. her otherness) and thus rehumanizes her: the other turns out to be more similar to the self than previously believed (Brons, p. 73).

This potential of transcendence is one that I embrace and elaborate on in the final discussion. The flaw in my argument (in article 2) was revealed through experience and confrontations, and I learned in the field that disabled people have the capacity to be both mobile and sexually capable (indeed that the disabled body may be so to a larger degree and/or in different ways than non-disabled bodies). Brons uses the ‘principle of charity’ (Wilson 1959) and the ‘principle of humanity’ (Grandy 1973) – ideas about how we should or can interpret others – to elaborate on the potential of transcendence: ‘The shared core idea is that in

interpreting some statement by some other, the interpreter must interpret that statement as reasonably as possible, and not attribute irrationality, incoherence, or obvious falsehoods to the other' (Brons 79). To avoid dehumanising the 'Other', the 'Self' should, according to this approach, investigate the preconceptions for the argument that lead to uncharitable attributing. This is an analytical point I draw on in the final discussion.

### 7.4.3 'Othering' in this thesis

The title of this thesis 'Becoming the Other' relates to the study's perspective on disability as not something you *are*, but something you *become*.<sup>28</sup> It is a matter of construction, not of essence. The choice of words attempts to embrace the complexity and fluidity in processes of 'Othering'. Theorisation of 'Othering' will always depend on the context in which it is produced. That a person or group is constructed as 'Other' in one situation or context does not prevent them from attaining the status as 'Self' in other situations or contexts. For example, a young, male driver may be conceptualised as 'Other' by majority society due to deviant driving practices while simultaneously being conceptualised as 'Self' by his peers for the same reason. Or, a person with a brain injury may become 'Other' in the context of the rehabilitation clinic while he may become 'Self' in a context where he is surrounded by people who do not consider brain injury to be a disability, who do not know about the brain injury, or who use characteristics (e.g. socio-cultural positions) other than those attributed to the physical body to define who you are. These examples illustrate that the categories I use for analytical purposes are simplifications. Binary conceptualisations – such as 'Self'/'Other', disabled/non-disabled – assume common identities, but these are constructions and they 'cannot be sustained across all experiences, bodies, histories, cultures, representations and relationships' (Ramazanoğlu and Holland 2002, p. 108).

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<sup>28</sup> In addition, the title seeks to make an association with the work on 'Otherness' by Beauvoir (2000 [1949]) since it is central to the thesis.

Theorisation of ‘Othering’ critically investigates conceptualisations of difference where something is set in a dualist, subordinate relationship to something else. This does not mean that all forms of ‘Othering’ are equal; the concept has been used to explore various kinds of asymmetrical power relationships and their consequences. Feminist researchers have examined unjustified power relationships in intimate relationships as well as between large groups of people and between nations. ‘Otherness’ has been examined in relation to people, language and symbolic representations. Effects that have been under scrutiny include racism, sexism, ‘ableism’ and material differences when it comes to state regulations, personal freedom, access to resources and so forth (Ramazanoğlu and Holland 2002). In sum, this theoretical field is broad.

In this thesis, ‘Othering’ is related to different kinds of discrimination, as I will soon outline. However, the process of ‘Othering’ in all three articles is the same. ‘Otherness’ is understood as discursively produced in asymmetrical power relations. In articles 1 and 2, ‘disability’ and ‘ableism’ are produced in hegemonic biomedical discourses in which the disabled body is constructed as inferior (‘Other’) to that of non-disabled people (‘Self’). In article 3, I argue that traffic injury prevention experts draw on a hegemonic discourse of ‘rationality’ in the research literature. Here, a particular group of young men are discursively produced as the opposite of ‘rational’; they are constructed as ‘irrational’ and ‘careless’ pathological objects. They become the ‘Other’ in this discourse. In the analysis, I have chosen to emphasise this particular discourse and the relationship between the producers of knowledge – i.e. traffic agency experts – as the ‘Self’ and ‘young problem drivers’ as the ‘Other’. Although I strive to give insight into the insider perspective of the study participants, my ‘Self’ will always influence the presentation of the results (Ramazanoğlu and Holland 2002). It is therefore important to acknowledge that the emic perspectives presented in article 3 are interpretations

produced by the researcher. In the article, I attempt to reframe the young men's driving practices by using the term 'traffic safety agency'. The aim is to highlight that the men do cultivate safety (although they also drive in a risky manner) and that they are (also) caring subjects although this often goes unnoticed in the current debate about 'young problem drivers'.

An alternative or overlapping approach in article 3 would be to analyse the 'Othering' that occurs (at least partly) as an effect of sexism and age discrimination. By this I mean that the knowledge produced about 'problem drivers' in the research literature draws on static, stereotypical notions about men and age. Young men are generally positioned as immature and irresponsible. One approach could have been to analyse this discourse as a form of sexism in which young men are positioned as 'Other' in a dualist relationship with young women, who in this particular situation are positioned as 'Self', i.e. mature and responsible. This could be a promising approach for future research on this topic.

## **7.5 The Social Model of Disability**

In article 2, we credit and use the social model of disability as a theoretical framework and a tool for analytical discovery. Since the social model of disability has stirred controversy in the academic community over the years, I will use some space to elaborate on the debate, how we have used this model, and how it contributed to the findings in this study.

Originally, the social model of disability was outlined by Oliver (1983) after he had read and become inspired by the Fundamental Principles of Disability, which state that disabling barriers in society are what make people disabled (UPIAS 1976). The social model of disability is an approach in which disability is not seen as located in the body itself, but in the surroundings, and thus disability is understood as socially constructed. The social model of

disability is often contrasted with the biomedical model (also known as the medical or individual model) in which disability is seen as pathology located in individual bodies.<sup>29</sup> Framed by the social model of disability, the problems disabled people face in society are moved away from the (impaired) body and towards the surroundings. Hence, the model's political potential is great, and this is also a point that Oliver has stressed (Oliver 2004; 2013). It has the potential to unite disabled people in a political movement to work together for change. Indeed, this frame of conceptualising disability has motivated a discursive shift and led to, for instance, a focus on universal design (Tøssebro 2010; Lid 2013). Moreover, it might empower disabled people because it allows for a celebration of unusual bodies.

Since Oliver's introduction of this conceptualisation of disability into the academic community, the model has been used extensively (see e.g. Morris 1991; Thomas 1999; Soffer and Chew 2015), but it has also been under continuous debate in the field of disability studies (see e.g. Shakespeare and Watson 1997; Barnes 2003; Oliver 2013; Shakespeare 2014). Mainly, the social model of disability has been criticised for failing to acknowledge the complexity of disability, thus treating disabled people as one group, for leaving no room for impairment, and for failing to present a holistic explanation of disabled people's experiences in the world (Oliver 2013). In the words of one of the most critical voices, that of Shakespeare: 'The strengths of the social model are also its weaknesses' (2014, p. 20). In the social model, disability is what makes impairment a problem, and this distinction between biological impairment and the social creation of disability is what Shakespeare (2014) finds to be the model's weakest point. He argues that the biological and social are always intertwined, so it is not possible to separate the two: 'It is difficult to determine where

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<sup>29</sup> Several models have been introduced and developed in disability studies over the years to add to the theorisation of disability (see e.g. Tøssebro 2010; Grue 2014; Shakespeare 2014; for an introduction to other models).

impairment ends and disability starts'<sup>30</sup> (p. 25). In the everyday lives of disabled people, he argues, their impairments are (most often) pressing. Thus, according to him, the social model of disability does not deal with the everyday realities of impaired people. In practice, he argues, this model represents a utopia. Notably, the critique raised by Shakespeare (who positions himself in opposition to post-structuralist, post-modernist and social constructionist thinking) takes a strong interpretation of the social model of disability as a point of departure. Here, disability is seen as located in the surroundings alone, and all attention must therefore be directed at social barriers and social oppression according to social modellers who argue from this standpoint. Shakespeare himself finds that '[d]isabling barriers make impairment more difficult, but even in the absence of barriers, impairment can be problematic' (p. 33). Let me emphasise that I agree on this point<sup>31</sup> and that I do not support a strong interpretation of the social model of disability in the discussion. Rather, I see the social model of disability as one of several possible discursive *alternatives* for exploring disability. In the study, this alternative helped to reveal that the researcher (myself) leaned heavily on a medical discourse when I entered the field. Moreover, it allowed me to see that one consequence of such a frame of thinking was 'ableism' and to explore alternatives with a broader, more inclusive view of different bodies. I do not promote the social model of disability alone as a solution to the problem of 'ableism' (although I think disabling barriers are part of the problem disabled people face in social life). Rather, I found it to be a framework in which we could ask questions about what disability means to non-disabled people and how it is manifested in hegemonic discourses that surround us. I use the social model of disability as a way of challenging the taken-for-grantedness of non-disabled superiority and to question the notion that impaired bodies cannot be used as well as bodies that are not impaired. Thus, to us it is a tool to give nuance to notions of the body. In sum, I credit the model's capacity to challenge

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<sup>30</sup> Pain is one example of an experience that might be created by impairment and not by disabling barriers in the surroundings (Morris 1991).

<sup>31</sup> See the section 'The materiality of the body' for a discussion of this matter.

dominant discourses in mainstream society and highlight ways in which it offers alternatives to 'ableist' world views.

## **7.6 Summary**

In this chapter, I give an overview of the theoretical framework used in this feminist study. I outline the feminist approach, introduce feminist theory and situate the study within it. The study is also situated within a relativist, constructionist epistemology and explains how power, discourse theory, hegemony and hegemonic discourses are used and understood in the study. Finally, I outline the study's use of the theoretical concept 'Otherness' and the use and understanding of the social model of disability.





# 8 Methods and methodology

## 8.1 Study design

This study has an exploratory design, which means that the focus and research questions were discussed and adjusted during the research period in order to make and pursue discoveries that I had not had in mind prior to the fieldwork (Fangen 2010; Moen and Middelthon 2015). This flexible design was chosen because the study is concerned with emic perspectives and hegemonic discourses, which are not necessarily immediately accessible to the researcher. Ongoing exploration allowed for the opportunity to investigate issues that I could not have known about before I followed the study participants over some time and became familiar with them and their world views, as well as myself and my own world view. In interactions and discussions with the study participants and colleagues, I have sought to transcend my knowledge and produce new insights into the research process (ibid.).

I used a combination of repeat qualitative interviews and participant observation in this study. These methods provided opportunities for the study participants and the researcher to get to know each other, develop trust and explore topics of interest together over time (Stewart 1998; Glesne 2006; Mason 2006). The study incorporates an awareness of the study participants as subjects and co-producers of knowledge (Rapley 2004; Gubrium and Holstein 2003), and I therefore chose a collaborative approach in which the subjects were invited to participate in the processing of empirical material.

Overall, the study used several methods and analytical techniques that I will outline in this chapter, where I give an overview of the methodological framework of the study and the research process. First, I present the study participants and the recruitment process. Second, I

outline the process of doing repeat qualitative interviews and participant observation and elaborate on the study's approach to collaboration and the production of empirical data. Third, I outline the process of data analysis, the use of reflexivity and autoethnography, and the work method of the research team. Finally, I discuss criteria and ways to judge qualitative research in relation to this study.

## **8.2 The study participants**

In this section, I will present the study participants more thoroughly than in the articles. In order to protect the anonymity of those who participated, however, I provide a general overview of their age, the accidents they were involved in, and their injuries, background, occupation, and relationship status.

Altogether, 14 individuals participated in this study. Two of them were women, and 12 were men. Six had grown up in the city while eight had grown up in rural areas. All of them had been born and brought up in Norway and were between 20 and 36 years of age when the fieldwork started in 2013. Ten were in their twenties at the time. All the study participants had been drivers in one severe traffic accident when they were between 16 and 24 years of age and had sustained injuries as a result, which varied in terms of character and severity. The accidents had occurred between 2 and 15 years before the fieldwork started, and this time span was chosen for several reasons. I was advised by medical staff at the hospital to recruit participants who were no less than a year or two into their rehabilitation process. This was mainly due to ethical considerations because patients who have sustained severe injuries, particularly head injuries, tend to be confused and distressed in the first period of rehabilitation. Also, patients need time to rest, concentrate on regaining functionalities (e.g. speech), establish new routines and adjust to their new life situations. The amount of time that had passed since the accidents occurred would, of course, have impacted their reasoning

and meaning-making in various ways. On one hand, I found it probable that if the accidents had occurred less than two years ago, the meaning-making of the individuals would be mostly concerned with their current situation and getting through the day. Thus, two years was chosen as a minimum period of time because it would have given the study participants the time and opportunity to get used to their situation, reflect on their experiences, and get familiar with their own thoughts about the accident, the rehabilitation process and future prospects. On the other hand, if too many years had passed since the accident had happened, issues that were central to the study, such as the rehabilitation process, might no longer be as relevant in the everyday life of the individual as it once had been. Thus, 15 years was chosen as the maximum period of time. This ensured a certain homogeneity in the sample since all the individuals that participated could be categorised as young adults that shared similar, but not the same, experiences. Therefore, the time span as well as the criteria mentioned earlier in this section are purposive, an attempt to engage with individuals who share particular characteristics and experiences which may provide 'information rich' cases (Sparkes and Smith 2014).

When I use the term 'severe accident' above, it is because it was not uncommon that the study participants, as part of their narratives about themselves and their driving experiences, told me about less severe road traffic accidents that they had been involved in as drivers or passengers on other occasions as well. On one hand, six of the study participants experimented with speeding, drifting, and/or driving under the influence (of drugs and/or alcohol) on a regular basis, and over the years had occasionally driven off the road. These additional accidents had not resulted in long-term injuries, although some had resulted in wrecked cars. On the other hand, a few of the study participants emphasised that they usually drove according to traffic regulations, including at the time of the accident, which was the

only accident they had ever experienced. In other words, the participants represented different practices, attitudes and identities in relation to road traffic accidents and driving.

In this section I describe the kind of accidents that the participants in this study experienced so the reader can gain insight into the context of their background stories. Six of the accidents in which the study participants had sustained long-term injuries were head-on collisions involving another car. In five of these cases, the study participant was alone in the car, while in one case, he had a passenger, his parent, who was not injured. In one case, the person in the other car died. The study participant told me that a medical examination after the accident established the cause of this fatality as a heart attack, which probably had occurred before the collision, and the study participant was therefore not held responsible for the death. In all the other cases, the person or persons in the other car survived. In eight of the accidents, no other car(s) was involved; the study participant had driven off the road. In three of these cases, the study participant was alone in the car. In the five other cases, the study participant had one or several passengers. In four of these accidents, the passengers sustained minor, or no, injuries. In one case, however, two of the passengers sustained rather substantial injuries and the driver informed me that they still suffered from chronic pain at the time of the fieldwork.

The injuries that the study participants sustained in the accidents varied. Three had sustained spinal cord injuries (SCI). Eight were diagnosed with traumatic brain injury (TBI). Three in this latter group had sustained additional injuries affecting the face, legs, back, neck and/or hips, and three had sustained multiple traumatic injuries (but neither TBI nor SCI). Ten of the study participants were still receiving rehabilitation services at the time of the fieldwork, and four were not.

How the injuries affected the lives of the study participants physically and practically at the time of the fieldwork varied greatly, from almost not at all to substantially. Some were in pain daily, for example, while others never felt pain. Those who had sustained SCI were paralysed from the waist down and needed to think about logistical details to move around. Those who were diagnosed with TBI were not visibly impaired most of the time, but had varying degrees of cognitive challenges often associated with TBI, such as fatigue, reduced visual acuity, loss of memory and concentration, headaches and aphasia (Romsland 2011). Typically, the study participants diagnosed with TBI had to learn to walk and talk all over again after their accident. Some of the study participants had visible scars from the accidents and/or from surgery that made their appearance unusual, and some had unusual ways of talking and/or patterns of movement that stood out due to injuries in their legs, hips or back. Overall, the challenges they faced due to their impairments and the way they handled their everyday life as disabled people differed between individuals. Diversity was a characteristic of the sample.

When the accidents occurred, four of the study participants were pupils in upper secondary school and the rest were college students or working. At the time of the fieldwork, their situations varied in terms of their occupations. However, all the study participants expressed the desire to work in full-time jobs. Four did, while six worked in some kind of part-time job, sometimes in addition to studies, and four were unemployed. Six had a higher education, and several had taken some university courses or planned on doing so. The working class, middle class and upper class are all represented in the study. During the project period, one man got married and one man separated from his partner. In addition, one of the study participants was already married (and continued to be so), three were in long-term relationships, and eight were single. Two were fathers, and one became a father during the study period.

## 8.3 Recruitment

Nine of the study participants were recruited through the hospital in which they received rehabilitation services. A formal document with information about the study was outlined in accordance with requirements from the Privacy Ombudsman for Research at the rehabilitation hospital and sent to potential study participants by hospital staff. Those who wanted to participate in the study contacted me by phone, e-mail or letter.<sup>32</sup> In the recruitment phase, I also put a call for study participants in one issue of a periodical published by the Norwegian Association for the Traumatically Injured.<sup>33</sup> In addition, I wrote a piece about the study that was published in *Aftenposten*.<sup>34</sup> After these publications, three individuals contacted me and became participants in the study. In addition, two individuals were recruited through personal networks. They contacted me on their own initiative after hearing about the study from someone we both knew. During the project period, one person who was recruited through the rehabilitation hospital chose to use the right to withdraw from the study with no explanation (National Committees for Research Ethics in Norway, 2017). In line with guidelines for research ethics, all data material concerning this person has been excluded from the study (ibid.).

## 8.4 Qualitative interviews

Qualitative interviewing was the main method in the study. Kvale (1996) describes this method as conversations that have both a structure and a purpose; it entails not only talking,

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<sup>32</sup> Details of this process are outlined in the section ‘Ethical considerations’.

<sup>33</sup> This is an organisation that provides legal advice and other services to people in the aftermath of various accidents. Originally, the organisation’s work was directed at people who had sustained injuries in traffic accidents, and many of the members are still in this category. More information about the organisation is available on their website:

<http://www.personskadeforbundet.no/>

<sup>34</sup> A Norwegian, nationwide newspaper, online version available at:  
<http://www.aftenposten.no/>

but careful questioning and listening with the purpose of obtaining knowledge. I chose qualitative interviews as the main method because this frame of interaction gives an opportunity to introduce, follow and concentrate on specific topics and systematically explore people's experiences and understandings (Kvale 1996; Gubrium and Holstein 1997; Fangen 2010; Moen and Middelthon 2015). The method's qualities suited this study well since I was pursuing separate topics concerning the study participants' experiences and world views.

In total, I conducted 28 semi-structured interviews with the study participants during the fieldwork. Five of the 14 participants were interviewed once, five were interviewed twice, and four were interviewed three or more times. I conducted repeat interviews because the time in between interviews allows both the interviewee and the interviewer to reflect on the issues raised and come back to topics with additional questions and input (Moen and Middelthon 2015).

Initially, I had made an interview guide (appendix 3), but in accordance with the study's exploratory design, I did not follow it strictly. Instead, I used it as a tool to remember to ask all the study participants about certain topics (e.g. their driving practices) so that I might compare their answers in the analysis part of the project. Sometimes I would present topics for discussion, but I often asked the study participants what they wanted to talk about and let the conversation evolve from there, so we often discussed and discovered things that we had not yet thought of when the conversation began (Moen and Middelthon 2015). I used an engaged and collaborative interview format. The idea is that researchers may contribute to the production of elaborative data by strategically using themselves and their own experience in these settings (Rapley 2004). For instance, when we talked about speeding, I shared my teenage experience of being a passenger in the back seat of a car with a young, male driver who drove ferociously fast on a country road or my own joyful experiences with different

kinds of extreme sports. This might have made it easier for the study participants to confide in me and tell me details about their own driving practices, especially when these deviated from normative standards. Moreover, not only did I seek to record that which the study participants had already thought through, I also aimed to ‘facilitate further reflections, and a concomitant articulation of these’ (Middelthun 2001, p. 24). The study participants had the status of subjects in the interviews and engaged in meaning-making processes together with the researcher (Curium and Holstein 1997). Hence, conversations about, for example, un/employment were not limited to how this was experienced by the study participant. Often we discussed issues of interest in a much broader sense than that. In terms of un/employment, we typically talked about the meaning of work, why it is so important in our society to be employed, what prejudices one might face as an unemployed person, the prejudices each of us had or did not have towards people receiving welfare money, what we feel or do not feel when the question ‘What do you do?’ comes up when we attend parties, and so on. These conversations contextualised the study participants’ situations and made us more familiar with each other and with the issues we explored, and as the trust between us grew, the conversations got better (Glesne 2006).

Typically, the interviews lasted somewhere between one and four hours. The locations varied. In some cases, the study participants lived far from where I lived, and in these instances, I travelled to their hometowns by train or bus. I wanted the study participants to be comfortable in the interview situations, so I asked each person in advance where they wanted to meet. If they did not know, I made some suggestions, including their home, a café, or – if they lived close – my place. In the end, five preferred that I come to their home, three preferred my place, five preferred meeting at a café or restaurant, and one was interviewed on Skype for practical reasons. (The distance between us was great, and we did not manage to arrange a meeting face-to-face). Most of the interviews were conducted one-to-one.



However, one man was interviewed together with his father, and, on another occasion, the participant's wife walked in and out of the room during the interview and sometimes sat down and joined the interview.

In addition to the 14 study participants, 'key person' interviews were conducted with three people. The term 'key person' refers to people that 'have knowledge of particular relevance for a theme under investigation (they could, for example, be experts of various kinds, policymakers, activists or community elders). However, they are not core study participants in the sense that it is not their life, work, communities or experiences we are inquiring into' (Moen and Middelthun 2015, p. 323). In this study, the key persons were a neuropsychologist at the rehabilitation hospital, a consultant at the Norwegian Labour and Welfare Administration (NAV), and a consultant from the Norwegian Association for the Traumatically Injured. The latter is a nationwide organisation that offers legal and political help to civilians post injury. Grace Inga Romsland, one of the study's supervisors, asked the first two, whom she knew professionally, if they might be willing to contribute to the study by participating in an interview. When they agreed, I contacted them by e-mail to set a date for the interview. In the latter case, I contacted the organisation by e-mail, they replied positively, and an interview was scheduled by e-mail. These three interviews were conducted with the aim of gaining background information about the structural apparatus surrounding the study participants, in addition to the processes they went through during rehabilitation. This was necessary because the study participants sometimes referred to procedures and concepts that were unfamiliar to me. The interviews with the three professionals clarified what the study participants were talking about (such as the use of scores in tests at the rehabilitation hospital, which is the focus of attention in article 1). I met the neuropsychologist at the rehabilitation hospital, and this interview lasted for about one hour. Our conversation took place in the cantina at the rehabilitation hospital. The interviewee had

brought his computer and showed me some of the tests that the study participants typically went through during the rehabilitation process. Also, we had some contact through e-mail after the interview because I had some additional questions. The interviews with the NAV consultant and the consultant from the Norwegian Association for the Traumatically Injured both took place on the phone and lasted for about 45 minutes. In these two instances as well, I asked some questions for clarification by e-mail after the interviews.

## **8.5 Participant observation**

I chose to supplement the interviews with participant observation as a way to produce data, because of this method's rich potential for adding new and/or broader perspectives to the study. Participant observation entails researchers' using their own body and experiences as an instrument of enquiry and involving themselves with others in some form of participatory role (Stewart 1998; Fangen 2010). The key assumption underlying participant observation is that one will better understand (in contrast to other methods) the beliefs, motivations and behaviours of those involved in the study by entering into close, prolonged interactions with them in their everyday lives (Sparkes and Smith 2014). Although the study did not allow me to conduct traditional ethnography in the sense that one spends a long period of time in the field, I embraced the opportunities I found to examine the life of the participants as it happened in 'real time' (ibid.) since, as noted by Glesne:

Through participant observation – through being a part of a social setting – you learn first-hand how the actions of research participants correspond to their words; see patterns of behavior; experience the unexpected, as well as the expected; and develop a quality of trust, relationship, and obligation with others in the setting (Glesne 2006, p. 49).

To develop trust, which potentially would make the relationships and conversations more rewarding and comfortable for all parties, and in search of potential discoveries, I seized opportunities in which I could conduct participant observations with the same people I interviewed during the fieldwork period. The role of the participant observer is dynamic and can take many forms, and I was always in the position of an outsider – the researcher. My role moved on the spectrum from a ‘complete observer’, who does not actively participate in the field but observes what and how things happen, to the ‘observer as participant’, who is marginally involved in the situation, accepted not as a member of the group but as a ‘colleague’, a position which opens up the possibility to ask questions (Sparkes and Smith 2014), which I often did on these occasions. The most evident opportunities for participant observation were, in my case, social activities before and after interview settings. This entailed taking strolls that lasted about one hour each with three different study participants in connection with their interviews, and I sometimes asked the study participants if they might pick me up with their cars when I arrived at a station before an interview. These drives, which lasted 10–30 minutes, gave me a chance to experience being their passenger, see how they manoeuvred their cars, and so on. In addition, I went to the store with Oliver (as described below), I spent an evening at a restaurant together with two of the study participants, and I attended the wedding ceremony of another. In addition to these occasions, I arranged for two of the study participants to meet each other at my place twice. In these meetings, we ate together, and the two men talked for several hours. Apart from asking a question or introducing a topic now and then, I was positioned in the background as an observer, and thus free to use my senses and fully concentrate on the words, gestures, sounds, smells, movements and interactions in the research setting (Glesne 2006). The point of this method was to allow emic knowledge to emerge, and it did. The men, both of whom had sustained traumatic brain injuries in accidents, asked each other questions that I would not

have been able to ask. For example, one asked the other, ‘Do you sometimes get... like *a veil* before your eyes?’ The other answered, ‘Yeah. Yeah, I know exactly what you mean. It is sometimes like looking through a veil now, after the accident.’ Then they continued to discuss and elaborate on their shared experience of living with brain injuries with words and descriptions that would hardly have come to the fore if they had spoken to me instead of each other. Sometimes, like in the setting described above, participant observation added substantially to my understanding of the study participants’ situations and gave me insight into their interactions with others, their encounters with their local community as disabled people, and their (as well as my own and others’) productions of normality and ‘Otherness’. These insights added context to the stories and understandings that emerged in the interview settings and have informed the discussions and findings in the study.

Benefits of using observational methods include that they enable the researcher to record ‘the mundane, taken-for-granted, and unremarkable (to participants) features of everyday life that the interviewees might not feel were worth commenting upon’ (Sparkes and Smith 2014, 100). Such insight into the everyday lives of the study participants may add valuable knowledge, and I will give an example to illustrate how participant observation came to nuance my understanding of disability in this study: In his traffic accident, Oliver had sustained a brain injury that severely affected his balance and motor control, i.e. control over how his body moved. I knew this in theory but did not grasp what it meant in practice until I went along to the grocery store with him. This encounter did not last for more than an hour, but it was still rewarding in terms of providing insight into his situation as a disabled person. Oliver told me that his brain did not respond to the impulse of slowing down. Hence, his body would keep moving faster and faster in a downhill situation. This would ultimately result in a fall unless he found a way to ‘brake’. As we walked, I learnt that Oliver had developed certain sophisticated skills to walk the rather steep streets around his house. He

knew every bump and hill, however small, and used them strategically, along with a zigzag walking pattern, to adjust the speed of his movements. This technique made his walk look unusual, but it worked well in terms of enabling him to get from one place to another without falling. Obviously, the walking technique demanded a lot of energy. Before long, Oliver's forehead was dripping with sweat, and his shirt was almost completely wet when we arrived at the store. When we returned to his house afterwards, Oliver was breathing heavily from the strain of our stroll. Later that day, when we talked about cars, Oliver told me that he owned one. In fact, he had owned it for many years although he had not been allowed to drive for a decade due to the state of his health. However, he had not given up hope, and was now in the process of trying to get his driver's license back. He told me that driving made him feel free and independent, and he badly wanted to drive again. Thus, the car was waiting in the garage. Had I not gone for a stroll with him and observed the energy he invested in every step, I would not have understood the depth of his statement or why he would want to own a car for years when he could not drive it. I would probably have perceived it solely as a symptom of his enthusiasm for cars, whereas I could now also understand it as a means of reducing disabling barriers in his surroundings. Such insights were made available to me through participant observation, which informed my ideas and broadened my views.

Participant observation was documented with thorough descriptions according to traditional ethnographic methods (Sparkes and Smith 2014) written as soon as possible after the event had occurred, later the same day when I was on my way home or when I had arrived at home. I wrote down the observations in as much detail as I could. During observation and in the writing phase, I used recommended control questions such as those provided by Holloway (1997) as a guide, including: What is happening in the setting, who can be found in the setting, where do interactions take place, why do people in the setting act the way they do? Also, I recorded what I saw, heard, smelled, thought and felt, what the person(s) involved did

and said, and what I did and said. This does not mean that I wrote down everything that happened or aimed to do so; I acknowledge that the work of the observer is always ‘incomplete’ (Joelsson 2013, p. 71). Rather, the aim was to use my senses and communicate what I had experienced at the time.

The data material produced by participant observation was used in a number of ways during the course of the study. First, the material was used as a part of my reflexive process; therefore, it was a part of my critical self-awareness and self-reflection on my situatedness in the study (Finlay 2002; Finlay and Gough 2003; Davies 2008; Berger 2015). By writing down observations throughout the study period (including diary entries), I had access to material that documented my process of thought and experience over time. I used it to reflect on my interactions with the study participants, my role in the field, and the lives of the people involved. Often, writing and reading observational data prompted new reflections and insights. Second, the material was used as preparation and a way to remember previous experiences. I often read previous entries to prepare myself when I was going to meet the study participants on other occasions. Sometimes, reading the material gave rise to new questions or comments that became a topic of conversation in interviews. Third, the material was also used as a way to detect and analyse emerging patterns. For example, it was by revisiting my field notes that I came to discover that I had been ‘ableistic’ on several occasions. Observational material provided data that made it possible to analyse how, when and why this had taken place in settings and interactions with the study participants and myself. I used several descriptions as data in the articles and they thus informed the analysis. Fourth, these entries gave contextual insight and shaped my broader understanding of the field and topics under investigation. It formed part of the background information I drew on throughout the study period.

## 8.6 Empirical material

Altogether, the empirical material produced in the project period is substantial, as is usual in ethnographic studies (Sanjek 1990; 2001). I always carried my notebook around, and often during the research period made 'scratch notes' (Sanjek 1990) where I jotted down a few words so that I would remember things I saw, felt, thought and experienced. Sometimes these scratch notes were developed into fuller written field notes or diary entries (Sanjek 2001). They typically involved descriptions of people I met, places I visited, encounters I was involved in and activities in which I participated. I also wrote analytical entries that were 'a place for ideas, reflections, hunches, and notes about patterns that seem to be emerging' (Glesne 2006, p. 55).

In addition to the above-mentioned notes, data also consisted of interview reports, text messages, e-mails and minutes from meetings. All the empirical data were written in Norwegian. The quotations used in the three articles were translated into English by an authorised translator. Every day I read all the news I came across about traffic accidents and disability. Although these media sources are not explicitly analysed in the study, they are a part of the backdrop against which I have oriented myself as a researcher.

I always brought my computer to the interviews and wrote down notes from the conversation in a Word document as the interview went along. When I came home, I wrote coherent reports from the interviews. I encouraged the study participants to contribute in further processing of the text. If they wanted to participate, I sent the report to them by e-mail and invited them to freely rewrite, add details, erase or elaborate on sections in the text before sending it back to me. Some chose to participate in the processing of the texts while others did not. Some read the texts and did not want to change anything. If they made changes, the text in which these were included was always considered the final version and was the one I

used for background and quotations in the articles. One specific encounter inspired this collaborative practice, which I have used throughout the study, including in key person interviews. (All three key persons chose to participate in the processing of the interview reports.) I will explain how it came about and some of the thoughts behind this approach:

Several of the study participants had sustained brain injuries in their accidents. Such injuries can cause cognitive challenges, such as memory loss (Romsland 2009; 2011) so that these participants did not necessarily always remember what we had previously talked about, or they might sometimes forget what they were going to say in the middle of a sentence. Given that many of the study participants had such trouble with their short-time memory, I will clarify the role of memory in this study both theoretically and in relation to our interactions. First, as this study is concerned with the experience of the study participants, and not with ‘facts’, it was never a worry that participants would not remember events ‘correctly’. Rather than seen as ‘correct’ or ‘incorrect’, memories in this study are perceived of as reconstructions. I acknowledge that I take part in a stimulation of the specific memories that are activated. Thus, memories are tied to the situation in which they are produced. Memories are ‘a dynamic amalgam of fact and fictionalisation – a matter of faction, if you will’ (Randall and Phoenix 2009, p. 288 in Sparkes and Smith 2014, p. 100). Memories are always open to change and revision, for anyone, for example, in the sense that in time we might change our perspectives, and thus the past changes too (Bochner 2016), but this does not make our memories and experiences at a specific time more or less ‘real’ or valuable; they are always situational, and understood as such in this study. Second, the study participants had sustained only moderate brain injuries, and made coherent and thoughtful reports on their experiences. They came across as knowledgeable subjects on what memory loss entailed for them and handled it from a point of pragmatism in our conversations. For example, Ola instructed me to let him know if he repeated something he had told me before and help him



‘back on track’ if he forgot what we were talking about in the middle of a sentence. Often, the study participants would initiate conversations about what it meant for them to have memory losses and tell me – indeed, teach me – about techniques they used (such as note-taking or how to memorise phone numbers) to manage situations in which this could be relevant. Thus, memory had the role in their meaning-making processes not only as a ‘loss’, disability or problem, but also as a skill and an ability which many had continued to develop strategically and which informed my understanding of their everyday lives and experiences. Third, considering the potential of memory loss during the course of the study and their vulnerability in this respect, I found it both ethical and practical to send the study participants reports of our conversations: ethical in protecting their right to withdraw if they did not want to keep participating and their informed consent by documenting what they took part in along the way (National Committees for Research Ethics in Norway, 2017), and practical in giving them the opportunity to remind themselves of what we had (or had not) talked about on different occasions. Later, I found this approach to be rewarding in other ways as well and decided to use it as a methodological strategy. It had a methodological dimension that fit well into the study design. It acknowledged the notion that research is a collaborative meaning-making process between the people involved and that the interviewee is a subject or even a co-researcher in the study (Stewart 1998; Rapley 2004; Gubrium and Holstein 2003; Moen and Middelthun 2015). If not exactly researchers in the strictest sense of the term, the study participants were indeed co-producers of knowledge in the study. Documents passed between us in an ongoing written dialogue. Also, it was a fruitful strategy in the sense that sometimes the changes they made became a topic of attention in our subsequent conversations. This increased my understanding of their experiences and understandings and provided opportunities for exploration. I hope that the study participants experienced this approach as respectful and empathic.

I realise that my choice not to use a tape recorder is unusual, so I will briefly explain the reason for it. I did in fact start out by using a tape recorder (in addition to making notes on my computer) to record the interviews and transcribe them verbatim because I had not really thought about the alternative of doing something else. However, I found that transcribing was very time consuming and that my handwritten interview reports provided just as good or better accounts of the conversations, in addition to a richer opportunity to explore topics and stories together with the co-producers of knowledge (study participants). Hence, I chose to abandon the tape recorder early on. In line with the argument of Middelthon (2001), I found that note taking has a temporal character that gets lost somewhat in tape recording, as ‘the presence on tape becomes a frozen presence deprived of fluidity; of a possibility for alteration, modification, or change’ (p. 17). The potential to alter and explore the text was essential in this project, and this potential became more accessible when the notes did not appear ‘fixed and finished’, as in tape-recorded transcriptions.

## **8.7 Data analysis**

Since this project combines the strengths of different qualitative methods (Mason 2006) and includes several types of empirical data, the process of data analysis was diverse as well. It was inspired by different qualitative techniques and approaches that were meaningful to use in the analytical work. Overall, data analysis was not so much a phase as an ongoing process throughout the study period (Moen and Middelthon 2015). This process included the continuous activity of writing, which is a part of analytical reflection (Sparks 2002; Braun and Clarke 2006; Glesne 2006) and the verbal and textual processing of empirical data between the study participants and myself (as described earlier in this chapter). It also included discussions and explorations within what I refer to as the research team. In relation to the fieldwork, article 1 and article 2, the research team consisted of Kåre Moen, Grace Inga Romsland and myself. In relation to article 3, the research team consisted of Ulla-Britt

Lilleaas and myself. I will outline the overall analytical process in the study before presenting the different analytical strategies that I used in each of the articles.

In the period when I conducted the fieldwork, the research team regularly discussed different methodological approaches, recruitment and my encounters with the study participants. For instance, we discussed my unintentional ‘ableism’ (a topic which was developed and later became article 2) and difficult situations that occurred in the field. Sometimes, I would send full interview reports, or parts of interviews, to the supervisors (Kåre Moen and Grace Inga Romsland) so they could familiarise themselves with the data. I introduced topics of analytical attention, and these were often discussed in the research team, and we shared experiences and ideas. The process of analytical interpretation often meant that I went back and forth between close readings of empirical data on one hand and readings that captured the whole on the other hand (Braun and Clarke 2006; Kvale and Brinkman 2009). The aim of this process was to remind myself of the context: to make sure that fragments of the text were considered in light of the overall meaning that was produced within the text as a whole. In particular, I searched for hegemonic discourses and aimed to identify and examine that which seemed obvious, taken for granted, ignored and covered up (Alvesson and Kärreman 2000; Jørgensen and Phillips 2010; Springer and Clinton 2015).

In the writing phase of the study, I produced a rough draft of each article and sent it to the co-authors. After they read the draft, we engaged in extensive discussions about the arguments and analytical entries I had presented, relevant literature, the structure of the texts and so on. Sometimes, we read relevant literature that one of us had suggested and discussed if, and how, it might inform the study. I read, refined and rewrote the draft several times, as recommended in analytical processing of data (Braun and Clarke 2006). We continued the discussions until we reached a consensus within the research team, and the texts were

submitted to academic journals. The ongoing teamwork described here has the potential to transcend our individual views (Moen and Middelthon 2015) and has hopefully helped to broaden the analytical investigations and ensure the quality of the study.

Different analytical techniques and empirical material were used in each article. The first article used thematic analysis inspired by Braun and Clarke's (2006) guidelines. This process entailed reading and re-reading the empirical material (mainly interview reports, but also field notes) several times to become familiar with the data and get a good overview. I then manually coded the material. In the first phase of this process, I used the approach recommended by Tjora (2010), first coding sections with emic words and phrases that were particular to the data set. In the second phase, I developed broader categories for what had emerged, such as 'experiences with un/employment', 'having a disabled body' and 'experiencing the rehabilitation process'. The research team read and discussed excerpts along the way. As I got more familiar with the material, I discovered that talk about percentages emerged within these themes and sorted 'talk about percentages' into a separate theme. I initially selected this theme to focus on not because it was the most prevalent in the data set but because it captured an important element of meaning (Braun and Clarke 2006). I reviewed the material again and sorted everything that had to do with percentages into a separate section. Emerging patterns and sub-themes within the theme of 'talk about percentages' were then discussed by all of the researchers, and I organised it into sub-themes. Here, I aimed to capture and interpret the *meaning* of the discourse (i.e. 'the language of percentages'); hence, I sought to understand what this discourse meant for the study participants and how it structured their social realities. The material was considered in light of different theoretical propositions. The process of revising this article in accordance with suggestions from three peer reviewers that had different approaches was demanding. The co-

authors engaged in the writing of the text and refining the discussion in the final phase of re-submitting this article.

The second article used an autoethnographic approach, and the empirical material consisted of my diary entries and field notes. Here, I used the concepts ‘anthropological astonishment’ (Hastrup 1992) and ‘revelatory moments’ (Trigger, Forsey and Meurk 2012) as analytical tools to capture and theorise awkward cultural encounters. In the first phase, I used my memory and searched the empirical material manually for fieldwork experiences that were significant in the sense that they had ‘prompted reflection and insight in an especially effective manner’ (Svendby et al. 2018, p. 4) and thus had the potential to reveal discourses that, in hindsight, I had not been equipped to be aware of before these encounters (Tuana 2006). These excerpts were read and discussed by the research team. Teamwork was especially important for maintaining analytical distance since I was close to the data material. In intense consideration of data (Stewart 1998), we discussed what the revelatory moments might mean, what they might tell us about cultural notions of disability, and so on. In this article, the writing is an integrated and traceable part of the analytical process in the sense that autoethnography is used for analytical (self) reflection and exposed textually.

I reviewed all the empirical material produced in the study for article 3. However, as the article was about driving practices and I had interviewed each study participant about this topic in particular, the attention was focused especially on these interview reports in the analytical process and selection of quotes. Analytically, I used thematic analysis<sup>35</sup> (Braun and Clarke 2006). Fragments in the material were studied in depth and compared to other fragments (e.g. excerpts from different study participants about the same topic, such as

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<sup>35</sup> Our approach to thematic analysis and coding was similar to that which I described in connection with article 1.

‘speeding’ and ‘safe driving’), and I searched for dilemmas, frictions, deviance and conflicts in the discourses produced in the data material (Springer and Clinton 2015). To avoid simplification, I brought these into the analytical discussions, for example, by exploring what it meant when study participants said that they drove safely and then told me about excessive speeding practices.

## **8.8 Reflexivity**

### **8.8.1 Introduction: The concept and its purpose**

The academic debate of the role of the self in knowledge production has expanded over the years, and the issue of reflexivity is part of this conversation. Reflexivity challenges conventional ideals in science where professional distance and objectivity have been seen as superior to engagement and subjectivity (Finlay 2003). In contemporary social sciences, it is accepted knowledge that the researcher is central in influencing the research process, including the interaction in the field, collection of data, analytical explanations and the production of knowledge (Finlay 2002; Finlay and Gough 2003; Davies 2008; Berger 2015). Reflexivity, in which the researcher addresses such influences through a continuous inner dialogue and self-examination, is therefore seen as a necessary part of any qualitative study (ibid.). To take a reflexive stance means a ‘turning of the researcher’s lens back onto oneself to recognise and take responsibility for one’s own situatedness within the research and the effect that it may have on the setting and people being studied, questions being asked, data being collected and its interpretation’ (Berger 2015, p. 220). For example, by unpacking relevant social positioning such as age, gender and ethnicity and how it may affect the production of knowledge, the researcher may engage in a critical self-evaluation of her positionality as well as its potential effect on the study. Although it is not unproblematic even to assume that it is possible to pin down and unfold something of our intersubjective

understanding (Finlay 2002), it is essential to attempt to do so because the role of the subject may be seen as a threat to the scientific accuracy of qualitative research.

The purpose of reflexivity is to acknowledge and address preconceptions that may affect the direction and outcome of a study in various ways, and as such it is an effort to enhance the trustworthiness, transparency and accountability of the research<sup>36</sup> (Finlay 2002). However, to coin the concept of reflexivity is not easy, as the term is contested, and diverse traditions and aims have been attached to it (Finlay and Gough 2003; Davies 2008; Ramazanoğlu and Holland 2002). Finlay (2002) traces the evolution of reflexive analysis across different qualitative research fields back at least a century. She draws a line from traditional anthropological ‘realist tales’ in which the researchers attempted to prove the trustworthiness of their findings by recording their observations to more recent and radical post-modernist variants of self-reflexivity in which the nature of research is deconstructed and the researcher may experiment with rhetorical genres, for example, by using irony and parody to represent the world (Finlay 2002). The multiple uses and understandings of reflexivity (see e.g. Davies 2008 for an overview) illustrate that how one approaches the act of reflexivity and what one seeks to uncover by this act will depend on the researcher’s theoretical approach to science itself. For example, the ‘realist’ use of reflexivity seeks to reinforce the authenticity of analysis, while the ‘postmodern’ use of reflexivity tends towards disruptive narrative coherence and highlights the constructed nature of analyses (Gough 2003) which results in a totally different approach to and outcome of a study. It is therefore important that the researcher theoretically situates herself and the aim of reflexivity.

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<sup>36</sup> I outline the study’s relation to trustworthiness, transparency and accountability elsewhere in the thesis.

This study is theoretically positioned within a feminist framework which influences the take on reflexivity. Feminist reflexivity emerged in the 1970s from concerns about the hidden and unexamined power of the researcher in the context of qualitative studies (Finlay 2002). Today, reflexivity is seen as a principle of good feminist research practice and aims to recognise and address power relations in the research process, emphasise reflections on ethical choices in the study<sup>37</sup> (including possible harm that could come from the research and how to avoid it) and stresses that the researcher should be held accountable for the production of knowledge (Ramazanoğlu and Holland 2002). I hereby seek to do so by making explicit the impact of social positioning in the research process of this thesis and the complex productions of power in relations between the researcher and the study participants. This is a challenging task because it involves the act of writing, selecting data and making interpretations which by its nature is already coloured by the person involved in the act and thus limited by her conceptualisations. For instance, Ramazanoğlu and Holland (2002) note that the researcher may see similarity where the study participants see difference and that which appears obvious to the researcher may be perceived differently by the study participant. They emphasise that the researcher takes decisions on selecting, refining and interpreting the data; prior assumptions, meanings and expectations influence the process; words she uses to convey meaning already carry meaning; and disagreements over interpretations may readily occur: ‘At best you can be as aware as possible that interpretation is your exercise of power, that your decisions have consequences, and that you are accountable for your conclusions’ (Ramazanoğlu and Holland 2002, p. 161). In line with a feminist approach, I acknowledge these difficulties and openly admit that critical capacities are always limited by the knowledge, culture, experience and personal skills and values of the researcher (Smith 1989), including the very creation of the presentation I hereby make. Thus, reflexivity needs to be both collective and contested, and I as a feminist researcher seek to

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<sup>37</sup> This is outlined in the chapter ‘Ethical considerations’.



make the research process and my decisions transparent and invite the audience to challenge my knowledge claims (Ramazanoğlu and Holland 2002). In this chapter, I will explicitly reflect on how my social background, the intersection of gender and age, and ethnicity may have influenced the research process in various ways in order to make it possible for the reader to follow my steps and inspect them.

### **8.8.2 Impacts of my background from a rural, working-class environment**

I grew up with my two brothers in a working-class<sup>38</sup> environment on the countryside, in the small village of Feiring. My older brother was passionately engaged in driving and motor vehicles from an early age. His main hobby as a young adolescent was to repair and assemble bicycles, motorcycles and – later – cars and tractors. In my childhood, I spent much time wandering in and out of his garage and hanging around the yard where my brother and his buddies played and ‘talked motor’. My background in these surroundings came to matter in the course of my research in the sense that I easily connected with the language, meaning-making and experiences of the working-class car enthusiasts in this study due to familiarity from my own upbringing. To some extent – since I am also different from these men in the sense that today I also identify as a middle-class academic who lives in the city – this positioned me as an ‘insider’ which in a research setting may render several benefits. It may give easier access to the field due to increased willingness on behalf of the participants to share their experiences with someone they feel related to, some topics may be addressed more easily due to the researchers’ ability to approach issues with some knowledge, and one may be more sensitive to implied content, to hear the unsaid and take hints that others may

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<sup>38</sup> I use the concept ‘class’ with ambivalence because it is difficult to establish how one might identify and differentiate various class positions from each other (Adkins and Skeggs 2004). Although Joelsson (2013) relates to a Swedish context, I follow her line of thinking when she defines class as concepts that refer to groups of people who are diversely positioned in relation to the economy and labour market. The common dimension is that the working class in some ways does not conform to the ideologies and norms of the (admittedly diverse) middle class which inhabits norms and values that have a hegemonic status in the society.

miss (De Tona 2006; Berger 2015). Such benefits became apparent in my interactions with study participants, as I will soon elaborate on.

During the fieldwork, my background was presumably easily detectable to the study participants due to my dialect and clothing (wool sweater and large trousers) with which I positioned myself as a 'bygding',<sup>39</sup> and I felt an immediate acceptance from men with backgrounds similar to my own. Both parties drew on shared 'insider knowledge' in the conversations. For example, having explained to me the utter importance of getting the driver's license at the first moment possible (the day he turned 18), one participant added: 'Oh, well, coming from Feiring you know all about it'. In this context, I found that the participant was implicitly drawing on the knowledge that one will not get around due to long distances and lack of communication transport in the countryside. Also, I had the benefit of knowing things that may have eased the access to experiences that the men might otherwise not have disclosed in a research setting. For example, I knew that certain activities related to driving are culturally accepted by the police and older generations on the countryside although they are illegal – such as driving from an early age (and before one gets a license), drifting, burning and playing around with cars and tractors on the fields. I drew on this insight in the interviews (by disclosing my knowledge in situations where it was relevant), and it created an atmosphere of trust and relatedness in which I believe it felt safe for study participants to open up about their experiences with 'deviant' and illegal driving practices without the worry that I would be shocked or judge them (which might have been a concern if I was an uninformed 'outsider').

As an 'insider', I sometimes had the benefit of hearing the unsaid. For example, when one participant made the point that he had never 'fixed' his moped, I knew that he was not talking

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<sup>39</sup> Norwegian slang for a person who comes from a rural area.

about repairing the vehicle. Instead, I understood that he was referring to the act of tuning it, i.e. manually adjusting the moped in order to making it drive faster (than legally permitted). This impacted my interpretation of data in this context. The way I saw it, he was implicitly positioning himself as a man who had been driving the moped lawfully. This impacted the way I understood him, the direction of the conversation and thus the production of knowledge in the sense that I followed up with questions about why it was important to him to avoid tuning the moped, his view on speeding and so on. The risk of the 'insider' position includes that the researcher may project her bias onto the result, she may push stories in certain directions and that which is implicit may get lost in the interactions (Berger 2015). To increase awareness of such impacts, I used repeat interviews, continuously examined my own biases and frequently revisited the data in order to detect that which might have been blurred or missed. This led me to discover that my social background might have posed a barrier in my interactions with one of the study participants. In contrast to the easy-going conversations I had had with working-class men with a rural background, the interview with this particular participant, an upper-class man from the city, did not go well. I felt that the look he gave me when he opened the front door and saw me for the first time was sceptical. I was filled with doubt and felt that we would not easily gain each other's trust. Also, I felt weirdly strained when I entered his luxury home. Our interaction did not have the flow that had characterised my previous encounters. Instead, the conversation was formal, and I felt that he was holding something back when he politely answered my questions with no elaborations whatsoever. On a later occasion, when I revisited and compared data, I noticed that in this interview, I had used the interview guide rather strictly, and the data lacked the 'thickness' (Geertz 1973) that characterised previous interviews. If I had been more attentive to how our different positioning affected the interaction in this particular research relationship earlier in the fieldwork, I might have been able to use the position as an 'outsider' strategically, instead of being restricted by it, because facing the unfamiliar may give way to new perspectives and

dimensions in the data (Hastrup 1992; Fangen 2010; Berger 2015). Or, by having a dual class positioning as both working class and middle class, I might have drawn more on the latter in this case to attain mutual understanding and ease the interaction. Or, perhaps trust and relatedness which in turn would have led to interesting discoveries might have grown between us if I had initiated a conversation about our differences (or similarities). Instead, this example illustrates how social background influenced (the lack of) access to data in this context where I had not yet gained sufficient experience as a qualitative researcher to reflect on these issues. Also, it illustrates that my background influenced what data this study includes and excludes because ultimately it is determined by the researcher (Ramazanoğlu and Holland 2002). The implication I draw from this discussion on the impact of my social background is that overall, although the selection represents participants with diverse social backgrounds, the perspectives of rural, working-class men are most prominent in the study since it was in these interactions that the production of knowledge reached its most intense, informative and engaged dimension.

### **8.8.3 Impacts of the intersection of gender and age**

While I shared the cultural background with many of the study participants and drew on our similarities and the benefits of an ‘insider’ position, I was simultaneously different from most in terms of gender and age (and the position as a researcher), and in this respect held the position of an ‘outsider’. Twelve of the study participants were male, and all were younger than me. (Most were 5-10 years younger, and I was in my early 30s at the time of the fieldwork.) In this section, I will discuss how the intersection of age and gender came to impact my interactions and understandings in the field. Gender and age are understood here as cultural constructions, something that is ‘done’ by agents in an ongoing process of creating and recreating identities by drawing on different discourses of masculinity and/or femininity

(West and Zimmerman 1991) or ideas of what practices are considered ‘normal’ and suitable at specific ages (Heggli 2004; Kåks 2007).

The gender dynamic I encountered during interactions in the field was often characterised by gender performances in which the young, male study participants positioned themselves as ‘knowledgeable men’ and I was positioned as an ‘unknowledgeable woman’ who needed things explained to her. This resonates with the experience of Pini (2005), who discusses from a feminist perspective the complexities of the power dynamics that occurred when as a younger woman she interviewed 15 older male leaders in an Australian agri-political organisation. In these interviews, the men drew on several masculine discourses, including the position of being ‘knowledgeable’ and ‘expert’ men. During these interactions, the knowledge of the researcher gained from academic study or life experience was not acknowledged. Instead, she was positioned as ‘innocent and a little dim’ (Pini 2005, p. 210). Although I never encountered hostility from study participants in interactions as described by Pini in her account, I relate to her experience of not being acknowledged as a knowledgeable person and/or researcher. For example, the study participants sometimes took the role of ‘knowledgeable’ and ‘expert’ men who would lecture me on topics, such as accident statistics, despite the fact that I was an academic studying this subject and that I was older and more highly educated than any of the people I interacted with in the field. In ethnographic fieldwork, the researcher uses her body as an instrument (Stewart 1998; Fangen 2010) and thus the presence of her body, including display of gender and age, will have an impact on the interaction in the field. The ‘knowledgeable’ and ‘expert’ positioning of the men in the study may not only be part of a gendered dynamic in which the ‘men’ positioned themselves in relation to a ‘woman’, but intersects also with my particular display of age. I used large, unisex clothes, sneakers and wore no make-up, which in the academic community that surrounds me is (relatively) unusual for a woman of my age and in my position (as a

researcher). This ‘uniform’ lacked the display of authority and, moreover, might have given the impression that I was younger and more inexperienced than I was and thus allowed the men to position themselves in authoritative positions vis-à-vis me.

The experiences outlined above stand in contrast to the account by Thurnell-Read (2016), who explores intersections of age and gender in his academic career as a man researching (both older and younger) men. Thurnell-Read describes how he used the privileges that came with his position as a (white, middle-class) male researcher to ‘fit in’. He was allowed the position of a ‘knowledgeable’ man in different situations. His familiarity and embeddedness in masculinity became a resource that he used to achieve masculine status, be taken seriously and gain access to the lives of the study participants through homosocial bonding (ibid.). These are gendered strategies that I did not have access to as a woman researching men, and this illustrates the possible impacts that age and gender might have in the research process in terms of the nature of interactions in the field, the data that may or may not be accessible from different gender positions, and thus also the production of knowledge.

Same-gendered interactions in the field entail the risk of taken-for-grantedness, and thus shared gender experiences and assumptions may be left uninvestigated (Pini and Pease 2003). Interactions between a female researcher and male study participants may produce explicit articulations about gendered experiences that otherwise would have gone unnoticed. I found that this was probably so in relation to topics and emotions that concerned the male body and homosocial relations. For example, while a male researcher has the ‘insider’ privilege of joining homosocial arenas with which he is familiar and blends in, I as a woman had the ‘outsider’ privilege of being offered detailed accounts of the social and emotional importance of homosocial interactions as it was understood by the study participants. Also, I was offered detailed accounts of how it felt to ‘be a man’ when the body does not function ‘as it should’.

In such conversations, I was offered insight into the men's gendered experiences and emotions which might not have been articulated the same way, or at all, if the interviewer was a man due to implicit assumptions that he would already be familiar with them.

Although I had the benefit of the position as an 'insider' due to my shared background with most of the participants, and thus had the status of an 'equal' in this respect, the power dynamic was influenced by my gender which positioned me as an 'outsider'. Moreover, many men performed what I interpret as a traditional working-class masculinity in which I was not only an 'outsider', I was also positioned as subordinate in an assumed heterosexual and a gendered power dynamic in which some men took the dominant role of 'courting' me and 'looking after' me. This meant, for example, that doors were held open for me and accompanied by the phrase 'ladies first', and one man insisted on referring to me as 'miss'<sup>40</sup> although I repeatedly asked him in a friendly tone to please use my name. These gendered power dynamics illustrate that the presumed power of the researcher over the researched (Ramazanoğlu and Holland 2002) was ambiguous and under negotiation in social settings during the fieldwork. For example, by using 'miss', the participant obscured my professional authority as the researcher and reminded me instead of my rather young age, my female gender and my potentially sexual relation to him as a man. Notably, the interaction with the two women in the study was mutually respectful and never activated asymmetrical relations similar to those I encountered in interactions with male study participants.

Although the gender dynamics with male study participants was often asymmetrical and therefore problematic in a feminist perspective which strives for equity, it had benefits in terms of academic knowledge production. It gave way for interesting accounts that in

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<sup>40</sup> In some countries, referring to a woman as 'miss' might be part of polite and respectful social interaction. In contemporary Norwegian discourse, however, the use of 'miss' (*frøken*) has connotations relating to courting or derogatory positioning of a woman.

addition to the study participants' emic views (e.g. how a car works, how it feels to drive a car and accident statistics), simultaneously uncovered ways in which they viewed the world and their ways of acting in it as gendered beings. The men tended to rely on a discourse in which their achievements as men were central. For example, some emphasised their financial, sexual or physical achievements. I sometimes got the feeling that elements of these stories, such as details about how much they earned, elaborations on the beauty of women they had slept with or descriptions of their exercise regime and fitness, were conveyed in order to impress me as a woman; it was a way to construct themselves as attractive, successful men who had managed well despite the fact that they had been through a severe accident in which they had become disabled men.

#### **8.8.4 Coming to see ethnicity**

Kimmel describes the moment in which he became aware of his position as a *white man*. Belonging to these two categories had up until then allowed him to walk through life in the belief that he was 'neutral', he had no gender and no colour on this skin. He had basically seen himself as an 'objective' representative of the human species. The insight that he had been totally unaware of his gender and his colour, (and not least the convenience of such a privileged position) dawned on him when he listened to a black and a white woman talk about feminism. The white woman said that she saw *a woman* when she looked in the mirror, whereas the black woman said that she saw *a black woman*. 'I', Kimmel said to the audience, 'saw a *human being* when I looked in the mirror'.

I wrote the vignette above about a lecture held by Michael Kimmel at the research conference *Emerging ideas in masculinity research – Masculinity studies in the North* in Iceland in 2014.



When I use it here, it is because the point made by Kimmel in this story sheds light on the muted role of race and ethnicity in this study. In contrast to Kimmel, as a white *woman* I have numerous experiences related to my *gender* and how it affects my being in the world. But, similar to Kimmel's experience of being *white*, I have largely been 'unaware' of my skin tone during the course of this study. This stands in stark contrast to, for example, the personal experience described by Boylorn (2016), who explains how she is constructed and constructs herself in relation to discourses that 'blacken' her in her everyday life. The ability of black people to see themselves through the eyes of others while they are aware of themselves (ibid., p. 174) is one that I have not easily accessed with similar consciousness as a white person. During the fieldwork, I was rather unconscious of the impact my whiteness had on the interactions with the study participants, who were also white, and the effect this had on the production of knowledge. However, one incident occurred in which the issue of race/ethnicity rose to the surface, and thus its impact became more accessible to me. This happened during interactions with the study participant Arild. I described the situation with the following words in my field diary in the evening after we had an interview:

*Today, Arild dropped a racist comment in the middle of an interview. Yes, that happened! I almost jumped out of my seat. I felt uncomfortable. A moment passed, and another racist comment followed. My heart sank. What am I to do? Confront him? Pretend I do not react to racism? Was it wrong not to say anything? I find this disturbing.*

In the aftermath of the conversation I had with Arild, I wrote reflexive notes which helped me to sort out my feelings in this situation, how it affected my interactions with Arild, and possible ways to handle the situation. Initially, I thought that what I had uncovered was that I drew on an anti-racist discourse which in turn had an impact on my interactions in the field.

Sophisticating this interpretation in conversations with colleagues, however, I found that this understanding was too simple. It would mean that I conveniently positioned myself as anti-racist on the expense of Arild, who then would be unfavourably positioned as racist. This was problematic given that although I am striving towards the ideal of anti-racism, I might not be as free of prejudice as I wish to be. (I had learnt so much through confrontations with my ‘ableism’ in the process of creating article 2.) Moreover, I did not know the motive for his comments – perhaps it was not in fact racism, but his sense of humour or an attempt to impress me by ‘talking tough’? I did not have sufficient data to analyse this matter. However, I find that the strengths of reflexive practices in qualitative research are well illustrated by this example both because it added nuance to my interpretations and because it enabled me to take decisions on what to do. These decisions were guided not by my emotions alone, but rather informed by the feminist ethics of care that frame the study’s ethics. This means that respect, relatedness and care for the study participant is central (Edwards and Mauthner 2012), and awareness of the powerful position of the researcher is stressed (Ramazanoğlu and Holland 2002). In this particular situation, the intersection of Arild’s positions in relation to me (as disabled, younger than me, a participant in the study) made him vulnerable, and I found that the best approach was to keep my opinion to myself and create a tolerant environment so that the study participant would feel safe to express himself freely (McKay, Ryan and Sumsion 2003). Consequently, I did not confront Arild with the racist comments in the course of the study due to overall ethical concerns.

Ironically, since I had an impression of myself as being anti-racist, I discovered during this reflexive process that I had been ignorant of the issue of ethnicity in previous phases of the study. I had been acting in a way that has been criticised by the theorist bell hooks, among others. She has been particularly critical of white academics who continue to treat black presence with ignorance and absence (1991). This critique can be extended to involve ethnic

diversity of any kind. Reflections on the interaction with Arild exposed that the researcher – and thus the study – have largely been ignorant of issues related to ethnic diversity. On one hand, this ‘lack’ may be seen as legitimate since race/ethnicity is not in fact the focus of this study. On the other hand, it does impact the knowledge production and raise questions: Why were all the study participants white? Should I have been more conscious in the recruiting phase in order to embrace a greater variety? I pose these questions to acknowledge and highlight not only that there is a possibly unfortunate lack of ethnic diversity among the study participants, but also that this particular homogeneity both resulted in, and was the result of, my inability for quite some time to see ethnicity in the research process: I was initially not consciously aware that the study included only the perspectives of white people. This insight highlights the role and power of the researcher in qualitative research. It is an example of how the knowledge and ignorance of the researcher have an impact on the production of knowledge. It illustrates that qualitative research is inexorably connected to the subjects involved in any particular study. The study would have been different if more ethnic variety had been included. Also, it would have been a different study and other knowledge would have been produced had I had a different class background, or if I had been a man – or quite simply if the study participants and I had been someone other than who we are.

### **8.8.5 Conclusions**

In this chapter, I introduce the concept of reflexivity and discuss its use and purpose in qualitative research. I theoretically position the study in the framework of feminist reflexivity and use empirical examples to discuss how my social background, the intersection of age and gender, and ethnicity have influenced the research process. In conclusion, these reflections illuminate the power of the researcher in the study; her values and (undetected) biases will influence what she sees and does not see, and thus what she chooses to include and exclude in the study. The discussion of reflexivity in this chapter helps to gain clarity on the kind of

knowledge this particular study has produced. For example, the perspectives of rural, working-class men are most prominent in the study, the intersections of age and gender have allowed for knowledge about gendered experiences to emerge, and the study is homogeneous in terms of ethnicity as it includes the perspective of ethnic Norwegians only.

## **8.9 Autoethnography**

### **8.9.1 Introduction; defining autoethnography and locating the study**

Autoethnography is a method and a process in which the author uses his or her lived experience as data, relates the personal to the cultural, and creatively explores different expressions of communicating research (Plummer 2009; Ellis, Adams and Bochner 2011). It is a hybrid genre that ‘blurs lines between personal and social, self and other’ (Simpson 1996, p. 372). Holman Jones, Adams and Ellis (2016) offer four characteristics of autoethnography which define it and distinguish it from other ways of writing and conducting scientific inquiry. I will give a brief overview of these four characteristics in order to clarify what autoethnography is, and then articulate how the work in this thesis displays these characteristics.

*The first key characteristic is purposefully commenting on/critiquing of culture and cultural practices.* This means that the writer reflects on the nuances of her experience(s) in a way that illustrates more general cultural phenomena and/or shows that the experience works to ‘diminish, silence, or deny certain people and stories’ (Holman Jones, Adams and Ellis 2016, p. 23). In contrast, if the writer tells a story about herself and does not view it in light of cultural practices or cultural phenomena, the writing is autobiographical. Thus, the difference between, for example, confessional tales and autobiographical work on one hand, and autoethnographies on the other hand is the intent to describe cultural experience in the latter.

*The second key characteristic is making contributions to existing research.* This means that the text is situated within the research conversation on the given topic(s) under investigation. Autoethnographies demonstrate knowledge of past research and seek to contribute to the academic dialogue. *The third key characteristic is embracing vulnerability with purpose:* an intentional subject is presented in autoethnographies. This entails that ‘secrets are disclosed and histories are made known’ (Holman Jones, Adams and Ellis 2016, p. 24), and thus the autoethnographic writer makes herself vulnerable in ways that other traditional scientific methods do not by making her experience available for potential criticism and consideration. *The fourth key characteristic is creating a reciprocal relationship with audiences in order to compel a response.* This indicates that the autoethnographer seeks to connect with the readers and ‘explicitly acknowledges, calls to and seeks contributions from audiences as part of the ongoing conversation of the work’ (Holman Jones, Adams and Ellis 2016, p. 25). The reciprocal aspect of autoethnographic work implies that readers are not passive receivers of the work, but are considered active participants with whom the writer seeks an engaged connection (ibid.).

In this study, the autoethnographic account (article 2) displays the four key characteristics outlined above in the following ways: First, it purposefully critiques culture and cultural practices by exploring cultural ‘ableism’. My personal experience of interacting with disabled people is used to discover and problematise taken-for-granted cultural notions (and actions that might follow from such notions) which draw on a pathology-focused lens that positions disabled people as subordinate and that maintains non-disabled privilege and superiority. Second, the autobiography is situated in the field of disability studies. It shows awareness of previous work on autoethnography, ‘the social model of disability’ and ‘ableism’. It seeks to contribute to the ongoing academic conversation on ‘ableism’ in disability studies by exploring the phenomena from the perspective of the non-disabled researcher. Third, I

embrace vulnerability with a purpose in the sense that I expose myself as ‘ableistic’ in order to ‘call attention to the vulnerabilities that other human beings may endure in silence and shame’ (Holman Jones, Adams and Ellis 2016, p. 24). I seek to give voice both to social scientists and to non-disabled people who make ‘mistakes’ in the field and/or in their everyday lives by discriminating against disabled people against better knowledge, but who might end up hiding it due to shame or embarrassment. Fourth, the autoethnography is deliberately written in an easily comprehensible language in order to reach a broader audience than only academics. With words, I paint pictures that seek to compel feelings and recognition in the audience. The autoethnography is written in the hope that the reader will respond emotionally and take part in the conversation.

### **8.9.2 Purposes of autoethnography (what it might do)**

Initially, the autoethnographic approach stirred a great deal of controversy in academic circles when it emerged in the 1980s as a part of academic criticism at the time of the idea that research may be objectively captured (Ellis, Adams and Bochner 2011). Instead of attempting to capture ‘the truth’, the autoethnographer resists the idea that this is possible and fully acknowledges that he or she is part of the process and outcome of research (Plummer 2009). In this sense, autoethnography resonates with the feminist critique of objectivity in research (Keller 1985; Harding 1986; Harding 1992; Haraway 1996) and its positive attitude towards the exploration of creative research methods, such as using stories and descriptions of, for example, thoughts, memories, and feelings as data (e.g. Briggs 1986).

Autoethnography emerged ‘to account for the role of personal experience in research, to illustrate why the personal is important in our understanding of cultural life, and to more fully articulate the complex research and decision-making processes researchers engage in in the conduct of their work’ (Holman Jones, Adams and Ellis 2016, p. 33). In the study, the purpose of using autoethnography includes the desire to carry on this feminist critique by

embracing traits that are not always acknowledged in traditional research, such as uncertainty and emotionality, and thus calls into question the superiority of objectivity, control and predictability in traditional research by disrupting norms and supplying an alternative (Holman Jones, Adams and Ellis 2016). Notably, autoethnography does not claim or seek to produce 'better' research than other methods, but offers another approach for the study of cultural practices (Holman Jones, Adams and Ellis 2016), and I wanted to offer such an approach to the examination of 'ableism'. Also, the purpose of using autoethnography in the study is to make scientific work accessible to a broad audience by writing in an engaged and creative way that appeals not only to academics (Smith and Sparkes 2008; Holman Jones, Adams and Ellis 2016). The work seeks to create connections of empathy and understanding by sharing acts of confession that extend beyond the self and reach out to other people (Sparkes 2002). Finally, the purpose was to make use of its potential as a tool for critical self-reflexivity (see e.g. Simpson 1996; Hage 2009) through reflexive writing over time and by openly discussing how I matured as a researcher in this process. In general, many purposes and benefits of using autoethnography could be added. For example, it breaks the silence when understudied, hidden and sensitive topics (such as eating disorders or sexual abuse) are studied (Holman Jones, Adams and Ellis 2016). It is a tool with which to use personal experiences to critically discuss positions of relative powerlessness (see e.g. Rogers 2009; Sobre-Denton 2012; Mainsah and Prøitz 2015; Owton and Sparkes 2015), and it contributes to greater representativeness in the academic dialogue by including voices that are seldom heard, such as experiences from the position of indigenous or disabled people (see e.g., Whitinui 2014; Howie 2009).

### 8.9.3 How autoethnography has influenced the study

*I was thrilled when I first came across autoethnography. What a beautiful, awkward, poetic and insightful portal to new knowledge, I thought. I read several accounts and found it increasingly appealing. Not only that, I felt it would suit the frame of the study perfectly. In the same manner as disability research celebrates the extraordinary, autoethnography insists on being acknowledged on its own terms. It does not submit to normative ideals, but holds the potential for substantial contribution to knowledge through its difference. Eager to share my discovery, I enthusiastically told my colleagues at the weekly lunch meeting at the Centre for Gender Research that I wanted to write an autoethnographic article as a part of my dissertation. I was surprised by the response. My colleagues were not at all enthusiastic about the idea. Two senior colleagues explicitly advised against it. In their opinion, autoethnography was not 'real' research. This response made me reconsider. I put the idea aside. For some months, I did not read autoethnography. Then, one day at the office, I looked through my notes and found some old diary entries. I re-read my passionate words about the potential of autoethnography. Again, I was intrigued. I read some more autoethnographic articles and pondered. Some of them offered new perspectives. They adhered to a high academic standard. It seemed like 'real' research to me. What was it with the negative attitude towards autoethnography, anyway? Could it be that the hybridity of autoethnography itself was the reason why it was put aside as something other than 'pure science' in the stratified world of academia? Was there no room for its difference? I read. I wrote. Increasingly convinced, I decided to give it a go.*

The excerpt above from my field diary describes a part of the reflexive process in which I decided to include autoethnography in my doctoral work. In anthropological terms, I am



tempted to describe autoethnography as ‘matter out of place’ (Douglas, 1997 [1966], p. 50) in the world of scientific research traditions, i.e. as a phenomenon that escapes established categories and therefore risks exclusion from the (academic) community. Among the criticisms voiced about autoethnography is that it may be either ‘too artful and not scientific, or too scientific and not sufficiently artful<sup>41</sup>’ (Ellis, Adams and Bochner 2011). I have conducted the study in an academic environment that is unfamiliar with autoethnography and in which sceptical voices were raised against it, as illustrated in the diary entry above. Given that autoethnographers are encouraged as part of an ethical process of self-care to consider the risk of using the approach because it can hurt professionally<sup>42</sup> (Tullis 2016), I carefully considered whether and to what extent it would be a professional risk to use autoethnography as a part of my thesis. Initially, I wanted to be more experimental in relation to writing the whole thesis, and at one point considered using an overall autoethnographic approach in the work. However, I eventually decided that the potential risk of having the thesis rejected by the faculty or the doctoral committee (especially since I did not know beforehand whether or not the members of the committee would be amongst the critics of autoethnography) or of being excluded from future employment in academia due to this untraditional choice was too high. However, I considered the risk of including one autoethnographic article to be relatively low if it was published before the thesis was submitted, and thus already peer reviewed and acknowledged by fellow academics when the thesis was submitted for evaluation, so I was willing to give it a go.

Although I decided not to use autoethnography as the overall approach to the work, it has influenced the work theoretically by using myself and my experiences as a tool to understand

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<sup>41</sup> Its ambiguity is one of its characteristics, and whether the analytic, narrative or cultural aspects are to be emphasised in autoethnographic productions is an ongoing academic debate (see e.g. the special issue of the *Journal of Contemporary Ethnography* [2006, 35 (4)]).

<sup>42</sup> It can also hurt personally and relationally, which I discuss in the chapter ‘Process ethics’.

culture and more generally in the study process both methodologically and in terms of the content and form. Methodologically, autoethnography influenced the study in the sense that exploring my encounters with the study participants, including, and perhaps especially, my ‘mistakes’ as a researcher in the field, made me more familiar with the many twists and turns in ethnographic fieldwork and less hesitant to experiment with theories, thoughts and empirical data in the study process. Whereas I had struggled to understand how field notes could be used in academic publications and in reflexive dialogues with my colleagues, I learnt through autoethnography that I did not have to hide my descriptions of awkward encounters, politically ‘incorrect’ feelings and thoughts. Rather, they could be written and spoken out loud. I benefited immensely from sharing, discussing and analysing such experiences openly. Such interactions with other people enabled me to transcend my views (Moen and Middelthon 2015). Also, by using my diary entries and emotions as data, I drew on a broader empirical repertoire in the thesis than I otherwise would have. In terms of the content, the study’s emphasis on ‘Otherness’ and findings related to this is influenced by autoethnography because it increased my awareness of how I myself am embedded in cultural discourses in which groups of people are positioned as ‘Others’. It was the exploration of my cultural ‘ableism’ in encounters with the study participants that opened my eyes to the discursive production of ‘Otherness’ in other fields as well, such as in the culture of rehabilitation (article 1) and in the literature about ‘young problem drivers’ (article 3), which is discussed in this thesis. Autoethnography influenced the form in the sense that I have deliberately used an accessible language to connect with the readers and creatively explored the use of colourful descriptions in which situations may ‘come alive’ to them in an attempt to communicate my experiences as I felt and lived them myself.

## 8.10 Judging the quality of qualitative research

### 8.10.1 Ontology and epistemology

In this chapter, I discuss criteria and ways to judge qualitative research in relation to this study, including an assessment of the study's autoethnographic account. I use an approach in which I compare qualitative and quantitative research in order to illustrate the points made. Also, I treat these two approaches to research separately to keep the discussion accessible. It is important to keep in mind, however, that one might also choose to focus on their similarities and overlaps (Sparkes and Smith 2014). Moreover, some combine the two approaches in their studies and the ways in which researchers positions themselves ontologically and epistemologically varies. For example, Crotty (1998) notes that a constructivist epistemology works well with a realist ontology although this is often presented as incompatible. Thus, I emphasise that in this chapter my approach to quantitative and qualitative research is rather conventional. When I speak of quantitative research, I speak of quantitative research conducted in an objectivist epistemology, and when I speak of qualitative research, I speak of qualitative research conducted in a constructionist or subjectivist epistemology (while not suggesting that this is the only possible combination).

In quantitative research, there is relative consensus that one should aim for objectivity, reliability, generalisability and validity in order to achieve good quality of the studies (Tracy 2010). Qualitative research, however, is traditionally based on different ontology and epistemology which make these criteria less meaningful (Guba and Lincoln 2005).

Ontologically, i.e. that which concerns the study of existence (Crotty 1998), quantitative research often relates to a realist or external view in which the reality exists externally (Sparkes and Smith 2014). Qualitative research often relates to a relativist or internal ontology. This entails that although physical things exist, the meaning and interpretations of

them and of people's actions and utterances are connected to, for example, language and cultural symbolism; realities are perceived of as multiple, subjective constructions dependent on the human mind. Qualitative research aims through the individual case to investigate how people construct meaning in given phenomena (Sparkes and Smith 2014). Epistemologically, i.e. that which concerns the study of knowledge (Crotty 1998), quantitative research often takes an objectivist stand in which the object of study can be investigated through procedures that in this line of thinking make it possible to attain theory-free knowledge and observation. In qualitative research, there is no theory-free knowledge, and the subject under study is always intertwined with and inseparable from the researcher who mainly relates to a subjectivist or constructionist epistemology (Sparkes and Smith 2014).

### **8.10.2 The strengths of qualitative research**

Traditionally, quantitative and qualitative research have been constructed in a dualist, hierarchical relationship in which quantitative research has the favourable position. This entails that the ontological and epistemological premises developed to understand, conduct and assess quantitative research may occur as universal, and qualitative research is often viewed in light of them. Consequently, qualitative research will often fail to achieve these standards and may even fall outside the definition of what counts as 'real' research (Smith and Hodgkinson 2005; Denzin and Lincoln 2018). It is therefore vital to acknowledge the ontological and epistemological differences that traditionally occur in these two types of research in order to fairly assess the nature and quality of qualitative research and to be able to recognise its strengths and value. Quantitative and qualitative research are equally important because they produce different kinds of potentially valuable knowledge. For example, focusing on causal regularities requires quantitative procedures, while focusing on the meaning and significance of people's lives and experiences requires qualitative procedures (Delmar 2010).

I will highlight the strengths of qualitative research noted by Atieno (2009) in relation to this study: The strengths of qualitative research are that it allows for explorations of meaning and process; it allows for contextual understandings to arise; it allows for researchers to connect with people and produce knowledge from insider perspectives; it allows for research designs in which questions and understandings may emerge, change and become the topic of inquiry as it unfolds in the field; and it allows for complexities and new ways of seeing the world to arise. This study produces knowledge within a flexible, open research design that inhabits these strengths. The qualitative approach has entailed the emergence of unpredictable insights – for example, the effects of ‘the language of percentages’ on ways in which rehabilitees view themselves and their bodies. Also, taken-for-granted assumptions – for example, the cultural idea that disabled bodies are incomplete versions of able bodies or the notion that ‘young problem drivers’ do not care about road traffic safety – have become the issue of critical inquiry along the way and sought to be nuanced and viewed in a new light. The qualitative approach has allowed for contextualised knowledge about the meaning and personal experience of being positioned as disabled, rehabilitee and a ‘problem driver’ to arise. For example, exploring medical procedures in the context of rehabilitation culture and from the insider perspective of rehabilitees provides an understanding of meanings and personal experience that would not have emerged in a quantitative research design. Another strength of qualitative research is that it can potentially make a difference on a political and practical level because it explores lived experience and produces knowledge about the world and humans in it that ‘make the world visible (...). These practices transform the world’ (Denzon and Lincoln 2018, p. 10). Sparkes and Smith (2014) note, for example, that qualitative research can generate new theories and challenge taken-for-granted theories, improve healthcare practices, inform intervention programmes, generate behavioural change and develop applied practices, influence policy development, improve public services,

contribute to the creative economy and cultural enrichment, and by extending knowledge beyond academia, contribute to civil society and social justice (p. 241). A strength of this study is its contribution to knowledge that could potentially change policy and practice. For example, it offers new ways of understanding ‘young problem drivers’ and may change ways in which traffic safety experts regard and develop safety interventions directed at young men.

### **8.10.3 The debate about criteria in relation to this study**

Since the criteria to judge quantitative research often does not fit the design and goals of qualitative research, other, parallel criteria have been offered to judge the quality of different kinds of qualitative research. The view on what criteria would be meaningful to use, and strategies on how to do it, is a major debate with lack of consensus. In this complex and ongoing debate, different views are held among different groups and according to different traditions in the social sciences (Tracy 2010; Sparkes and Smith 2014). While some theorists encourage the use of different sets of criteria depending on the particular theoretical position adopted in a study (see e.g. Creswell 2007), others argue that despite the complex terrain of different paradigms, it is possible for qualitative researchers to unite and use the same basic criteria to develop and judge ‘goodness’ in research. Suggestions on how to do so have been promoted (see e.g. Tracy 2010). Others point to the political aspects in the act of promoting criteria. For example, Smith and Hodkinson (2005) highlight that lists of criteria are themselves socially constructed even though they may appear as final and objective ways to judge ‘good’ from ‘bad’ research. They illustrate that lists of criteria offered by governmental authorities, for example – and in which what counts as legitimate and illegitimate research are defined – are products of context-bound political processes and social interactions in which economy and self-interests, for example, are at play. I support the relativist<sup>43</sup> view of

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<sup>43</sup> By ‘relativist’ I do not suggest that everything has the same value. In line with Smith and Hodkinson (2005), I find that it is within the scope of ‘relativism’ to make judgments in which some things are preferred over others.

theorists who argues that criteria are and ought to be open-ended and subject to change (Richardson 2000a; Smith and Hodkinson 2005). The terrain in which ways to judge the quality of qualitative research have been debated illustrates the complexity of this issue, since a vast variety of different criteria and strategies have been promoted over the years. In the next section, I will give a brief overview of some of them in connection with criteria used in quantitative research and in relation to the study.

### **Objectivity in the study**

Qualitative researchers use their bodies and selves in the process of conducting research (Stewart 1998, Fangen 2010) and acknowledge that it is not possible (or desirable) in this kind of scientific work to achieve objectivity in the same way as in quantitative research. The concept of ‘confirmability’ (Lincoln and Guba 1985; Guba and Lincoln 1989) has been offered as a parallel to objectivity. This relates to the degree to which the research is ‘rooted’ in the data in contrast to simply being the outcome of subjectivity and biases. To avoid the latter, the researcher is encouraged to relate to context and other persons in order to transcend her views. This study is conducted in line with feminist theory that contests the traditional perception of objectivity and that views objectivity not as the elimination of bias, but which instead stresses the necessity to situate oneself in order to achieve objectivity and openly reflect on bias (Haraway 1996). It is with such an understanding of objectivity that strategies to achieve it have been chosen. I have sought overall to be reflexive about my work, uncover and confront biases, and reflect on how these might affect the research process from start to finish (Finlay 2002; Finlay and Gough 2003; Davies 2008; Berger 2015). I have also contextualised the data (e.g. by describing medical procedures at the rehabilitation hospital in which ‘the language of percentages’ was produced) and engaged in academic discussions with others who have perspectives different from my own (e.g. at interdisciplinary seminars). This might work to uncover taken-for-grantedness and offer new discoveries (Moen and Middelthon 2015). Lincoln and Guba (1989) suggest that the researcher should reveal her

decision-making process in order for readers to make their own assessments of the ‘confirmability’ of the study. While drawing on a feminist conception of objectivity, I have sought to do so in terms of offering accounts and examples of ethical decisions, the reflexive process, the context of the study and situations in which data have been produced, and the theoretical frameworks that have guided my steps in order for the readers to make their own assessments.

### **Reliability in the study**

Reliability relates to the consistency, repetition and reproducibility of quantitative research, and is valuable in, for example, laboratory, medical and product safety research. In qualitative research, the idea of reproducing the same data twice is not a goal. Although some qualitative researchers relate to the parallel criteria of ‘dependability’ – which concerns the consistency, stability and accuracy of the study – others do not find reliability relevant in their work, and this is legitimate as long as it is an informed decision (Sparkes and Smith 2014). In this study, reliability is not a meaningful concept since I have conducted it within a theoretical framework that does not seek or aim at consistency, stability and accuracy. Rather, in the constructionist approach of this work, realities are multiple, and the study embraces multiple meanings, contradictions and complexity (Tracy 2010).

### **Generalisation in the study**

In quantitative research, generalisability is often arrived at by using random statistical sampling procedures in which findings can be applied to other settings, cases or a whole population (Tracy 2010; Sparkes and Smith 2014). Qualitative researchers use other forms of samplings, such as in-depth studies of a small number of people, and therefore seek forms of generalisations other than statistical ones. For example, qualitative researchers may seek to generalise theories, focus on ways in which findings can relate to the broader lives and experiences of the readers or seek generalisation by emphasising ways in which research



results can be ‘matched, transformed or “exported” to comparable situations’ (Delmar 2010, p. 118).

This study is qualitative, and thus not generalisable in the sense that it says something general about the population from which the sample is drawn. Instead, it gives insight into the specific situations, contexts and understandings in which the data were produced (Gubrium and Holstein 1997; Stewart 1998). However, in line with many qualitative researchers, I find it essential that the research results are ‘portable’, i.e. that they may be relevant and useful in contexts outside of the study setting as well (Moen and Middelthon 2015). This study seeks to do so by aiming at ‘transferability’ (Lincoln and Guba 1985). This means that I have aimed to create the research in a way – in this case through rich descriptions and accessible writing – that will enable the readers to transfer the research report to their own situation and/or action (Tracy 2010). In particular, I sought to do so by implementing autoethnography in the study. This allowed me to use relatively thorough descriptions and accessible language directed at a broad audience although the format was a scientific article (which often does not leave much space to engage with empirical material or creative expression in the written product due to strict requirements). Qualitative researchers have developed several approaches that in line with ‘transferability’ are related to generalising findings by looking at ways in which the research may have an impact on the reader. For example, ‘naturalistic generalisations’ (Stake and Trumbull 1982) focus on how researchers’ narratives stimulate and extend the readers’ understandings in a social process: ‘That is, people make some generalizations entirely from personal or vicarious experience. Enduring meanings come from encounter, and they are modified and reinforced by repeated encounter’ (Stake 2005, p. 454). A similar approach on how to generalise by focusing on the experience of the reader is ‘recognisability’ (Delmar 2010), which I will outline in relation to this study.

‘Recognisability’ means that generalisations are arrived at when the recipient relates to the typical and universal in a story. Delmar (2010) argues that the uniqueness of a situation is not a barrier to achieving generalisability in qualitative research because any situation also has typical traits and recognisable patterns which may give meaning to the recipients when they relate to similar experiences in their personal lives: ‘It is this recognisability that contributes to the “generalisability” of qualitative studies’ (Delmar 2010, p. 122). This study primarily concerns the personal experience of being a rehabilitee, disabled and/or a young, male driver. These are context-bound situations and stories that are as unique as each individual who tells them. Readers might (or might not) personally relate to the specific experiences and positions held by the participants and thus find (or not find) the particularities of these stories recognisable. However, I argue that these stories and experiences simultaneously contain aspects of general concern which make the study generalisable and recognisable for people in general. For example, the study tells stories about the pain and fear of being seen as something ‘Other’ or less than human (article 1), the right and need to be fairly treated and live in a safe environment where one is not discriminated against (article 2), and the need to be acknowledged as a rational human being also when one chooses to engage in non-normative practices (article 3). I argue that although these issues – pain, fear, safety, justice, rationality, inclusion – are never independent of the discourses in which they are constructed and thus will differ in terms of how they are interpreted by each reader, they may be understood as relevant for any person in the sense that they address human feelings, needs and rights. To achieve full ‘recognisability’, however, the recipient must not only recognise and personally relate to the universal in a story; the work must also lead to a practical transformation (Delmar 2010). At this point, only the readers can judge if I have succeeded to do so with my work. However, I have aimed to achieve full ‘recognisability’, in part by writing articles that attempt to enter into dialogue with people who work with rehabilitees and young, male drivers. Hopefully, the findings will be useful in practice.

The study made use of ‘category zooming’ (Halkier 2011). This is a form of analytical generalisation that ‘goes into depth with the details and complexities in one single point of the study’ (ibid., p. 792). This is particularly so in relation to the analysis of ‘the language of percentages’ in article 1. The aim was to build an analytical generalisation that captures a particularity that cuts across the data material and considers this ‘language’ and its meaning in the broader context of the rehabilitation culture that surrounded the study participants. In line with the theoretical framework of this study, I do not claim that ‘the language of percentages’ is a stable representation or that it is universally applicable. I do suggest, however, that it goes beyond the individual perspectives outlined in this study. It is generalisable in the sense that it is a social construct embedded in the culture of rehabilitation, and thus theorising ‘the language of percentages’ holds the potential of understanding ways in which medical discourses create normative ideas about bodies and humanity that move beyond the study setting.

### **Validity in the study**

In quantitative research, the concept of validity relates to the truthfulness of findings and conclusions in a study: ‘A valid or truthful instrument measures what it is intended to measure’ (Sparkes and Smith 2014, p. 188). In qualitative research, the issue of validity relates to the trustworthiness and credibility of findings and conclusions, but how to understand or achieve validity is debated, and researchers take different positions. Sparkes and Smith (2014) illustrate the diversity of this terrain by describing three perspectives: First, you have ‘the parallel perspective’ of credibility in which the idea is that by using a specific set of different strategies, methods and techniques,<sup>44</sup> the study will be more credible. This perspective supports the use of a static form of criteria, and critical questions such as why

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<sup>44</sup> See e.g. Lincoln and Guba (1985), Guba and Lincoln (1989) or Stewart (1998) for an overview of these.

some techniques are chosen over others remains unresolved. Second, you have ‘the diversification perspective’ in which validity is conceptualised in order to fit the particular inquiry undertaken. Third, you have ‘the letting-go perspective’ which abandons the criteria of validity and uses other ways and standards to assess the quality of a study.

This study draws on ‘the diversification perspective’ in relation to the question of validity. Also, it draws on an open, relativistic approach to criteria in the sense that the use of particular criteria and strategies are not seen as absolute (Sparkes and Smith 2014). I will discuss the trustworthiness and credibility of this study by emphasising criteria that I find relevant and meaningful given the constructionist and feminist frame in which this particular study is conducted. Currently, this includes the following criteria: ‘crystallisation’, ‘thick description’, ‘member reflection’, ‘self-reflexive practice’, ‘transparency’ and ‘meaningful coherence’ (Tracy 2010).

This study relates to the idea of ‘crystallisation’ (Richardson 2000b) in which a diverse range of methods, researchers and frameworks are used to embrace ‘not a more valid singular truth, but to open up to a more complex, in-depth, but still thoroughly partial, understanding of the issue’ (Tracy 2010, p. 844). This study embraces diversity, such as through its interdisciplinary nature and heterogeneity in the choice of theories. The strategies discussed below further illustrate how ‘crystallisation’ is used to increase the trustworthiness and credibility of this study.

‘Thick description’ (Geertz 1973) is a relevant strategy used in this study to illustrate the complexity of data. Using thorough, detailed descriptions, I have sought to give insight into contexts and situations so that the readers can reach their own conclusions about the trustworthiness of findings and conclusions based on the data I have presented.

The study has a collaborative approach (which includes study participants, the researcher herself and colleagues) to capture multiple meanings and detect and confront taken-for-grantedness. This includes a moderate form of ‘member reflection’, i.e. that findings and data are taken back into the field and discussed with the participants. This strategy enhances credibility by providing new data and embracing the potential of richer analysis (Tracy 2010) that transcends the mind of the researcher by providing external stimulation. In this study, final interpretations and texts were not discussed with the participants as some feminist researchers do in order to, for example, confront possible disagreements or include their voices in the written product. However, ongoing conversations in which interpretations and themes were developed between the researcher and study participants often occurred. Also, the data were discussed with colleagues in order to further sophisticate interpretations, analysis and textual presentations of the research.

Self-reflexive practice is a strategy used throughout the study. This strategy works to increase honesty, authenticity and credibility by offering accounts of, for example, strengths and shortcomings in the research (Tracy 2010). I give the reader insight into my assessments and my field diary in order to disclose, for example, the rationale behind decisions concerning ethical dilemmas and the impact the researcher has had on the study.

The self-reflexive practice is connected to the issue of ‘transparency’ which is the attempt to be as sincere and honest as possible and to provide the readers with sufficient information to assess the study’s credibility on their own. For example, I have sought to be honest about challenges in the research process, provide detailed descriptions about the methods I have used and the level of participation, and give credit to the many people (e.g. the funder and my amazing colleagues) who have contributed to the study in valuable ways (Tracy 2010).

Finally, the study seeks to achieve credibility through a meaningful coherence (Tracy 2010). By this I mean that I have done my best to stay true to the inner logic that guided this study by connecting with relevant literature and following the paths of the ethical, theoretical and methodological frameworks in which this research is conducted.

#### **8.10.4 Judging the quality of autoethnography**

The major debate on how one might judge ‘good’ from ‘bad’ qualitative research and what criteria one should (or should not) use for such assessments includes an ongoing conversation about how (or even if) one might evaluate the quality of autoethnography. To simply set one specific standard or use a checklist to assure and evaluate the quality of autoethnography – or even suggest that it is possible to do so – is not unproblematic. After all, autoethnography represents a critique of the priority of traditional, dominant ways of producing scientific accounts over creative freedom and new, untraditional ways of scientific knowledge production and discoveries (Holman Jones, Adams and Ellis 2016). This might very well include a distortion of the notion that one might do it ‘right’ or ‘wrong’, it might question the idea that an account might ‘truly’ be ‘good’ or ‘bad’ or that such an assessment is possible given, for example, the various expressions celebrated in the autoethnographic approach and the broad audience that autoethnographers seek to connect with.

In an essay about the evaluation of autoethnography, Gingrich-Philbrook (2016) beautifully problematises the act of evaluation itself and the role of the evaluator. He suggests that evaluations occur alongside, and not above, the autoethnographic work under consideration. Although an evaluation may seem to possess the benefit of history and reflection since it comes after autoethnography and is part of a larger conversation about knowledge, there is no way to guarantee that the evaluation stands in an epistemologically privileged temporal

relationship to the specific autoethnographic account under investigation, he argues. Also, although the evaluation comes from someone who has been given the judgmental authority by academia (as part of the orienting story which the autoethnographer might seek to rebel against), the evaluation might be seen as

simply another story from a highly situated, privileged, empowered subject about something *he or she* experienced. To evaluate autoethnography in a genuinely useful way, you have to open yourself to being changed by it, to heeding its call to surrender your entitlement (p. 618).

This way of addressing and nuancing the power relationship between the evaluator and the creator of the account under consideration is appealing to me as a feminist researcher who works within a theoretical framework that strives towards equity and critical reflection in all phases of the research process (Ramazanoğlu and Holland 2002). To critically assess the powerful role of the evaluator and the evaluation does not abandon the idea that it is possible to make an evaluation or that evaluations may be useful and even necessary. However, it questions its ability to speak about the value of a body of work ‘once and for all’ and encourages critical reflection on its authority (Gingrich-Philbrook 2016). On one hand, having a checklist of how to do ‘good’ autoethnography may be reassuring to the researcher who wants to do it the ‘right’ way and it may ease the task of the evaluators assigned to assess its quality as part of academic procedure. On the other hand, as Gingrich-Philbrook warns, it might easily become a ‘magic contract’ which determines what gets to be counted as ‘good’ and ‘bad’ when such an evaluation might be seen as ‘an artefact of particular constellations of power and ignorance about our immersion in dominant culture’s illusory mastery of time’ (p. 624). By entering the territory of standing evaluative criteria, he argues, one might ‘already have forfeited much of autoethnography’s potential’ (p. 620). I follow

Gingrich-Philbrook when he problematises the use of criteria by, for example, highlighting that the evaluator who considers the conventional value of the work may miss its value to ‘other’ readers; some readers have never seen the checklist, and there are many ways in which the autoethnography may be regarded as valuable and ‘good’: ‘For example, it’s hard to know how many of our disciplinary colleagues assign our essay; what the essay meant to how many students who read it, how many of them used it in their own writing, let alone if it made even one of them lie down and cry and figure something out’ (Gingrich-Philbrook 2016, p. 620).

Having highlighted in theory the problematic aspects of using specific criteria, I do acknowledge, however, that in practice it is necessary to discuss the quality of the autoethnographic account in this study in accordance with the formal requirements of this particular scientific product. It is a Ph.D. thesis shaped within and limited by the frame of rules set by the institution I rely on (Ramazanoğlu and Holland 2002). When I use criteria to assess the quality while at the same time I am critical of using criteria, it is also because ‘criteria, quite simply, are useful. Rules and guidelines help us learn, practice, and perfect’ (Tracy 2010, p. 838). Many autoethnographers (more or less critical of doing so) have made attempts to develop frameworks that make it possible to simultaneously sustain a high academic standard and embrace the freedom of creative expression which is so characteristic of the autoethnographic account. In recent years, a host of work has focused on methodological and theoretical aspects such as issues relating to authenticity and trustworthiness, ethics and transparency in autoethnographic research (see e.g. the special issue of *Qualitative Inquiry* [2000, 6]; Hughes et al. [2012]; Gergen [2014]; Chang [2016]). Before I go on to present specific criteria and discuss the quality of my autoethnographic account, I will add a reflexive note written in the process of creating this chapter:



*I don't know how many times I have tried to write this section by now. Awww... I know I have to do it. Still, it just doesn't feel right. The words I need to do it won't come, instead these words of resistance are flooding in. They are NOT what I need right now. It's just that.. I really feel torn between the necessity to relate to a list in order to comply with formal requirements that I cannot escape and the feeling that doing so is to limit the creative space that autoethnography celebrates – and to join forces with some kind of authority which in turn represses its potential for creative freedom. I am filled with 'no's' and 'not's'. Also, there are so many lists, so many different opinions and views on criteria... I am drowning here! Which one am I to choose? How can I even begin to legitimise my choice of one in particular and not another? Should I put together a new list based on other lists? No. The 'not's' are yelling that it is not a good idea. Hmm... I think I will have to rely on my emotions in this case. Yes. I feel a 'do' coming on. I will use the list that I am most drawn to, the one that feels... if not right exactly, then at least less wrong. Maybe I'll even add something about my feeling of resistance in this chapter. Hey... that's a thought. Yes. That feels right. I feel the 'do'.*

I have added the reflexive note above to reveal the ambiguity with which I use criteria to evaluate the autoethnographic account in this study. Perhaps doing so is my way of rebelling against the requirement with which I will soon comply. Also, it is my way of honouring the act of writing autoethnography since doing so involves moving into the space of dialogue, to refuse closure and categorisation, to bend and challenge the rules of how one should be writing academic texts (Holman Jones 2005). In the process of choosing a list to use I have read several, such as guidelines offered by Richardson (2000b) and Holman Jones (2005). Because they resonate with me, I have decided to use the guidelines for desirable

autoethnography developed by Chang (2016) as the baseline to tell one story (of several possible) about the quality of the autoethnographic account in this study.

### **The quality of the study's autoethnographic account**

Chang proposes that one should use five standards to judge the 'goodness' of autoethnographic research. The first standard is '*Authentic and Trustworthy Data: Does the autoethnography use authentic and trustworthy data?*' Chang argues that by using not only memory, but also other techniques such as self-observation, self-reflection, self-analysis, interviews, document and artefact collection, the possibility of making rich, authentic and trustworthy data will be increased. Thus, she argues that the autoethnographer must use a variety of data and reveal his or her data sources in order to create good accounts. In debates about qualitative methods, the idea that using several sources of data will increase the quality of a study has been critiqued (i.e. Tracy 2010; Sparkes and Smith 2014). However, it might 'open up to a more complex, in-depth, but still thoroughly partial, understanding of the issue' (Tracy 2010, p. 844). In the autoethnography that is a part of this thesis, I have used self-observation, self-reflection and self-analysis as techniques in the thinking and writing process of creating the work. Also, I have explicitly stated that the data is drawn from my field diary. Thus, my assessment is that the account meets this criterion although its richness might have been further strengthened by using 'member reflection' (Tracy 2010, p. 848). This means that others presented in the work had been given opportunities to reflect upon the work in progress to provide space for 'additional data, reflection and complexity' (ibid.). Before I move on to the second standard, I will comment on issues relating to authenticity and trustworthiness in autoethnographic work.

How may autoethnography speak to the ideal of not fabricating data, and avoid accusations of doing so, when it actively engages with literary work, art, poetry, performance and aesthetics and (to a greater or lesser degree) refuses to play by the traditional rules of scientific work?

Of course, I do not have – and do not wish to impose – any defining answers as the issue is contested and might be seen from different point of views. Some theorists (e.g. Reed-Danahay 1997) argue that autoethnography is more authentic and truthful than other scientific genres given the insider position of the self, and some (e.g. Allen-Collinson 2012) reject the use of evaluation criteria such as validity because autoethnography operates within an alternative methodology. According to Sparkes (2000), issues of authenticity and believability are about connection and ‘if connections are to be made to the story of another, then there must be a sense of authenticity about both the teller and the tale’ (p. 33). He refers to Lincoln’s (1993) account of authenticity which entails that in addition to faithfully following the story line of the author, authenticity emerges when the ‘feeling tone’ of the lived life reaches the reader who is invited into the experience described in a way that may involve ‘a range of mood, feeling, experience, situational variety, and language’ (Sparkes 2000, p. 33-34). In my work, I have sought to create trustworthy, authentic accounts by offering a coherent story line and thick descriptions in a language that I hope will activate resonance and engagement in the readers. In the end, it is for the reader, and not me, to decide if I have succeeded. After all, issues of authenticity and trustworthiness in autoethnography come down to whether or not one is willing to accept autoethnography on its own terms, as different and unusual – and embrace this scientific genre with an open mind. This calls for responsibility on behalf of the reader or evaluator, who is encouraged to step into a space that offers other ways of knowing and understanding than traditional research does (Sparkes 2000) and who is free to embrace or reject this invitation.

The second standard is ‘*Accountable Research Process*: Does the autoethnography follow a reliable research process and show the process clearly?’ This relates to transparency and self-reflexivity in the process of research. The process must be explicitly described, explained and self-critiqued in order for the reader to know how the researcher arrived at her conclusions

since autoethnography allows for creativity which means that the reader cannot assume that standard research procedures were used. Thus, Chang argues that one must describe and reflect on the research process. The autoethnography I have written illustrates my process of maturation as a researcher through description of moments of personal and academic growth during the fieldwork. The article does not sufficiently offer descriptions, explanations and self-critique of the research process. However, in this thesis I have provided supplementary material to give insight into the research process. This includes assessments of how the work relates to (formal) requirements of making an autoethnography, how the work was planned and discussed with others, how the data were produced and the ethical decisions taken in the process of creation. My assessment is that altogether, the autoethnographic work meets this criterion, and the insight into the process which is offered in this thesis allows the readers to make up their own minds.

The third standard is '*Ethics Toward Others and Self*: Does the autoethnography follow ethical steps to protect the rights of self and others presented and implicated in the autoethnography?' This relates to the ethical standard that is used to protect both the others that are presented in the autoethnography and the researcher herself. Chang argues that considering the complexities of ethical issues in writing autoethnography, the autoethnographer must make the best attempt to protect the rights of others and herself in a variety of ways. Thus, she argues that the autoethnography must show good effort at adhering to ethical standards in protecting the people presented in the accounts. In the process of planning, writing and publishing the autoethnography, I have done my best to protect all people involved according to a feminist ethics of care and CRRRE. My assessment is that the account meets this criterion. I invite the readers to see the chapter 'Ethics' for detailed descriptions of the process in order to judge if the account meets this criterion.

The fourth standard is '*Sociocultural Analysis and Interpretation*: Does the autoethnography analyse and interpret the sociocultural meaning of the author's personal experiences?' The autoethnographers must move beyond their own personal experiences and express what they mean in relation to others' experiences, what sociocultural values shaped their experiences and what their societal reaction to their experiences was. Thus, Chang argues that the account must provide analysis and interpretation of sociocultural meanings of the personal experience of the autoethnographer. In the autoethnographic account, I have sought to discuss and analyse my personal experiences in light of 'ableism' and highlighted the role of sociocultural values related to the biomedical discourse. It is my assessment that the account meets this criterion. I invite the reader to see the chapter 'Autoethnography' in this thesis and article 2 in order to judge if the account meets this criterion.

The fifth standard is '*Scholarly Contribution*: Does the autoethnography attempt to make a scholarly contribution with its conclusion and engagement of the existing literature?' Chang argues that the account must be relevant and transferable to the wider community of researchers and audience of the research. It is not enough to create personally compelling stories that do not connect with other published work because the contribution will then be limited. The autoethnographer must make a serious effort to meaningfully engage with related literature so that the reader will gain a broader perspective on the topic and understand how the study connects to the scholarly context. In the autoethnographic account, I have sought to connect with the literature on 'ableism' and 'the social model of disability' in order for the reader to understand and relate to the topic personally and in terms of the academic contribution. I invite the reader to see the chapter 'Autoethnography' in this thesis and article 2 in order to judge if the account meets this criterion.

### **8.10.5 Conclusions**

In this chapter, I outline the ontological and epistemological differences often ascribed to quantitative and qualitative research. I emphasise the significance of evaluating qualitative research on its own terms. I outline the strengths of qualitative research in relation to this study, such as its capacity to produce context-bound, unpredictable insights and to challenge taken-for-granted assumptions. I give an overview of the ongoing debate about how one might judge the quality of qualitative research. In connection with criteria used to judge the quality of quantitative research – namely objectivity, reliability, generalisation, validity – I describe a variety of parallel criteria and strategies that have been offered by qualitative researchers in order to judge qualitative research. These are discussed in relation to this study. The chapter includes a discussion about the challenges concerning evaluating the quality of autoethnography due to its non-conventional nature. Finally, I use the guidelines for desirable autoethnography developed by Chang (2016) to assess the quality of the autoethnographic account in this study.

### **8.11 Summary**

In this chapter, I give a thorough overview of the methods and methodologies of significance to this study. I present the study participants and the recruitment process, the empirical material and process of analysing data. I discuss and give insight into the process of conducting fieldwork, including the understanding of repeat qualitative interviews and participant observation, which were the two main methods used for data production. The chapter includes a discussion of reflexivity in which I explicitly reflect on how my social background, the intersection of gender and age, and ethnicity may have influenced the research process in various ways in. Finally, I discuss criteria and ways to judge qualitative research in relation to this study, including an assessment of the study's autoethnographic account.

# 9 Ethical considerations

## 9.1 Procedural ethics

In the planning phase of the fieldwork, I applied for approval to conduct the study from the Regional Committees for Medical and Health Research Ethics (REK), which administers issues regarding ethics and privacy according to the Norwegian law on medical research; the Norwegian Social Science Data Services (NSD), which assists researchers with issues of ethics and privacy, data analysis, data gathering and so on; and the Privacy Ombudsman for Research, who manages ethical considerations and approval regarding research at Sunnaas Rehabilitation Hospital. REK replied that the study did not require their approval as they defined it as social science and not as a medical research project. The Privacy Ombudsman for Research approved the study by mail and NSD by letter (appendix 1), and posed requirements that I have followed regarding informed consent, confidentiality and storing of the data material.

Consent should always be voluntary, explicit and informed (National Committees for Research Ethics in Norway, 2017). To secure consent in the context of this study, according to the Privacy Ombudsman for Research and NSD, the participants had to be thoroughly informed about the study's purpose and methods, that the University of Oslo was responsible for the study, how to contact the researcher, and that they could withdraw their consent at any time without explanation. According to guidelines from the Privacy Ombudsman for Research, this information was to be sent in writing to potential candidates. Therefore, a document containing the required information was produced (appendix 2) and sent during the recruitment phase to potential study participants associated with the rehabilitation hospital. It was also explicitly stated in the document that the decision to participate or not in the study would not influence any further treatment at the hospital. The hospital did an internal ethical review as to who would receive the document in the first place and who would not. I was not

part of the evaluation but was informed in a meeting at the hospital that patients who were addicted to drugs/alcohol, depressed or potentially suicidal would not be informed about the study or in any way be accessible for recruitment. This was a strategy to secure the health, well-being and rights of (particularly vulnerable) patients, which, in accordance with the Declaration of Helsinki (2013 [1964]), must always come before the generation of knowledge in medical research. The participants were not compensated with gifts, payments or other material rewards for contributing to the study. The reason for this was to avoid any persuasion or pressure to participate (Davies 2008).

According to guidelines from NSD, the required information should be given (at least) verbally to all study participants.<sup>45</sup> To be sure that the study participants recruited through channels other than the hospital received all the necessary information, I first informed them verbally, then asked if they wanted the information in writing and sent it by e-mail to those who did. In addition, I repeated this information at the beginning of each interview throughout the study period to protect the rights and integrity of the study participants, as some might not have remembered that we had talked about it earlier due to the nature of brain injuries (Romsland 2011) that several had sustained.<sup>46</sup>

Confidentiality is a central concept in the social and medical sciences. It means that researchers must not produce data that might reveal the personal identity of the subjects in a research project and that they are entitled to have their personal information treated respectfully (National Committees for Research Ethics in Norway, 2017). The most common way to ensure confidentiality is to change revealing information such as the names of people

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<sup>45</sup> The guidelines from NSD concerned all the study participants, while the guidelines from the Privacy Ombudsman for Research (to send the information about the study in writing) concerned only the study participants recruited through the hospital.

<sup>46</sup> I comment on the role of memory in the study and how the issue of memory loss was handled in order to protect the participants' right to informed consent in the chapter 'Empirical material'.



and places. In some cases, publications that are not anonymised might influence the lives of the subjects substantially, and it is the obligation of the researcher to avoid potential damage (National Committees for Research Ethics in Norway, 2017). To ensure confidentiality, I have used pseudonyms for all the study participants. I have used the same pseudonyms for the same people within each article. However, to avoid giving away too much information about each individual, I have chosen to use different names when the same people are mentioned in other articles. In this text (the thesis), for the same reason, I use one pseudonym for each individual within one passage/excerpt/diary entry, but change it if the individual is mentioned elsewhere. Moreover, I have not described the accidents in detail, as this could have revealed the identity of the people involved.

In accordance with guidelines from NSD and the Privacy Ombudsman for Research, I stored anonymised data material on a password protected computer to which I alone had access to protect the confidentiality and privacy of the participants. The list of names and contact information of the study participants (the code) was kept in a locked drawer, separate from the empirical material. This code has since been destroyed. Currently, all the data material has been anonymised.

## **9.2 Process ethics**

### **9.2.1 Introduction; ethics framed by feminist ethics of care and CRRRE**

In the previous section, I described how the study was informed by a mandatory code of ethics, often known as procedural ethics. It has been emphasised, however, that research ethics should move beyond such foundational concerns and include process ethics due to the complex in-depth and long-term relationships that may develop in qualitative studies and the many ethical issues that may arise throughout the study period (Ramazanoğlu and Holland 2002; Davies 2008; Lahman et al. 2010; Sparkes and Smith 2014; Denzin & Lincoln 2018).

In this section, I will position the study's approach to ethics theoretically and illustrate how this was integrated into the study's process ethics in practice. My background in critical, feminist-oriented studies led to the choice of framing the study's ethics with the feminist ethics of care and culturally responsive relational reflexive ethics (CRRRE). I will start by introducing these two approaches.

Research ethics have been extensively debated in the social sciences, and different approaches and models on how to achieve 'goodness' in research, and what 'goodness' is, have been promoted and discussed. For example, driven by principles such as honesty, justice and respect in the 'duty ethics of principles', actions are judged on intent rather than consequence, while in the 'utilitarian ethics of consequences' model, what is 'right' and 'wrong' is judged by their consequences rather than intent (e.g. Edwards and Mauthner 2012; Sparkes and Smith 2014; ). Instead of emphasising outcome, justice and rights, feminists have questioned and critiqued universalist ethical models and promoted ethical frameworks in which care and responsibility are of the essence. Such critique, and debates on what care-based ethics entails and how to do it, is a continuing conversation in the field (e.g. Denzin 1997; Young 1997; Ramazanoğlu and Holland 2002; Edwards and Mauthner 2012). In spite of differences in feminist approaches, common features in feminist ethical thinking are the emphasis on personal experience, context, power relations and nurturant relationships (Edwards and Mauthner 2012). In this study, a feminist ethics of care in which attention is directed at contexts and specificity entails that ethics is connected to concrete practices and dilemmas, and it is this attention that provides the guideline for ethical actions and decisions (ibid., p. 25). Ethical dilemmas are 'rooted in specific relationships that involve emotions, and which require nurturance and care for their ethical conduct' (ibid., p. 19). In line with feminist political theorists, I do not seek moral principles that stand above power and context, but acknowledge that ethics 'is about *how* to deal with conflict, disagreement and

ambivalence, rather than attempting to eliminate it' (ibid., p. 25). I seek to do so by emphasising *responsiveness*, *relationality* and *reflexivity* guided by CRRRE in my overall take on ethical issues in the study.

In CRRRE, the researcher acknowledges that it is impossible to fully understand all aspects of the culture under study, that she is open to examining the perspective of the individuals involved in the study to the extent she can, and that she acknowledges the need for reflexivity (Lahman et al. 2010). In tune with feminist ethics of care, CRRRE does not claim to have a resolution. Instead, it provides a framework that honours the process of working through challenging ethical situations and encourages reflection on mistakes and dilemmas in order to promote personal growth and a higher ethical stance in research (Lahman et al. 2010). The researcher strives to engage in a *responsive* process in which she accommodates participants with care and sensitivity, she respects the participants and provides ongoing information in the research process, and seeks awareness of the culture that she is embedded in as well as tries to understand others' cultures (ibid.). *Relational* research entails an emphasis on mutual respect and relational concerns in the study process. It relates to care and feminism in the sense that the researcher takes a theoretical stance in which she strives to achieve and maintain reciprocal relationships, trust and recognition through caregiving (Lahman et al. 2010). Research is therefore balanced with the care for and connection with those who are involved in the study (Etherington 2007), and the researcher seeks 'goodness' guided by principles that will differ depending on the situation (Lahman et al. 2010). *Reflexivity* is used to promote self-awareness, and may help the researcher to notice reactions in research situations and adapt 'in a responsive, ethical, moral way, where the participants' dignity, safety, privacy, and autonomy are respected' (p. 1403). Also, it may help the researcher to recognise biases and possible power balances in specific situations. Also, it is a tool for transparency so the work 'can be understood, not only in terms of *what* we have discovered,

but *how* we have discovered it' (Etherington 2007, p. 601 in Lahman et al. 2010, p. 1403).

The ethical framework in this study puts emphasis on the researcher's personal responsibility and willingness to engage in a continuous process of maturation in which she seeks to refine her ethical decision-making to the extent possible for her. I will now elaborate on the nature of this process in relation to this study.

### **9.2.2 A caring approach to protection of the study participants**

Guided by CRRRE and feminist ethics of care, I carefully considered and took measures to assure the safety and well-being of the study participants. Given that the people involved in this study are vulnerable in the sense that they belong to a marginalised group in the context of this study (disabled people) and that the conversations would touch upon topics that might stir painful emotions and psychological reactions in them, I had made an informal arrangement with Grace Inga Romsland as part of my preparation before conducting the fieldwork. With a background as a home-care nurse, municipal health manager and leader in a rehabilitation hospital, she has extensive experience working with disabled people, and we agreed that she would assist by providing support to the study participants if it would become necessary during the fieldwork. In addition, I had been invited by medical staff at the rehabilitation hospital to contact them if I had questions or was in need of advice. Thus, if the study participants had been in need of medical assistance, I would have called for help, and actions would have been taken to assure their well-being. No situation occurred during the fieldwork in which I considered it necessary to take such steps. This does not mean that study participants did not display strong emotions during our interactions. For example, talking about the percentage scores that study participants had received from others in power over them during their rehabilitation process sometimes caused upset, anger and distress (as described in article 1). During such and similar situations, I paid close attention to their words and body language. In tune with CRRRE and feminist ethics of care, I asked them if they wanted to continue the conversation when they showed signs of distress, and reminded them

that we could take a break at any time or change the topic whenever they felt like it. This was part of a responsive, relational approach to specific situations in which I attempted to prevent them from feeling pressured to talk about sensitive issues if they did not explicitly want to. Also, with this approach I sought to be aware of the researcher's powerful position (which I outline in more details later) and stay true to the study's ethical approach which includes the promotion of equality and mutual respect in interactions between the participants and the researcher.

It is not enough to seek informed consent only at the start of an ethnographic study. Rather, this should be an ongoing process in which ethics are continuously addressed because one cannot predict how the study will unfold and what ethical issues the research will raise (Davies 2008; Lahman et al. 2010; Sparkes and Smith 2014). Drawing on CRRRE and a feminist ethics of care, I used *process consent* (Sparkes and Smith 2014, p. 214) whereby informed consent has been negotiated on a regular basis. Before the interviews, I asked the study participants if they still wanted to be a part of the project, and I reminded them of their right to withdraw from the project at any time. I also found it necessary to discuss with the study participants if I might or might not use what I considered to be particularly sensitive material as data in the articles. Thus, the study participants were sometimes explicitly part of the decisions that were made. One example that illustrates how such negotiations took place occurred in the planning phase of an article about disability and sexuality in a gender perspective. In interviews, Jan had talked a lot about his sexual life and sexual encounters in his rehabilitation process. This material was analytically interesting, and I thought of using it as data. Although the empirical material had been produced during the fieldwork in a setting where Jan had given his informed consent, I felt that due to the sensitivity of the topic, it was necessary to ask him specifically if he would be comfortable if these particular aspects from his life story were used for such a purpose. This was particularly important from an ethical

perspective of care because researchers are responsible for providing information that will enable people to assess the likely effect the research may have on them in a manner that is comprehensible to the persons involved and to ensure that they will not be harmed by the use of data (Davies 2008; Ramazanoğlu and Holland 2002). Together, we discussed what use of the data might entail, how the article would address the issue, the purpose of using the data, if the data might compromise his anonymity and so on. Jan was initially positive and felt comfortable with the data being used in the article. In order not to haste the decision so that he might regret it later, we agreed that he should take some time to think about it. Later, Jan decided that he was not comfortable with this material being used as data after all. In line with the ethical framework of this study, in which responsive actions are essential and the respect and integrity of the study participants are prioritised over the research, the material was never used, of course. I find that this example illustrates the importance of having an ongoing negotiation of informed consent and basing ethical decisions not simply on what one has the formal right to do as a researcher, but always taking the context and integrity of the individuals involved into the account. Had I used the material without asking Jan, this would have been a misuse of his trust and not in accordance with CRRRE and a feminist ethics of care.

### **9.2.3 Ethics and care in observational studies**

Observational studies call for extended attention on behalf of the researcher to secure ‘informed consent’, to handle data with care to ensure the confidentiality and integrity of the study participants, and to be mindful of the nature of social relationships that evolve over time in the field. The study participants were informed in the recruitment phase that the study entailed not only interviews, but also participant observation. It might be difficult to understand what participant observation means for someone who is unfamiliar with the term. It is the responsibility of the researcher to communicate the essence in a comprehensible way

to protect the participants' right to 'informed consent' (Davies 2008; Ramazanoğlu and Holland 2002), and the researcher needs to be extra attentive when vulnerable groups are involved, such as in this study. Therefore, in an introduction before the interviews, I gave a verbal explanation until I felt that it was understood what participant observation entailed. For example, I explained that I would study social interaction and behaviour in order to get a better, more nuanced understanding of their everyday lives, how they interacted with others and maneuvered their bodies, drove their cars and so on. Finally, I asked if they were comfortable with being observed and if they still wanted to participate in the study. Although some found participant observation to be a 'funny' thing to do, all seemed comfortable with being observed.

In observational studies, the people under study may forget or become unaware of the fact that they are being researched and disclose information that they otherwise would not have shared (Ramazanoğlu and Holland 2002; Fangen 2010). From a feminist ethics of care and CRRRE, this puts emphasis on the researcher's responsibility to ensure that the material produced is handled with care and in a way that respects and nurtures the trusting relationship between the study participants and the researcher. When I have used observational data, I have carefully reflected on what I used and how I used it. I have sought to honour the integrity of those I have observed in my interpretation and presentation of them and to protect their anonymity (by using techniques described elsewhere in this thesis).

When researchers take part in the lives and activities of study participants, social relationships can sometimes grow into mutual friendships. Misunderstandings about what the relationship entails can also occur due to cultural and personal differences. This calls for continuous reflection by the researcher on the relationships that develop in the field (Davies 2008). During the course of this study, I did not enter into ethical dilemmas related to

different perceptions between the study participants and myself on the matter of our relationships. However, I discovered through reflection on how the relationships evolved that I had a tendency to pay most attention to data produced in interactions with people that I felt connected to and identified with than data produced by people that I felt less connected to. This awareness made me more conscious of my ethical responsibility as a researcher to take action not to exclude or ignore data due to my personal attunement with particular subjects.

#### **9.2.4 Self-care as part of ethical conduct**

A part of qualitative research that is acknowledged less than the safety of the study participants is protection of the researcher – physically, but also in terms of emotional self-care when she interacts in the field and explores the lives of others (Morse 2007; Sugden 2012; Sparkes and Smith 2014). As described earlier in this chapter, I had prepared measures to protect the study participants if anything bad happened to them during our interactions, but had not reflected on my own security until I was in a situation where I realised that I had forgotten to take into account this part of an ethics of care. This happened on an occasion when I was interviewing one of the study participants, Jonas, alone in his home. Jonas was well into a story about how he had once smashed an object into the head of another person until this person fell to the ground, bleeding and unconscious. Moreover, Jonas explained that he had a violent temper and that he might ‘explode’ out of the blue. In the aftermath of this episode, I took a reflexive stance and wrote about my own reactions and emotions in that particular situation:

*The thought that kept running through my head in that moment was that if I said or did something that upset him now, he might ‘explode’. I looked at him and felt scared and shaky. Suddenly, I was acutely aware of our embodied presense in the room. Not only was I much smaller than him; he was fit from years of exercise. His upper arms*



*were huge. I rememberd how he had swung himself into the wheelchair as if it was the easiest task in the world to him. A feeling of helplessness and powerlessness overwhelmed me. The door seemed miles away and his body suddenly felt too close to mine. If he attacked me, I would't have a chance to escape. I felt sick to my stomach.*

In the situation described above, I continued the interview with Jonas as planned although the shaky feeling of fear did not leave me until I arrived at home. In retrospect, it might have been a better solution to end the interview both to protect myself and because my attention was disrupted and I was no longer in line with CRRRE, an attentive, responsive researcher engaging in an open conversation with the study participant. In the aftermath, however, reflexive writing increased my awareness of the importance of including the researcher in an ethics of care. Also, it contributed to my continuous effort to mature ethically as a researcher because it gave way to further explorations on how to deal with ethical dilemmas in the field. I agree with Wolcott (2010), who states that is not possible to predict all the possible ethical dilemmas that researchers in qualitative studies may encounter, but that one should talk about ethical issues and try to avoid unnecessary risks. In an attempt to achieve this, I engaged in conversations with my colleagues about our sometimes emotionally demanding experiences in the field (such as the above outlined feeling of danger in an interview setting). I also approached colleagues, and the research team, to debrief when I had emotional reactions in relation to the study. On a practical level, I became more attentive to the choice of location when I was about to meet study participants for the first time. When I met Jonas, I made sure that at least one person was informed about my approximate whereabouts, and I was mentally prepared to leave the situation if I felt unsafe. In retrospect, it might have been a possible solution inspired by CRRRE's emphasis on open-mindedness and seeking to understand the perspective of the other to the extent possible to engage in a conversation with Jonas about my experience of danger in relation to him and explore in greater detail this particular aspect

and how it influenced the interactions between us, for example, concerning our trust or relatedness towards each other. However, I was not comfortable with such an approach at the time. This being said, I feel that the portrayal of Jonas should be supplied with additional information in order to avoid a one-dimensional presentation of him, to honour his contribution to the study, and in respect of other and more positive aspects of our relationship. Guided by a feminist ethics of care, I will therefore add a note from my diary written in the process of producing this chapter:

*I am worried that by revealing my feeling of fear in the conversation with Jonas, one will get the impression that he is violent and dangerous. This is not fair given the fact that this is only one of many possible stories that could have been told about our interactions, and it takes only my perspective in that particular context into account. Jonas is of course a complex human being with many sides. When he talked about his family and friends, he expressed love and passion. He was polite and considerate towards me. He never actually attempted to attack me, and I did not give him the chance to respond to my feeling of fear because I hid it from him. There might be many reasons why he told me about his violent actions. I hope the reader will understand that this was only one aspect of our interactions. He was funny and made me laugh several times, so our interactions included feelings of well-being, and some of his stories gave rise to interesting discussions and insights on 'ableism' and driving.*

### **9.2.5 The powerful position of the researcher**

In particular, issues of power in research relationships and how these may impact the research process need to be addressed in feminist research ethics (Ramazanoğlu and Holland 2002).

Elsewhere in this thesis, I have discussed how social positions may have influenced

interactions between the researcher and the study participants during the process of study. The example above from my interaction with Jonas in which I felt helpless and powerless illustrates the context-bound nature of power which may float between the study participants and the researcher in unpredictable and multidimensional ways. In the following, I will address the possible impact of the privileged position of the feminist researcher and strategies guided by CRRRE and a feminist ethics of care in order to avoid exploitation in the process of knowledge production. In line with the ethical guidelines used in this study, I start by recognising that the position of the researcher is powerful in the context of conducting a study. In interactions with study participants, the researcher may choose to ignore some aspects and emphasise others. She chooses theories and data for interpretation, and the interpretations are merged with her ideas and values. She is the author of the written product, and may be unconscious and fail to recognise her privileges in interactions with study participants (Smith 1998; Ramazanoğlu and Holland 2002). It is an ethical responsibility on the part of the feminist researcher to make explicit and be accountable for the understandings that are produced. In order to achieve this, I have attempted to make explicit my situatedness and the frameworks in which the knowledge is produced accessible and transparent to the reader. I have sought to establish relationships with the study participants that are caring and based on mutual respect to the extent I could and not position them as ‘objects’ of study, but subjects of knowledge that have been given an opportunity to join in on a collaborative approach (described earlier in the method section). I have sought to critically examine my role as a researcher and my position in the field (e.g. by tracing my ‘ableism’ and its impact in the field in article 2), develop a higher ethical stance and self-awareness faced with ethical dilemmas through reflexive notes (as illustrated in this section) and emphasise inconsistency and variation in the data so that my understandings do not come out as ‘one single truth’ about the lives of the study participants.

### **9.2.6 Ethical issues regarding autoethnography**

Ethical issues in traditional qualitative research concerning ‘informed consent’, confidentiality, and righteous and respectful conduct in relation to data and study participants are equally essential in autoethnography, but need to be addressed in accordance with the particularity of the autoethnographic approach. Also, undertaking autoethnography calls for attention towards its key ethical issues concerning the protection of others and self-care due to the nature of this approach which entails vulnerability and exposure of others and self. In this section, I will address how ethical issues regarding autoethnography have been recognised and resolved in the study.

When the autoethnographer writes about herself, she also writes about others (Ellis 2009) and must be aware of her ethical responsibility to protect both others and herself. Although it is not possible to predict or know all the possible outcomes of an autoethnography, the researcher should take into account possible positive and negative costs of participating and seek to do no harm (Tullis 2016). Guided by CRRRE, I have used reflexivity throughout the process of writing autoethnography in order to increase my awareness and develop my ethical decisions to the highest possible stance (for me). This entailed developing the autoethnography in this study over a long period of time to ensure that when the result was published, it had been through a process of refinement and considerable thought as to, for example, how the subjects involved (including the researcher) were presented and how the work most probably would be received by the audience.

To protect others, I carefully considered if the individuals that appeared in the autoethnography were presented in a respectful, context-conscious way that embraced their integrity and autonomy and that ensured the autoethnography would not be harmful to them. This process was complex and involved a variety of concerns that were taken into account. It

is disclosed in the autoethnography, for example, that one participant had been unfaithful to his wife. Although this study participant was protected by anonymity, and the benefit of using this data was substantial in relation to the topic under study because it confronted ‘ableistic’ and ‘heteronormative’ notions of sexuality, I would not have found these two aspects alone sufficient to legitimise the use of the data because of the (unlikely but possible) consequence that it might have interfered with his relationship with his wife. However, knowing that he had previously disclosed his unfaithfulness to his wife, that the relationship had ended and that they had both moved on with their lives, I considered it ethically appropriate to use this data. Similar processes of ethical considerations of care and nurturing relationships resulted in some data never being used or omitted from the article.

The researcher may seek to do less harm by distributing the risks among the people involved (Tullis 2016). I decided to use a number of accounts from interactions with several individuals in the autoethnography in an attempt to minimise the exposure of the people that appeared in the text. I was also careful to protect their identities and confidentiality by changing their names and by using relatively general terms when I described their appearance so that their anonymity would not be compromised.

In this study, I used ‘process consent’ and a collaborative approach in which the study participants were invited to discuss and alter texts (as previously described). Tullis (2016) proposes that as part of the ethical approach to autoethnography as well, one should engage in processes in which those who appear in autoethnographies are given the opportunity to comment upon the work and their participation along the way. In retrospect, I find it unfortunate that the people that appear in the autoethnography were in fact not part of the writing and reading process of this account. It would have been a better solution in tune with the theoretical framework of this study’s ethical approach if the people I present had been

actively involved in this part of the data production. By using ‘process consent’ they would have been given the opportunity not to appear in the text. Also, it would have been analytically and ethically rewarding to develop my interpretations in collaboration with them as it remains problematic that the ‘I’ speaks for ‘Others’ (Richardson 2000a). However, this is an insight that has evolved over time as part of my ethical maturation as a feminist researcher, which I did not have access to at the time. This being said, as part of the ethical approach I have explicitly stated in the article that I used texts I had written myself as data (to make it evident that the text is written from my particular, situated perspective), and I sought to make visible in the article the contexts in which my understandings were produced. Also, I attempted to use data in which it was myself and not the others who carried the main burden of exposure.

The autoethnographer is herself a participant in the study and deliberately puts herself in a vulnerable position that may carry risks personally and relationally<sup>47</sup> (Holman Jones, Adams and Ellis 2016). The autoethnographer must be aware that when the account is published, there is no going back; the work is subjected to the scrutiny of others, and it may be gratifying as well as hurtful to share a personal story (Tullis 2016). I carefully considered the effect it would have on me to include autoethnography in this thesis. I found, and still find, that the personal and relational risk is relatively low, and was clearly outweighed by the benefits of using autoethnography. Related to the personal risk, I have considered the extent to which I disclose my vulnerability; I have purposefully chosen which selves and experiences I have shared (Holman Jones, Adams and Ellis 2016) and feel that my self and integrity have been sufficiently protected in all phases of the work, including in the published result. The work matured in a reflexive process that prepared me for the (possible) burden of facing reactions from the audience. This process entails that I used several opportunities to

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<sup>47</sup> In addition to professional risks, which I discuss in the chapter ‘Autoethnography’.

discuss the work in progress with colleagues, and I presented parts of the autoethnography at an academic conference and discussed the use of autoethnography with the audience. The positive response encouraged me to continue the work. To me, the relational risk in the context of publishing this autoethnography is related to whether or not it might hurt my relationship with the individuals I write about. I have not presented any data that I would hesitate to show to the people that are mentioned in the texts (Tullis 2016), and it is my belief that the autoethnography pays respect to the nature of our relationships and that these will not be harmed if they read the account. The final decision to use autoethnography in this study was part of a responsive process in tune with CRRRE and what I consider to be my responsibility as a feminist researcher: It is an attempt to understand the culture in which I am embedded and to personally engage in the culture I encountered and seek to understand the experiences of those under study (Lahman et al. 2010).

### **9.3 Summary**

In this chapter, I have outlined the procedural ethics and process ethics concerning this study. I have situated the study theoretically within the framework of a feminist ethics of care and culturally responsive relational reflexive ethics (CRRRE) and illustrated through reflexive practice how these approaches have guided ethical decisions made in the process of research. This includes descriptions of measures taken to ensure the well-being of the study participants and the researcher, and ways in which the study has related to key ethical issues such as informed consent, confidentiality, ethical dilemmas and the powerful position of the researcher. Finally, I outline how the study's autoethnographic work relates to and solves key ethical issues in undertaking autoethnography, in particular concerning the ethical responsibility to protect others and selves. In conclusion, the chapter illustrates that the ethics in this study are deeply rooted in feminist values and that measures have been taken to resist

oppression and authority and to instead promote care, responsiveness, relationality, respect and equality in an ongoing process throughout the study process.



# 10 Synopsis of the articles

## 10.1 Article 1:

### **The language of percentages: Ranking bodies, shaping realities, and limiting opportunities**

This article explores the role of percentages in rehabilitation discourse – in particular, how the use of percentages is perceived by young adults in rehabilitation after severe motor vehicle accidents. We found that rehabilitees had become part of a discourse in which the use of percentages was taken for granted as a legitimate and useful way of talking about, and making sense of, disabilities. That discourse constructed one position as ideal – one hundred per cent – representing that which is complete and normal. We term this discourse ‘the language of percentages’.

The study participants responded with distress when test results and prognoses were conveyed to them in ‘the language of percentages’ and suggested that this was because they were constituted as incomplete subjects. In response, they strove to be associated with the one hundred per cent mark, not least through efforts to land full-time jobs.

We argue that ‘the language of percentages’ ranks bodies and reproduces ideas of difference as less valuable. In effect, rehabilitees are positioned, and position themselves, as ‘incomplete’ and are to some extent dehumanised in this discursive terrain.

## 10.2 Article 2:

### **Non-disabled ableism: An autoethnography of cultural encounters between a non-disabled researcher and disabled people in the field**

This article describes situations where preconceptions about disabled people were made apparent in my thoughts, words and actions in the course of fieldwork. The article uses these experiences as a starting point for discovery and analysis of cultural ‘ableism’ from my position as a non-disabled researcher. Theoretically, the article draws on critical theory and insights from the social model of disability. It takes an autoethnographic approach to highlight my preconceptions and process towards a more nuanced understanding of disability.

The discussion deals with how the cultural taken-for-grantedness of non-disabled privilege and superiority regularly came to the fore in my encounters with study participants. I was leaning heavily on the culturally shared ‘knowledge’ that disabled bodies cannot function as well as non-disabled bodies. For example, it did not immediately occur to me that a body in a wheelchair can function more effectively than a body not in one. Clearly, my way of seeing disability was largely the result of a gaze through the pathology-focused lens so characteristic of the biomedical project. Far from being limited to the clinic, this lens has helped to shape the overall take on disabled bodies (and non-disabled bodies) throughout the society in which I grew up. The understanding of ‘them’ as incomplete sets them apart as different, subordinate and underprivileged (Goffman 1990 [1963]) and allows for the consequences that follow in terms of ‘ableism’.

In the field, I found again and again that my focus and my preconceptions were out of touch with the perspectives and experiences of the study participants. These situations were filled

with bewildered astonishment and the unique kind of cultural insight that can occur when what is commonly taken for granted by ‘us’ is exposed as no more than *versions* of the ‘truth’ when alternatives emerge in encounters with ‘them’ (Hastrup 1992). It is remarkable that I did not have better access to the notions that have challenged, nuanced and critiqued the reliance on the biomedical lens in our ways of viewing disability. Various alternative articulations and framings have been promoted by disability scholars for decades (see e.g., Oliver 1983; Moser 2005; Gibson 2014; Grue 2014). Nevertheless, alternatives are not culturally accessible to the point where they provide non-disabled people with the resources needed to encounter unusual bodies without drawing on ‘ableistic’ conceptualisations. Hence, we argue for the necessity of continuing to address cultural prejudices towards different bodies and continue to explore and promote alternative ways of knowing to extend our imaginations.

### **10.3 Article 3:**

#### **Recognising young men’s care and ‘traffic safety agency’: masculinity, driving and safety among ‘young problem drivers’ in the aftermath of severe road traffic accidents**

This article contributes to the academic dialogue about young men’s driving practices by exploring from a masculinity perspective how young, male drivers at the time of the fieldwork understood themselves and their driving practices before and after accidents. We describe and analyse the men’s own takes on driving, safety, change and disability.

The findings suggest that the participants construct masculinity ideals in which physical strength and functionality is of the essence, they describe the accident as a turning point towards an increased care for others, and they distance themselves from the social category of

disability. We link the latter finding to hegemonic cultural notions in which disabled bodies are subjected to severe stigmatisation and subordination and are associated with ‘weakness’ and incapacabilities (Garland-Thomson 2005; Svendby et al. 2017; 2018).

We argue that the dominant discourse in the field of traffic injury prevention research, in which (some) young male drivers are constructed as ‘irrational’ and rather unequivocally as ‘problems’ and labeled with diagnostic terms (see e.g. Jonah 1997; Iversen and Rundmo 2002; Oltedal and Rundmo 2006; Ulleberg 2001; Scott-Parker et al. 2012), makes it difficult to recognise that young men are (also) rational, caring subjects. Such a recognition, we propose, is a premise for constructive communication and successful safety interventions.

We suggest that bringing nuances into the normative<sup>48</sup> discourse about road traffic safety makes it possible to recognise ongoing processes and negotiations of safety work and cultivations of care. Thus, we suggest that the experts who are in search of successful safety interventions seek to familiarise themselves with the internal logic that guides the driving practices of the young men in question.

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<sup>48</sup> Although normativity is often presented as problematic in this thesis, I do not mean to say that normativity is always problematic. Whether it is problematic or not will depend on what it promotes and the perspective from which it is assessed. For example, normative values of equality would be considered very positive indeed from a feminist viewpoint.

# 11 Discussion: Becoming the ‘Other’

## 11.1 Mechanisms and consequences of ‘Othering’

In this final discussion, I outline the thesis’ coherence, overall findings and contribution to knowledge by using the concept of ‘Othering’ as a theoretical tool. However, ‘Othering’ is, in fact, also a finding in this study since the common feature of the three articles is that they highlight and problematise ways in which the study participants are discursively produced as ‘different’ in relation to normative standards – they become the ‘Other’. The dissertations’ three articles each explore and problematise one hegemonic discourse in which the study participants are ‘Othered’. These discourses are produced in relations between medical professionals and rehabilitees (article 1), non-disabled people<sup>49</sup> and disabled people<sup>50</sup> (article 2) and traffic injury prevention experts and young, male drivers (article 3). ‘Othering’ captures dynamics of power in discourses that (as in the three mentioned above) differentiate between the ‘Self’ (the same) and its ‘Other’ (the different), and thereby

actively constitutes a social relationship privileging the ‘same’ who has the power to name, subordinate, exclude or silence the ‘other’. This is the power, for example, to define settled people as normal, as (universally) how people should be, and to constitute nomadic people as ‘other’, as abnormal, as not belonging, as subordinate and as lacking rights (Ramazanoğlu and Holland 2002).

From this definition, it is clear that a core element in processes of ‘Othering’ is the float of power which takes the shape of a hierarchy in relations between in-groups (‘us’) and out-

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<sup>49</sup> Represented here by the researcher.

<sup>50</sup> Represented here by the study participants.

groups ('them'). In processes of 'Othering', the latter group is stigmatised (Goffman 1990 [1963]). However, the example above of the nomadic people vs the settled people, the examples used by Beauvoir (2000 [1949]) of different types of 'Self-Other' relationships,<sup>51</sup> and, indeed, the three examples in this study all implicitly reveal the complexity and potential fluidity of the power dynamics constituted in them. These are mainly social identities, and thus they are not fixed, but negotiable, which highlights a potential for change (Okolie 2003) to which I will return at the end of this discussion. Moreover, this aspect of negotiability reveals that people are not only 'Self' or only 'Other'. This is always context bound, so people who are positioned as the 'Other' in one relationship might be constituted as the 'Self' in another (Ramazanoğlu and Holland 2002) and thus move back and forth between positions of privilege and disadvantage accordingly. With regard to these points, I stress the following: first, that I acknowledge the complexity of the terrain I encounter in this discussion; second, that I analyse only a part of the discursive terrain that surrounds the study participants; and third, that, in accordance with a Foucauldian understanding, I acknowledge that discourses offer multiple and sometimes conflicting representations of the world (Alvesson and Kärreman 2000), *but* also that some discourses have greater acceptance and dominance (Dick 2013). Hence, they have a hegemonic status and might have effects that need to be problematised. In this study, I highlight hegemonic discourses that work to produce and reproduce 'ableism' (Campbell 2009). I argue that the participants are 'Othered', both as disabled people (article 1 and 2) and as young, male drivers (article 3), and seek to identify the mechanisms and consequences of, as well as alternatives to, these processes.

For increased readability, I start by discussing each article in a separate section with the same formula: I present and unpack the discourses the articles address and the mechanism of

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<sup>51</sup> Namely men vs women, travelers vs new travelers, village people vs people not belonging to the village, Jews vs anti-Semites, blacks vs racist Americans, indigenous people vs colonists, proletarians vs the propertied classes (Beauvoir (2000 [1949]), p. 6-7).

‘Othering’ that occurs in them. I also introduce three concepts, one from each of the articles which have been developed in the research process and which capture core elements of the study’s findings. These concepts are ‘the language of percentages’ (article 1), ‘non-disabled ignorance’ (article 2) and ‘traffic safety agency’ (article 3). I end by highlighting unintentional consequences of ‘Othering’ in each of the discourses. In the second section, where I discuss all three articles together, I address resistance strategies and the potential for change.

### **11.1.1 Article 1**

In article 1, we found that the use of percentages was seen as a ‘natural’ way of conceptualising bodies and their functionalities in the discourse that encapsulated the study participants (and medical professionals) at the rehabilitation hospital. One hundred per cent represented both completeness and the ideal in this discourse. Percentages less than this represented that which was infirm and less than ideal. This frame of reference was used repeatedly by the study participants when they talked about their bodies, health and work achievements. It was seen as such an obvious conceptualisation that they engaged in this discourse with no explanation of its framing. Thus, it might be identified as a hegemonic discourse that, due to its obviousness, was protected from critical enquiry (Springer and Clinton 2015). We have termed this discourse ‘the language of percentages’. This term covers the overall conceptualisation in which one hundred per cent is seen as the taken-for-granted norm, and other percentages are seen as deviant.

When the study participants were tested and compared to samples that represented the norm (i.e. the ‘Self’), they were constructed and manifested in ‘the language of percentages’ as ‘Other’. They did not belong to the ‘normals’ (Goffman (1990 [1963], p. 15), i.e. abstractions of the universal idea of how people ‘should’ be. Instead, they were conceptualised and

constructed as abnormal and not belonging (Ramazanoğlu and Holland 2002) and surrounded by valourisation of normality in a rehabilitation culture that pursued ‘normal’ bodies (Gibson 2006), which they did not have. It was clear that they were constructed as subordinate because the attention was directed towards how they might become (as close as possible) to one hundred per cent. Thus, they were to strive to become similar, ‘as if’ they were no longer different (Stiker 1997), by imitating the bodies and accomplishments that were associated with the ‘Self’. With a parallel to the process of ‘sophisticated othering’ (Brons 2015), one might argue that ‘Othering’ occurs because (a) non-disabled bodies are complete (one hundred per cent); (b) the ‘Other’ is disabled; therefore (c) the ‘Other’ is incomplete (less than one hundred per cent). To become one hundred per cent (i.e. the ‘Self’) was the ultimate goal in the rehabilitation culture, in addition to being a personal goal of many of the study participants who thus positioned themselves as ‘Other’ in this discourse. The latter might be interpreted as a response to the study participants’ being encapsulated in, and relating to, the same discourses that render them as such (Sparkes, Brighton, and Inckle 2014).

‘The language of percentages’ is a tool of great practical value. It is, for example, an efficient instrument used by medical professionals to evaluate the nature of injuries and appropriate treatments in rehabilitation processes, and it offers a standardised frame of reference, which makes it easier for individuals to apply for financial compensation after an accident.

However, ‘the language of percentages’ is also a conceptualisation that is culturally meaningful and does something (Alvesson and Karreman 2000; Jørgensen and Phillips 2010; Springer and Clinton 2015) outside the walls of the clinic. Measures and evaluations in rehabilitation structure how we think about bodies, for example, how impaired bodies are conceived and acted upon, not only by medical professionals, but also by rehabilitees (Gibson 2006). In effect, one consequence of ‘the language of percentages’ is that it constructs social realities in which some individuals *become* disabled. Moreover, they cannot escape the



position of the ‘Other’ because they are constructed as less than one hundred per cent. Thus, having an impairment affects how the whole body is understood. Ultimately, such discourses structure how we think about what it means to be human (Rapley 2003; Gibson 2006). Indeed, some of the study participants experienced ‘being’ less than one hundred per cent as existentially threatening. With access to understandings in which difference is seen as something other than a deficiency that needs to be fixed, such effects might be reduced (Gibson 2006).

### **11.1.2 Article 2**

In article 2, we trace (part of) what is ‘known’ and ‘not known’ about disability among non-disabled people. We take the standpoint that what we know and what we do not know are intertwined parts of our knowledge production. We (humans) produce both knowledge and ignorance when we construct ideas about our surroundings (Tuana 2004; 2006), including the idea of disability and what it does and does not entail. According to Tuana (2004), ignorance is usually perceived of as a lack of or a gap in knowledge (and in some cases this may be so). However, in many cases, ignorance is actively produced; it may result from a loss of previously held knowledge or from the dismissal of knowledge that is no longer seen as important and functional. Here, I use the term ‘non-disabled ignorance’ and highlight that like knowledge, ignorance (about disability) is also constructed. This perspective highlights the dynamic characteristic of discourses and thus the potential for change.

In my encounters with disabled people, I drew on the hegemonic biomedical discourse on which ‘the language of percentages’ relies. Thus, my point of departure when I started the fieldwork might be seen as an illustration of an outcome when ‘the language of percentages’ has hegemonic status and the ‘realities’ it constructs are taken for granted as cultural truths. I was heavily influenced by the ‘non-disabled ignorance’ produced within this framework.

Disabled bodies were ‘known’ to me as incomplete, underprivileged people, and ‘unknown’ as complete and privileged people. In the conceptual frame that I was relying on, when bodies did not ‘perform’ (Goffman 1990 [1959]) normally to the extent that they ‘passed’ (Goffman, 1990 [1963]) as one hundred per cent, they were placed in the category of the ‘Other’.

The production of ignorance might be deeply linked with power<sup>52</sup> (Tuana 2006). In practice, ‘ableism’ was the consequence when ‘the language of percentages’ was the main, or only, frame of reference. Disabled people are disfavoured when taken-for-granted knowledge and ignorance about bodies, health and disability maintain a power balance in which disabled people are constantly exposed to ‘Othering’ while non-disabled people retain a privileged position as the ‘Self’. The ‘Othering’ occurred through a process of ‘sophisticated othering’<sup>53</sup> (Brons 2015) in which I (the ‘Self’) projected my world view onto the person I was facing and interpreted what I saw and heard through my non-disabled perspective. Working within the logic that what was true for me had to be true also for those I encountered (Brons 2015), I could not ‘know’ at the time that a disabled body might be more mobile than a non-disabled body and have a sexual life that was as fulfilling (or even more fulfilling). As long as my reasoning went along this line, with my ‘Self’ as the point of departure, I was prevented from seeing anything but the ‘Other’ (Brons 2015) when I faced the study participants.

Over the course of the fieldwork, I encountered alternative understandings which revealed the limitations of my ‘non-disabled ignorance’ and allowed for new discoveries. The social model of disability (Oliver 1983; 2004; 2013) was one framework that provided an

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<sup>52</sup> For example, the tobacco industry has actively produced ignorance about the harmful effects of smoking and thus engaged with productions of power (Tuana 2006).

<sup>53</sup> I remind the reader of the argument outlined in the chapter ‘Theoretical Framework’, which was as follows: a) to be mobile and sexually capable requires a non-disabled body; b) the ‘Other’ has a disabled body; therefore c) the ‘Other’ is immobile and sexually incapable.

alternative with which I accessed new insights. It revealed that my world view was rooted in a biomedical approach, and it offered me a portal to creatively explore social constructions of disability as a phenomenon. The social model of disability has been criticised for excluding the issue of ‘Otherness’. Because its focus is on disabling barriers, it does not adequately capture the way cultural values position disabled people as ‘Other’ (Oliver 2004; Goodley 2014). However, ‘ableistic’ discourses contribute to constructing disabled people as ‘Other’, and in our framing, the social model of disability offers a way to destabilise this kind of ‘Othering’. When acts of sexuality and mobility (the subjects of attention in article 2) are seen as a negotiation between the body and the terrain, impaired bodies might escape ‘Othering’. The potential to view bodies in more inclusive ways and to creatively explore new forms of sexual and mobile activities is more accessible. By using the social model of disability as an alternative lens, I accessed new ‘knowledge’ and (at least some of) my ignorance was ‘unlearned’ (Tuana 2004; 2006). This process helped to enable me to detect the discursive ‘Othering’ of young, male drivers in the field of traffic injury prevention research. One portal to this discovery was the autoethnographic process with article 2, which enabled me to expose my ‘ableism’ and provided me with resources to recognise mechanisms of ‘Othering’ more broadly.

### **11.1.3 Article 3**

In article 3, we explore how young, male drivers understand their driving practices both before and after their accidents. We use the term ‘traffic safety agency’ to describe what we perceive as an ongoing negotiation of safe driving practices by the individuals. However, in the injury prevention research literature, we found that this group of drivers (young men) were constructed as a ‘problem’ and described in pathological terms. In this discourse, the study participants do not belong to the category of the ‘Self’, who is rational, caring and drives as one ‘should’ drive. On the contrary, they are conceptualised as the ‘Dangerous Other’

(Balkmar and Joelsson 2014). Hence, they are constructed as irrational, uncaring and driving as one should not drive. This perception might be produced in processes of ‘sophisticated othering’ (Brons 2015) in which experts view the actions of young, male drivers from the position of the ‘Self’s’ view on safe driving. The argument might be as follows: (a) to drive safely and be rational and caring means to follow traffic regulations; (b) the ‘Other’ does not follow traffic regulations; therefore (c) the ‘Other’ does not drive safely and is not rational and caring. Here, the experts represent the voice of the ‘Self’, which, in this discourse, is constructed as people in the ‘in-group’ in opposition to those belonging to the ‘out-group’. The voices of young, male drivers (as typical of groups that are ‘Othered’) were silenced and excluded from the conversations (Ramazanoğlu and Holland 2002) about safe driving and injury prevention. The ‘Othering’ created a barrier between the ‘Self’ (the experts) on the one hand and the ‘Others’ (the young, male drivers) on the other hand, which, we argue, prevented dialogue and exchange of knowledge. It prevented the experts’ accessing alternative knowledge, namely that both groups – although by different means – want to avoid injuries and fatalities on the road. Consequently, what we have termed the drivers’ ‘traffic safety agency’ might easily go unrecognised by the experts. Unfortunately, we found that it did just that, when it could be an arena for new discoveries and potentially successful integration of injury prevention strategies, which is what we suggest in future approaches to connect with the target group.

## **11.2 Resistance to ‘Othering’ and the potential for change**

Findings in this study suggest that it is necessary to challenge the three discourses described above to allow for new discoveries and power dynamics, as they might have effects that are ‘ableist’ and problematic in a perspective of justice and human rights. In this discussion, I have implied that there *is* a potential for change because the relationship between the ‘Other’ and the ‘Self’ is ‘a fluid, socially constituted, repeatedly performed relationship’

(Ramazanoğlu and Holland 2002). Thus, the notions of who ‘naturally’ inhabits the categories of ‘us/them’, ‘knower/known’, and ‘inside/outside’ are not given. To follow Foucault, it will always depend on the continuing negotiation of power and the legitimization of positions of authority (Alvesson and Kärreman 2000; Jørgensen and Phillips 2010; Springer and Clinton 2015). I have both illustrated and emphasised that access to alternative frameworks offers the potential for change because alternatives work to destabilise discursive ‘hegemony’ and promote new insights. Moreover, I now suggest that alternative frameworks may grow from resistance and friction, which might also alter power dynamics in relatively stable hegemonic discourses. I will illustrate this potential for change by pointing to some of the resistance strategies and their effects in the discursive terrain I have outlined.

In effect, the study participants ended up in subordinate positions due to discursive ‘Othering’. However, these processes involved ongoing negotiations. In all cases of ‘Othering’, strategies of resistance were employed by the study participants. In article 1, resistance to being ‘Othered’ emerged when study participants protested the percentages they had been given by medical professionals, and when they engaged with their own individual projects to achieve their goals (such as starting their own firm or attaining full-time jobs) in spite of medical advice. In article 2, resistance came in the shape of the numerous confrontations and corrections I was subjected to by the study participants when I presented ‘ableist’ assumptions. In article 3, the drivers resisted normative ideals (e.g. traffic regulations) by continuing to drive according to their own convictions and emic notions of safe driving. These practices may be seen as examples of resistance strategies that work to destabilise power relations within the discourses involved because they identify and question taken-for-granted authority (Ramazanoğlu and Holland 2002). I have illustrated an effect of resistance in article 2, where resistance to ‘ableism’ from disabled people leaked into the social interaction with the researcher and allowed me to engage in new and less ‘ableist’

conceptualisations. The potential for change through resistance (and altering power dynamics) is also evident in article 3. As researchers, we actively sought to avoid reproducing the power dynamics in the hegemonic discourse we encountered in the field of traffic injury prevention research. We recognised this as a discourse in which young, male drivers were the objects of ‘Othering’ (Brons 2015) by experts who had interpreted the actions and understandings of these ‘Others’ by using their own (the ‘Self’s) logic as a reference. Rather than imitating this pattern, we were inspired by the ‘principle of charity’ (Wilson 1959) and the ‘principle of humanity’ (Grandy 1973). Thus, we were sceptical of accepting the attributions of irrationality and pathological traits associated with young, male drivers. Instead, we aimed to interpret their world view as being as reasonable as possible. We explored the logic that framed their understandings and practices on their terms instead of our own. If we had engaged in ‘Othering’ and interpreted their words and actions from the position of the ‘Self’, we would have concluded that the men were irrational, thereby losing the valuable perspective of their ‘traffic safety agency’. This process illustrates that the active strategy of charity may rehumanise the ‘Other’ and open the door for an exploration of sameness (Brons 2015).

### **11.3 Contextualising findings in the study**

In this section, I will locate the study in relation to the global discourses of neoliberalism. I start by outlining what I mean by neoliberalism and how neoliberal discourses affect disabled people in particular. Then, I move on to discuss the study’s findings in relation to neoliberal discourses with emphasis on how success in the labour market is constructed as a necessity to be counted as a useful citizen. Also, I discuss the intersection of disability, masculinity and age in relation to the findings.

Neoliberal measures have been implemented globally to various degrees in the 1970s, including in Scandinavian social democracies (Harvey 2005). In the 1980s and 1990s, many countries in Africa, Latin America and the former Soviet Union aimed at macroeconomic stability by implementing neoliberal reforms as a response to financial crisis. Many countries in Europe followed suit in the aftermath of the financial crisis in 2008 (Sakellariou and Rotarou 2017). Thus, contemporary qualitative researchers often speak of this particular historical moment as the time of neoliberalism<sup>54</sup> (Denzin and Lincoln 2018). Before I move on to discuss how neoliberalist discourses might influence ways in which the individual is constructed and relate it to findings in this study, I will specify what I mean by neoliberalism. Harvey (2005) defines neoliberalism in the following way:

Neoliberalism is in the first instance a theory of political economic practices that proposes that human well-being can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterized by strong private property rights, free markets and free trade. The role of the state is to create and preserve an institutional framework appropriate to such practices. (...) State interventions in markets (once created) must be kept to a bare minimum (p. 2).

From this definition, neoliberalism might be recognised as discourses in which the free market is prioritised over political processes and democracy. Neoliberalism is in tension with democratic rule because it easily comes into conflict with commercial interests. Specifically, neoliberalism can be seen in the processes of privatisation and commercialisation.

Privatisation entails the selling of state assets and services to private companies. Increased commercialisation entails changes in the conduct of the state through introducing the technologies, organisational models and principles of private business and the market in state

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<sup>54</sup> Some theorists rightfully caution against the tendency to use neoliberalism as a total concept since realities are complex and hybrid (e.g. Springer 2013; Mladenov 2015). I agree and emphasise that I speak of neoliberal trends and discourses and not of totalising systems.

institutions (Brown 2015). The doctrine of ‘radical marketisation’ (Mladenov 2015) entails an emphasis on ‘self-interest, calculability, competition, efficiency, profit’ (p. 3) which in effect threatens democracy and increases inequality in the population when it is introduced in state institutions (Brown 2015).

Critical theorists have highlighted that the influence of neoliberalism is severe and powerful (Brown 2015) and that it disadvantages disabled people in particular (Mladenov 2015; Sakellariou and Rotarou 2017). Neoliberal discourses – in which emphasis is placed on the free market, productivity and individual responsibility for your own success (including your health) – produces a power differential that afflicts this group. For example, commercialisation of public health services produces a logic in which budget cuts are continuously needed to reduce the cost of health services as well as of welfare benefits. Alongside this development, businesses and public service providers are facing increasing demands for efficiency, which produces less room for employees with health challenges or who need adaptations in order to work. As a consequence, disabled people, who have more health-related costs than the general population due to more extensive healthcare needs, are under both increased pressure to attain paid work and simultaneously less likely to engage in paid work than the general population due to their health situation and lack of adaptations to do so. Critics argue that disabled people are therefore led into poverty in what might be seen as a production of a category of disempowered people (Sakellariou and Rotarou 2017).

Grover and Soldatic (2013) suggest that ‘while the “disabled body” has changed little, the systems and processes that classify them as being capable or incapable of working have undergone a radical shift to limit the number of people categorised as disabled’ (p. 217). They argue that in Australia and Britain, neoliberal trends have changed the social security system, which is increasingly linked to the capacity of disabled people to (re)enter paid work. It has become more difficult for disabled people to claim benefits by tightening eligibility



criteria, the size of benefits has been reduced, and extensive mandatory labour interventions have been introduced in which claimants are tested in relation to work in/capacity. The consequences are severe and, in addition to increased pressure to work, also includes increased social isolation because ‘disability’ is stigmatised in neoliberal discourses, and disabled people are deprived of recourses necessary to participate in the social sphere (Dorn and Keirns 2010 in Grover and Soldatic 2013).

While global neoliberal discourses influence the social democratic policy in Norway as well, it is difficult to distinguish its effect, as it intersects with other powerful discourses (Tøssebro 2016). For example, Tøssebro (2016) notes in relation to the Norwegian context that an increased focus on individual choice and self-determination in policy documents is part of a trend towards neoliberal policies. However, this tendency intersects with the discourse of human rights, equality and the individual’s right to participate in processes concerning themselves promoted by disability organisations (ibid.). Another example is that older than neoliberalism is the ‘work line’, a powerful discourse in the welfare state in which the citizen is primarily constructed as a worker. In order to secure tax revenues to finance welfare provisions, high rates of employment have been considered essential (Johansson and Hvinden 2009). Incorporated in the system of public welfare provision is the idea that the right to enjoy social benefits is earned by the duties, efforts and contribution that the citizens fulfil. This is manifested in the system of unemployment insurance in which

an unemployed individual must be prepared to do what he or she can to return to work as soon as possible. This duty includes registering at the employment office, actively seeking work, and accepting all suitable jobs or offers for participating in labour market measures. Similarly, sickness and disability insurance benefits have combined conditions in the form of sufficient prior earnings or a contributions record and the

willingness to comply with the current requirements of the authorities (Johansson and Hvinden 2009, p. 7).

While this system entails relatively generous (although differentiated) rights to income maintenance (Johansson and Hvinden 2009), the criteria to receive welfare benefits are strict and the emphasis and value of work is explicit. This puts pressure on individuals who are not able to achieve this, and the influence of neoliberal discourses might further manifest the implicit notion of failed citizenship for people in this situation. In discourses where bodies are evaluated by their ability to achieve wealth and career realisation, the disabled body will often fail the success criteria and risks being viewed as a societal burden (Sakellariou and Rotarou 2017). Grover and Soldatic write:

Not only are they [disabled people] held to be financially burdensome (hence, a potential drag on the profit of capitalism), they are also held to have detrimental supply-side effects that are also held to reduce profitability (Grover and Soldatic 2013, p. 226).

As a consequence, one might argue that disabled people are ‘Othered’ and stigmatised. They are constructed as ‘problems’ in a neoliberal framing where it is paramount to contribute to increased productivity, which is key to being counted as successful – and in accordance with the Norwegian ‘work line’ – dutiful citizens. However, the emphasis on work may also be approached as a discourse of inclusion, as illustrated by Norwegian disability organisations who traditionally are engaged in activism to secure the right of disabled people to participate in the labour market on equal terms with non-disabled people (Tøssebro 2016).

In this study, the participants were embedded in a system where they were subjected to extensive testing and measurements procedures so that experts could assess their level of

disability in relation to work in/capacity and evaluate the degree to which they might or might not 'deserve' welfare benefits due to strict eligibility criteria (Svendby et al. 2017). Both the stigma of 'becoming' disabled (and thus financially burdensome instead of successful, useful citizens) and the pressure to attain work is actualised in these practices – as well as the right to work and participate in society on equal terms and/or to receive welfare benefits. The participants felt it was painful not to be able to work. This might be seen as a response to a complex intersection of discourses such the 'work line', 'neoliberalism', being constructed as disabled and/or as reactions to their particular bodily situations as impaired in which they experienced a lack of opportunities compared to their previous situation. Moreover, neoliberal discourses, in which responsibility is individualised and any dependency or need for help is disavowed, may become internalised on an individual level and cause much emotional strain for the persons involved (Peacock, Bissel and Owen 2014). Being independent was very important to the participants in this study. Their emphasis on independence and their desire to participate in the labour market suggest that neoliberal values are significant in their ways of seeing themselves in society. If neoliberal values are hegemonic, such an internalisation of neoliberal values is inevitable, regardless of ability and social positioning. Striving to become a contributor through attaining work functions as a way to claim legitimate citizenship within the neoliberal logic.

In terms of gender, the experience of being constructed as 'disabled' within the neoliberal discourse may be seen to cause increased pressure on (disabled) men. Many researchers have pointed out the conflict between disability, which often is associated with dependency and helplessness, and idealised masculinity, which is often associated with independence and autonomy (see e.g. Asch and Fine 1988; Shuttleworth, Wedgwood and Wilson 2012). The male study participants' desire to participate in the labour market and their negative experience of not working full time may be seen as a response to the experience of being positioned as disabled while negotiating masculine identities. As I have discussed above,

masculinity and disability do not easily unite, even in a liberal or social democratic order. Neoliberalism accentuates these challenges, as it involves an individualisation of welfare and well-being. The entrenched cultural connection between masculinity and the role of being financially independent and providing for oneself (and the family) is strong and goes back a long way (Slottemo 2009). Neoliberalism increases the risk of failing to be financially independent and relatedly to be excluded from the labour market, which in turn may be linked to the experience of being demasculinised and/or the fear of not being perceived of as a 'real' man (Kimmel 1994). When disability is associated with dependency and unemployment, the intersection of the two categories of disability and masculinity may cause serious tension for the people involved, as discussed in article 3. When the aspect of young age is taken into account, the pressure on disabled men intensifies because what they expect from themselves as young men in a neoliberal order is at odds with the realities of their lives. Sandgren (2015) finds in her study of older men and sexuality that young age in men is often associated with a strong, functional, potent and, in relation to older men, more able body. I follow her understanding that age, which may be seen both as a social category and as a material process of bodily change, and masculinity emerge and become intelligible in diverse ways in relation to different social and cultural contexts. In relation to neoliberal discourses, young age may increase the pressure on disabled men to (re)enter the labour market at all costs and make use of the functionality traditionally associated with young (male) bodies.

While I have now contextualised the study in relation to neoliberal discourses, I end by emphasising the point made previously – this terrain is complex and I discuss possible impacts rather than stating absolutes.

## 12 Conclusions

In this section, I sum up the study's overall contribution to knowledge.

This study offers an original contribution to knowledge by identifying and unpacking three hegemonic discourses and (some of) their effects. These are discourses that shaped the study participants' experiences in the aftermath of traffic accidents in which they had been injured.

The first article contributes to the dialogue in disability studies on normality and deviance. Specifically, it contributes to the dialogue about the construction of disability and what it 'does'. We identify a discourse that we have termed 'the language of percentages' (Svendby et al. 2017). This concept refers to a discourse constructed in rehabilitation practice when measurements expressed in numbers and percentages are used by professionals to depict and express the functional capacities of rehabilitees. The study contributes with a discussion of how this 'language' leaks into the wider context of the lives of the study participants and affects their understanding of themselves.

Our analysis of 'the language of percentages' illustrates that, in effect, the act of measurement works to rank bodies in specific and normative ways that are unable to express difference as a valuable instance of human diversity. This discourse constructs disability as a percentage of the 'complete' normative ideal, which is one hundred per cent, and may cause negative emotions in rehabilitees and lead them to question whether they are complete human beings. By describing this discourse and terming it 'the language of percentages', the study contributes with a tool in which this very 'language' and what it 'does' – in addition to its capacity as a medical instrument – rises to the surface and becomes accessible as a topic of critical discussion in disability studies. The study also offers implications for rehabilitation

practice by proposing that when medical professionals provide guidance and support for patients in rehabilitation, the wider consequences of the act of measurement should be addressed and taken into consideration.

The second article contributes to the dialogue in disability studies on discrimination based on disability, which is often referred to as ‘ableism’ (Campbell 2009) in the research literature. We identify a discourse that I have termed ‘non-disabled ignorance’ in this thesis. This concept refers to a discourse of ignorance about disability which is constructed and maintained through the cultural tendency to rely on a biomedical frame of reference in the understanding of unusual bodies.

This article contributes with an autoethnographic approach to disability studies which so far has not been widely used in this field of research. What this autoethnography offers is an account on how ways in which ignorance about disability became apparent during the fieldwork when much of what I, the researcher – as a representative of the non-disabled majority – ‘knew’ about disability was revealed as unquestioned cultural assumptions that exposed me as ‘ableist’ in encounters with disabled people. Seeing disability through the pathology-focused lens which is characteristic of the biomedical project, it did not occur to me at the time that being in the world with a disabled body could be a satisfactory possibility. Instead, I saw the study participants as people in a rehabilitation process where the ultimate goal was to return to the bodies and lives they had before their accidents. Using autoethnography increases the opportunity to reach a broader audience than academics only due to the use of an accessible language and emphasis on emotions, thoughts and experiences that may resonate with people in general. Therefore, the autoethnography may potentially help to encourage non-disabled readers to reflect on their relation to and knowledge about disability.

The analysis demonstrates that, in effect, the discourse of ‘non-disabled ignorance’ constructs ‘ableistic’ notions about unusual bodies while non-disabled bodies are constructed as superior. The study offers the concept of ‘non-disabled ignorance’ as a tool by which this very discourse may be confronted and further theorised in disability studies. As ignorance unfortunately works to construct and maintain ‘ableism’, we suggest that alternative ways of knowing should continue to be explored and promoted to extend the cultural imagination about disability and prevent ignorance in non-disabled people’s encounters with disabled people.

Gender – masculinity in particular – is under-theorised in the field of disability research and vice versa (Kittelsaa, Kristensen, and Wik 2016). The third article contributes to disability studies and masculinity studies with an intersectional analysis about disabled masculinities. In addition to these research fields, this article speaks to the field of traffic injury prevention research. While gender is pertinent in the context of road traffic accidents, it has rarely been treated as an entry point for analytical problematisation in traffic injury prevention research. We contribute to the research dialogue with an exploration of young men’s driving practices in which gender is treated not as essence, but as a cultural construct.

This article contributes with an analysis of the 12 male study participants’ views and practices regarding driving, safety and disability after a severe accident. We identify and explore a problem-focused gaze which is directed at a sub-group of young, male drivers who are constructed as ‘young problem drivers’ in the research field of traffic injury prevention. Members of this group are constructed as irrational and careless, and their road traffic behaviour is understood as pathological. As a result, we argue, young men’s situated knowledge regarding road traffic safety – their safety assessments and capacity to act as

caring subjects – remain (relatively) unrecognised by traffic injury prevention experts. The study diversifies the rather static notion of men as irrational, careless drivers by contributing an exploration of care and safety assessments among young, male drivers. We term the latter their ‘traffic safety agency’. This concept is introduced to highlight that such an agency exists and to make this knowledge accessible in the discourse about ‘young problem drivers’. We propose that stimulating young men’s ‘traffic safety agency’ and approaching them as rational, caring subjects may prove to be fruitful in future efforts to communicate with this group and promote safety measures that they are able and willing to adopt.

Critical discourse analysis is used in this study as a way of honing in on what discourses ‘do’ and how things could be otherwise by exposing the language and techniques of power. The final discussion in this thesis makes a contribution to the field of disability studies and the field of gender studies with an analysis of how the three discourses under scrutiny result in ‘Othering’. I argue that Othering occurs in relations between medical professionals and rehabilitees (article 1), non-disabled people and disabled people (article 2) and traffic injury prevention experts and young, male drivers (article 3). Also, the study contributes with a discussion about strategies that may work to destabilise hegemonic discourses that reproduce ‘ableism’ and dehumanisation of unusual bodies. First, resistance strategies. Such strategies and their potential to counter ‘Othering’ are exemplified in the discussion by actions of resistance employed by the study participants. Second, access to alternative conceptualisations of bodies and ways to view the world, which in effect challenge ignorance and hegemonic ‘knowledge’ about disability. One example of such an alternative conceptualisation is the social model of disability which gave access to a creative exploration of disability for me, in the role of the researcher, and challenged my ignorance and ‘knowledge’ about disabled people. Third, rehumanisation of the ‘Other’ by resisting ‘sophisticated othering’ (Brons 2015) and turning instead to the ‘principle of charity’ (Wilson



1959) and the ‘principle of humanity’ (Grandy 1973). This means that instead of taking the ‘Self’ as the point of departure and drawing conclusions based on his or her own world view to understand the ‘Other’, one attempts to understand people as rational beings when they act, look and think differently from oneself. This latter strategy is particularly recommended to traffic injury prevention experts. Instead of constructing young, male drivers as irrational due to their non-normative traffic behaviour, experts may find a platform to understand and communicate with members of this group by taking into consideration the internal logic and prevailing masculinity discourses that guide their choices.

In terms of the societal dimension, I have positioned the study in relation to neoliberal discourses. Medical procedures conducted within the Norwegian health system with emphasis on measurements to assess levels of disability, strict eligibility criteria which are used to grant or deny welfare benefits, and pressure on disabled people to (re)enter paid work (Svendby et al. 2017) may be seen – at least in part – as effects of global neoliberal discourses. The study participants seem to have internalised discourses in which the ability to be financially independent and participate in the labour market are linked to the status of becoming a useful citizen. According to neoliberal discourses, the responsibility to achieve success rests with the individual, as does failure, and may therefore lead to an experience of diminished citizenship for those who are not able to do so (Grover and Soldatic 2013). I argue that neoliberal discourses are highly gendered and in particular affect the lives of young disabled men. The male study participants are positioned at the intersection of conflicting discourses related to disability (dependency and helplessness), masculinity and young age (independence and functionality). Disabled people, and men in particular, risk ‘Othering’ and stigmatisation if they do not successfully conform to neoliberal ideals of productivity and profitability. This is worrying because it affects the lives and well-being of

disabled people and contributes to the construction of ‘a category of disempowered people’ (Sakellariou and Rotarou 2017, abstract).

Overall, the study has aimed to uncover and challenge hegemonic cultural notions that in effect are discriminatory, and has sought to explore the potential of alternative understandings and practices that promote social justice. Hopefully, the study will motivate researchers, medical practitioners and others to actively seek, explore and introduce alternatives that will keep challenging the discursive terrain and the processes of ‘Othering’ that have been unpacked and criticised in this study. By doing so, we can contribute to the celebration of unusual bodies, challenge ‘ableism’ and acknowledge as well as stimulate young men’s ongoing negotiations of road traffic safety and care for others.

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## 14 Appendix

1. Authorisation from the Norwegian Centre for Research Data (NSD) to conduct the study.
2. Information sent to the study participants in the recruitment phase.
3. Interview guide (living document that was used as a starting point for conversations), first version in Norwegian and second version translated into English.
4. Errata list
5. Article 1: The language of percentages: Ranking bodies, shaping realities, and limiting opportunities
6. Article 2: Non-disabled ableism: An autoethnography of cultural encounters between a non-disabled researcher and disabled people in the field
7. Article 3: Recognising young men's care and 'traffic safety agency': masculinity, driving and safety among 'young problem drivers' in the aftermath of severe road traffic accidents



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0317 OSLO

Vår dato: 28.01.2013

Vår ref:32764 / 3 / MSI

Deres dato:

Deres ref:

### TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 15.01.2013. All nødvendig informasjon om prosjektet forelå i sin helhet 24.01.2013. Meldingen gjelder prosjektet:

|                      |  |
|----------------------|--|
| 32764                | <i>Unge menn i trafikkekulykker</i>                    |
| Behandlingsansvarlig | Universitetet i Oslo, ved institusjonens overste leder |
| Daglig ansvarlig     | Rannveig Svendby                                       |

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, <http://www.nsd.uib.no/personvern/meldeplikt/skjema.html>. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://pvo.nsd.no/prosjekt>.

Personvernombudet vil ved prosjektets avslutning, 31.12.2017, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

  
Vigdis Namtvedt Kvalheim

  
Marte Sivertsen

Kontaktperson: Marte Sivertsen tlf: 55 58 33 48  
Vedlegg: Prosjektvurdering

## Personvernombudet for forskning



### Prosjektvurdering - Kommentar

Prosjektnr: 32764

Prosjektleder har avklart med REK at prosjektet ikke er helseforskning, jf. epost 24.01.2013.

Ifølge prosjektmeldingen skal det innhentes muntlig samtykke basert på muntlig informasjon om prosjektet og behandling av personopplysninger. Personvernombudet forutsetter at det gis muntlig informasjon om følgende, i tillegg til punktene i malen for muntlig informasjon:

- hvilken institusjon som er behandlingsansvarlig
- formålet med prosjektet
- hvilke metoder som vil bli benyttet
- hvilke opplysninger som samles inn
- hva opplysningene skal brukes til
- kontaktopplysninger til forsker.

Det vil i prosjektet bli registrert sensitive personopplysninger om rasemessig eller etnisk bakgrunn, eller politisk, filosofisk eller religiøs oppfatning, om at en person har vært mistenkt, siktet, tiltalt eller dømt for en straffbar handling og helseforhold, jf. personopplysningsloven § 2 nr. 8 a) - c).

Personvernombudet forstår det slik at det ikke er ønskelig å registrere tredjepersonsopplysninger, da det er informantene som står i sentrum. Vi anbefaler derfor at prosjektleder ber informantene omtale andre på en slik måte at de ikke kan identifiseres ifm. intervju (dvs. utelate navn og bakgrunnsopplysninger som f.eks. kjønn, alder og yrke) i den grad det lar seg gjøre. Dersom det fremkommer opplysninger om tredjepersoner under intervjuene (andre som var involverte i ulykken) vurderer personvernombudet at opplysningene kan behandles med hjemmel i personopplysningsloven § 8 d) jf. § 9 h). Behandlingen vil kunne være nødvendig for formålet, da det i mange tilfeller vil kunne være vanskelig for informantene å snakke om ulykken uten å identifisere involverte tredjepersoner. Forsker opplyser at fokus vil være på informantene og dennes erfaringer. Personvernombudet legger til grunn at tredjeperson, så langt det lar seg gjøre, får informasjon om prosjektet med mulighet for å reservere seg. Dersom det i noen tilfeller skulle vise seg uforholdsmessig vanskelig å informere tredjeperson, kan prosjektleder unntas fra informasjonsplikten, jf. personopplysningsloven § 20 b). Det kan også gjøres unntak dersom det vurderes utilrådelig å informere tredjeperson av hensyn til relasjonen til informantene, jf. personopplysningsloven 23 c).

Innsamlede opplysninger registreres på privat pc. Personvernombudet legger til grunn at forsker setter seg inn i og etterfølger Universitetet i Oslo sine interne rutiner for datasikkerhet, spesielt med tanke på bruk av privat pc til oppbevaring av personidentifiserende data. Det er oppgitt at navnelisten/koblingsnøkkelen oppbevares nedlåst.

Prosjektslutt er angitt til 31.12.2016. Etter prosjektslutt vil datamaterialet lagres med personidentifikasjon i 1 år i påvente av eventuelle oppfølgingsstudier. Det forutsettes at informantene har samtykket til dette. I de tilfellene hvor det ikke foreligger aktivt samtykke fra den registrerte til videre lagring, må datamaterialet om vedkommende anonymiseres ved prosjektslutt. Dersom det ikke blir aktuelt med oppfølgingsstudier, vil datamaterialet være anonymisert senest innen 31.12.2017. Anonymisering innebærer at direkte personidentifiserende opplysninger som navn/koblingsnøkkel

slettes, og at indirekte personidentifiserende opplysninger (sammenstilling av bakgrunnsopplysninger som f.eks. yrke, bosted, alder, kjønn) fjernes eller grovkategoriseres slik at ingen enkeltpersoner kan gjenkjennes i materialet.

Personvernombudet minner om at eventuelle oppfølgingsstudier må meldes til ombudet i god tid (senest 30 dager) før de igangsettes.

## Forespørsel om deltakelse i forskningsprosjektet

### *”Unge menns hverdag etter trafikkulykker”*

#### **Bakgrunn**

Dette er et spørsmål til deg om å delta i en forskningsstudie som handler om menn som er eller har vært under rehabilitering etter å ha blitt skadd i en trafikkulykke. I studien skal det intervjues 10-12 menn som har vært sjåfører i en trafikkulykke da de var mellom 18-24 år. Du blir spurt fordi du er i målgruppen.

Ulykkesstatistikken viser at unge menn er en høyrisikogruppe i trafikkrelaterte ulykker. Hensikten med dette forskningsprosjektet er å finne ut mer om unge sjåfører som skader seg i trafikken og hvordan de har det etter ulykken. Videre er det et mål i studien å gi innspill til hvordan rehabiliteringen av unge, trafikkskadede menn kan legges opp på best mulig måte. Det er Universitetet i Oslo som er ansvarlig for prosjektet. Trygg Trafikk er samarbeidspartner. Prosjektet er finansiert av Extrastiftelsen Helse og Rehabilitering.

#### **Hva innebærer studien?**

Dersom du sier ja til å være med i studien vil du bli spurt om å stille på 1-2 intervjuer (flere hvis du har lyst) med prosjektleder Rannveig Svendby. Det avtales på forhånd hvor intervjuene skal foregå, for eksempel på Sunnaas, hjemme hos deg eller på en cafe. Intervjuene foregår som en samtale. Du bestemmer selv hvilke spørsmål du vil svare på.

Hvis du tillater det vil Rannveig Svendby gjøre observasjoner av deg i tillegg til intervjuer. Det innebærer at hun er tilstede under opptreningssituasjoner og/eller i sosiale situasjoner på Sunnaas eller andre steder etter avtale.

#### **Mulige fordeler og ulemper**

Du vil ikke ha noen spesielle fordeler av studien, men erfaringer fra studien vil senere kunne hjelpe andre med samme diagnose.

#### **Hva skjer med prøvene og informasjonen om deg?**

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer/direkte gjenkjenning opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg.

Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger. Opplysningene blir senest slettet 31.12.2017

#### **Frivillig deltakelse**

Det er frivillig å delta i studien. Dersom du ikke ønsker å delta, trenger du ikke å oppgi noen grunn, og det får ingen konsekvenser for den videre behandlingen du får ved sykehuset.

Dersom du ønsker å delta, undertegner du samtykkeerklæringen på neste side og sender den i posten med den frankerte konvolutten. Da vil Rannveig Svendby ta kontakt med deg på mobil eller e-post for å avtale når det passer å ha det første intervjuet. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling på sykehuset. Dersom du senere ønsker å trekke deg, kan du kontakte Rannveig Svendby på mobil 41188993.

**Samtykke til deltakelse i studien**  
**"Unge menns hverdag etter trafikkulykker"**

Jeg er villig til å delta i studien:

Ditt navn og dato: \_\_\_\_\_

Ditt mobilnummer og/eller e-postadresse som Rannveig Svendby kan kontakte deg på:

Ditt mobilnummer: \_\_\_\_\_

Din e-postadresse: \_\_\_\_\_

Jeg bekrefter å ha gitt informasjon om studien

-----  
(Signert, rolle i studien, dato)

## *Intervjuguide, utgangspunkt for samtaler*

Hvilke minner har du om ulykkesdagen – hva skjedde før, under og etter ulykken?

Kunne ulykken vært unngått – i så fall hvordan?

Har du vært i andre ulykker? Har du søsken/venner som har vært i ulykker?

Hva var ditt forhold til kjøretøy og kjøring under oppveksten? Hva med i dag?

Hvordan kjørte du før ulykken? Hvordan kjører du i dag?

Hva er det forreste du har kjørt, når var det og hvilke omstendigheter?

Hva er synet ditt på alkolås, belte, fartssperre, og andre trafikksikkerhetstiltak?

Hva slags sjåfør er du? Hva er trygg kjøring for deg? Hva er risikokjøring for deg?

Hvordan har rehabiliteringsprosessen din vært?

Er det noe du ønsker skulle vært gjort annerledes i prosessen? I så fall hva?

Hvordan har du det i dag? Hvordan er hverdagen din?

Jobber eller studerer du? Hvordan opplever du å arbeide/studere/ ledighet?

Hvordan er det å være ute etter ulykken? Møte andre? Å være i kroppen din?

Hva tenkte og følte du om kroppen din før? Hva med i dag?

Hva slags forhold hadde du til familie og venner før? Hva med i dag?

Har noe endret seg sosialt etter ulykken? I så fall, hvordan?

Er det noe spesielt du vil at vi skal snakke om?

*Interview guide – starting point for conversations*

What are your memories of the day of the accident – what happened before, during and after the accident? Could the accident have been avoided – if so, how?

Have you been in other accidents? Do you have siblings/friends that have been in accidents?

What was your relationship to motor vehicles and driving growing up? How about today?

How did you drive before the accident? How do you drive today?

What is the fastest you have driven, when was it and what were the circumstances?

What is your opinion of alcohol locks, seat belts, speed limiters and other traffic injury prevention strategies?

What kind of a driver are you? What is safe driving to you? What is risky driving to you?

What was your process of rehabilitation like?

Is there anything you wish had been done differently in this process? If so, what?

How are you today? What is your everyday life like?

Do you work or study? How do you experience working/studying/unemployment?

How has it felt to be outdoors since the accident? To meet other people? To be in your body?

What were your thoughts and feelings about your body prior to the accident? How about today?

What was your relationship with your family and friends like prior to the accident? How about today?

Has anything changed in your social life since the accident? If so, how?

Is there something in particular you would like us to talk about?



| Errata list  |      |                      |   |   |                    |   |
|--|------|----------------------|---|---|--------------------|---|
| Name of the candidate: Ragnvald Svanhøj  |      |                      |   |   |                    |   |
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|  | 16   |                      | 3   | See the last page in the section 'Outlining' in the chapter 'Background' for a definition of article 2 in this thesis | cor                | See the chapter 'Theoretical framework' for a definition of article 2 in this thesis                                  |
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|  | 31   | 23                   |   | Asperger's (p. 187).  | cor                | Asperger's (p. 187).  |
|  | 42   | 17                   |   | Krifka, Kristensen and Wik  | cor                | Krifka, Kristensen and Wik  |
|  | 43   | 5                    |   | 2015, and young men   | cor                | 2015) and young men   |
|  | 45   | 10                   |   | (Harding 1992). Standpoint theory has   | cor                | (Harding 1992). Standpoint theory has   |
|  | 56   | 16-17                |   | Disability standpoint theory  | cor                | Disability standpoint theory  |
|  | 56   | 19                   |   | from a constructivist viewpoint   | cor                | from a constructionist viewpoint  |
|  | 64   | 10                   |   | and 'we do not even know what we do not know' (ibid.)   | cor                | and 'we do not even know that we do not know' (p. 6).   |
|  | 72   | 17                   |   | gendered beings. The men  | space              | gendered beings. The men  |
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|  | 130  | 22                   |   | which the autoethnography might seek  | cor                | which the autoethnographer might seek   |
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|  | 195  | Aller-Collinson      | <i>Physical culture</i> . Pp 191-212.   | cor   | cor                | <i>Physical culture</i> . pp. 191-212.  |
|  | 195  | Altemo               | <i>Problems of education in the 21st century 13</i> .   | cor   | cor                | <i>Problems of education in the 21st century 13-18</i> .  |
|  | 198  | Brown, W. 2015       | Undoing the demos: Neoliberalism's stealth revolution.  | italicization   | italicization      | <i>Undoing the demos: Neoliberalism's stealth revolution</i> .  |
|  | 200  | Davies               | Reflexive Ethnography: A guide to researching selves and others.  | italicization   | italicization      | <i>Reflexive Ethnography: A guide to researching selves and others</i> .  |
|  | 208  | Guo, J. 2015         | <i>International Perspectives</i> . P   | cor   | cor                | <i>International Perspectives</i> . pp.   |
|  | 210  | Harway               | Vitenskapssamfundet i Feminismen  | cor   | cor                | Vitenskapsrådet i Feminismen  |
|  | 213  | Kimmel 1987          | <i>Changing Men: New Directions in Research on Men and Masculinity</i> . Newbury Park   | cor   | cor                | <i>Changing Men: New Directions in Research on Men and Masculinity</i> . pp. 9-25. Newbury Park.                      |
|  | 214  | Kilks, H. 2007       | Linköping. Linköping University.  | cor   | cor                | PHD dissertation, Linköping University.   |
|  | 216  | McKey                | <i>A practical guide for researcher in health and the social sciences</i> .   | cor   | cor                | <i>A practical guide for researchers in health and social sciences</i> .  |
|  | 220  | Owton, H., and       | <i>Sport, Education and Society</i> . doi:  | cor   | cor                | <i>Sport, Education and Society</i> 22(6): 712-743. doi:  |
|  | 221  | Pini, B. and Peiris, | <i>Men, Masculinities and Methodologies</i> . London:   | cor   | cor                | <i>Men, Masculinities and Methodologies</i> . pp. 1-25. London:   |
|  | 222  | Reed-Daughy          | <i>AutoEthnography: Rewriting the self and the social</i> .   | italicization   | italicization      | <i>AutoEthnography: Rewriting the self and the social</i> .   |
|  | 225  | Smith, D.E. 1989     | <i>Feminism and Sociological Theory</i> . London: Sage.   | cor   | cor                | <i>Feminism and Sociological Theory</i> . pp. 34-64. London: Sage.  |
|  | 225  | Smith, D.E. 1998     | <i>Writing the Social: Critique, Theory and Investigations</i> .  | italicization   | italicization      | <i>Writing the Social: Critique, Theory and Investigations</i> .  |
|  | 228  | Svanhøj              | <i>Tidshæft for Børns Forskning</i> 42.   | cor   | cor                | <i>Tidshæft for Børnsforskning</i> 42(3): 162-183.  |
|  | 229  | Thussell-Road        | in M. Weed (ed.), <i>Gender, Power and Subjectivity: Reflections on Research Relationships in the Field</i> . Basingstoke: Emerald. | cor   | cor                | in M.R.M. Weed (Ed.), <i>Gender identity and research relationships</i> . pp. 23-41. Basingstoke: Emerald Publishing. |
| * In the text, I have written Shierlaworth et al., 2010 while 2012 is correct. I would like to correct this at p. 41, 42, 43, 186, 262, 263, 272, 275 and 279  |      |                      |   |   |                    |   |
| * In the process of converting the document to pdf an error has occurred and caused some layout issues that I ask your permission to correct. First, the number 6 has fallen out of the chapter headings in the text. Second, some of the footnotes do not occur on the same page in which they are inserted. Third, between some of the references space is missing. Fourth, bookmarks are missing in article 3 |      |                      |   |   |                    |   |









## RESEARCH

# Non-disabled Ableism: An Autoethnography of Cultural Encounters between a Non-disabled Researcher and Disabled People in the Field

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This article describes situations where preconceptions about disabled people were made apparent in a non-disabled researcher's thoughts, words and actions in the course of fieldwork for a qualitative study into the lives of disabled young adults. The article uses these experiences as entry points to discovery and analysis of cultural ableism. It draws on critical theory and insights from the social model of disability and takes an autoethnographic approach to highlight the researcher's preconceptions and her process towards a more nuanced understanding of disability.

**Keywords:** Autoethnography; Ableism; Sexualities; the Social Model; Disabilities

## Introduction

The sun was shining and people in summer clothing were streaming in and out of the grocery shop. They were speaking to each other happily, some carrying shopping bags. A bus went by. Everything was normal. But, that was outside. That was before I entered the hospital. Inside, everything was quiet. I walked past many closed doors. Now and then a nurse hurried past me. Somewhere, something beeped. Hospital sounds. Hospital smells. I heard voices, and prepared for someone coming towards me. But when they rounded the corner, I was startled nonetheless. I think I stopped completely. I saw someone in a wheelchair, and most of all the strange contraption he had around his head. I had never seen anything like it. It was a gigantic helmet of some sort, and it looked as if metal spikes went straight into his skull. He hung limply in the chair. He drooled and mumbled. His eyelids quivered. I realised I was staring. I felt scared. Shaken, because it suddenly hit me that *this is how some people live. This can happen to a human being*. I did not know how to behave. I tried to pull myself together. A woman was pushing the wheelchair, chatting gaily. She said my name. She smiled. She behaved like everything was normal. But it was not! She was wheeling around a man with spikes in his brain. His eyes were so empty that it looked like he was barely alive. Did he understand what was happening around him? Was it possible to speak to him? Was he in pain? My heart was racing and my palms were sweaty. Grief, confusion, uncertainty, anxiety, inadequacy: there was a barrage of emotions inside of me. 'Now it is important that I play along', I thought. 'Now it is important to pretend that everything is normal.'

The excerpt above describes my first moments of fieldwork for an ethnographic study into the daily lives of young adults who had experienced a major traffic accident. Until then, I had never worked with disability, neither practically nor theoretically. However, I had always cherished diversity, and the prospect of making a useful contribution to people who might be considered different from normative standards had motivated my choice of research area. I identified with values that Norwegians tend to claim as their own, as members of what we collectively understand as 'an innocent, humane, tolerant, anti-racist and peace-loving society that is committed to helping the needy' (Gullestad 2005, 43 in Mainsah and Prøitz 2015, 176). This rather self-satisfied perception was to be challenged in the course of fieldwork, and – as the excerpt above illustrates – the challenges started right at the outset. I was startled to find myself struggling with emotional distress as I faced the very first unusual person I was to interact with in the field, and there was plenty more in store for me. At the hospital, many social conventions, i.e., the understandings that are collectively taken for granted and that inform people's behaviour (Eriksen 2010, 49–50), were unknown to me. I felt inadequate and anxious because my cultural background had not provided me with the range of resources I needed to handle encounters with disabled bodies.

Hastrup (1992) has beautifully described anthropologists' discovery of cultural differences in the field as anthropological 'astonishment'. Among the things that astonished me in this fieldwork was that so much of what I knew about disability were unquestioned cultural assumptions that exposed me as an ableist. Here, I take the concept of 'ableism' to mean the unintentional discrimination of disabled people through 'a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human' (Campbell 2009, 5). How I was caught up in such an ableistic network became apparent in many of the questions I asked and several of the choices I made during fieldwork. However, experiences from encounters with study participants – in the form of conversations, confrontations and corrections – compelled a self-reflective process that made me aware of (at least some of) my prejudices. As I came to acknowledge my biases, I started to use them as analytic turning points.

The goal of this article is to discuss subtle forms of cultural ableism from my position as a non-disabled representative of the majority society. I am looking to trace both my own cultural ignorance about disability and the processes of reorientation and maturation that occurred as my preconceptions were challenged.

## Methods

### *Context and empirical data*

This article analyses conversations and interactions that occurred between the study participants and myself in a qualitative study focusing on young adults who had sustained serious injuries in a traffic accident in which they had been drivers of a motor vehicle. The overall aim of the study was to explore how young adults may experience their everyday lives after such an occurrence, including their experiences of rehabilitation, their approaches to motor vehicle driving, and their experiences of un/employment. There were 14 study participants, 12 men and 2 women, between 20 and 36 years of age. Their accidents had taken place between 2 and 15 years before the fieldwork for this study started. Most had been diagnosed with either moderate traumatic brain injury (TBI:  $n = 8$ ), spinal cord injury (SCI:  $n = 3$ ) and/or severe trauma affecting the face, legs, back, neck and/or hips ( $n = 6$ ).

In this study, we used semi-structured interviews and participant observation. I interviewed most participants two times or more, and joined a subset of them in a range of everyday life situations. In line with an anthropological approach, I engaged with the study participants not only as a distant researcher, but to a large degree as myself (Fangen 2011). For example, the study participants and I sometimes met at home (theirs or mine), took strolls together, or went out for dinner together. The purpose of participant observation is to get to know people and gain access to their realities through shared experiences. Personal interaction might promote better or different understandings and interpretations of what is going on in the field than other qualitative data. For instance, the researcher might get a fuller picture of people and their lives than she would have gotten if she had only conducted interviews (*ibid*).

Empirical material consisting of field notes, interview transcripts and diary entries has been produced from the start of the project in January 2013 until today. For this article, I reviewed texts I had written after what I had perceived as particularly significant fieldwork experiences in the sense that they had prompted reflection and insight in an especially effective manner. They were thus akin to what Trigger, Forsey and Meurk (2012) characterise as 'revelatory moments': intense, unplanned episodes in the field that often involve feelings of discomfort and surprise, and that give the researcher new insight. What the revelatory moments discussed here have in common is that they effectively threw light on the ways in which I, the researcher, was trapped in an epistemic framework that draws on clearly ableist assumptions.

Rather unfortunately, I did not discuss the discovery of my ableism with the study participants during fieldwork. On the contrary, I often felt so embarrassed to find myself struggling with the social 'performance' (Goffman 1990 [1959]) of smooth interaction with the Other that I sought to hide my immediate thoughts and feelings in an attempt to minimise the exposure of my prejudices. I did, however, discuss these experiences at length with the co-authors.

### *The authors*

As is always the case, the background and experiences of the authors helped to shape the text and the analysis it mediates. I will therefore give a brief presentation of the three of us. Among the things we have in common is that we speak from positions of considerable privilege. We are all relatively non-disabled persons, born and brought up in an affluent society. We share rather similar socio-political values and tend to emphasise the importance of diversity, inclusion and social justice, both in our work and in our lives. At the same time, we have differences, for instance in terms of age, gender and a range of work and life experiences.

The first author, Rannveig, who carried out the fieldwork for this study, is the person the first-person narrative voice refers to in this text. I am 35 years of age and have often found myself in opposition to normative ideals and in sympathy with people that tend to be considered as 'different'. This might be because I often perceive of myself as somewhat 'different', too. For example, I am bisexual and voluntarily childfree, and I often draw on my experience of otherness both in my personal life and in my research as a social anthropologist.

The second author, Grace, is 63 years of age. She has worked with chronically ill and disabled people for decades, variously as a home-care nurse, a municipal health manager, and a leader and researcher in a rehabilitation hospital. Her academic work draws extensively on insights from cultural studies, critical theory and social anthropology.

The third author, Kåre, is 53 years of age. He is a trained physician with additional degrees in community medicine, public health and social anthropology. His current research focuses primarily on populations that tend to be marginalised in preventative and curative health care, including same-sex attracted men in the African HIV epidemic and immigrant women in European cancer screening and prevention. Kåre does not have specific previous experience in the field of disability research.

Throughout the study period, the three of us have constituted a small 'epistemic community' (Haas 1992, in Moen and Middelthon 2015): a team of co-producers of knowledge who have collaborated closely on the planning and execution of fieldwork, data analysis and writing. All of us have contributed to the ongoing exploration of and reflection on the data, and in bringing the empirical material into dialogue with theoretical work. Recurrent themes in our discussions have been how (dis)ability might be understood from different theoretical angles, why non-disabled people apparently know so little about disability, and how ableism is culturally constituted. In the work on this article, the deliberations in the research team have played an important role in creating analytic distance, since the empirical material is so closely tied up with the personal experiences of one of us.

### **Theoretical approaches**

I use autoethnography, a reflection-based approach that thus far has not been very widely used in disability research. I will therefore present a short review of what autoethnography entails and what it can contribute to the field of disability studies.

Autoethnography is a method, process and product (Ellis, Adams and Bochner 2011) that emerged in the 1980s as academics challenged ideas about truth, objectivity and fact in research. An autoethnographic approach recognises that research cannot escape being influenced by the researchers by whom it is carried out (Ellis, Adams and Bochner 2011). Rather than attempting to hide this fact, autoethnography embraces it. Texts are usually written in first person, they put the scientist's self on the line, and they try to enter culture through thick descriptions (Plummer 2009). In autoethnography, data may include thoughts, feelings and actions, for example, as they emerge under or after conversations or other social interaction with others. The researcher seeks to 'use personal experience to illustrate facets of cultural experience, and, in so doing, make characteristics of a culture familiar for insiders and outsiders' (Ellis, Adams and Bochner 2011). Many autoethnographies are both political and critical and may 'provide a resistance to dominant cultures and dominant voices and narratives' (Plummer 2009, 268).

I write within the anthropological tradition, in which autoethnography has been referred to as 'autobiographical (i.e., confessional) ethnography – texts in which trained observers explicitly address and analyse their personal relations with the natives they are writing about' (Couser 2005, 126). I place myself within 'disability autoethnography', a narrow but independent strand within health studies.

Disabled persons' own range of perspectives on disabilities have not been adequately addressed in academia, and a valuable aspect of disability autoethnography is that it has contributed to a greater representativeness in academic knowledge production. It has also been used as a tool to analyse complex relations of power, such as in Rogers (2009) discussion of sexual surveillance and control. From the position of the mother of a sexually experimenting teenage daughter with learning disabilities, she questions if one has the right, or the obligation, to interfere in the sexual expressions of another human being. Furthermore, disability autoethnography may be an entry point to discover new practices and critique hegemonic discourses. For example, Hendriks (2012) used an autoethnographic approach to explore how professional clowns could use their bodies to communicate with persons with advanced dementia. Fürst (2015)<sup>1</sup> – writing from the position of a patient's wife – showed how the insight of next-of-kin may be given little weight in a biomedical context. These original and insightful academic contributions are examples of knowledge and ways of knowing that, without autoethnography, might not have been brought to the fore because they were produced in ways that do not easily fit with traditional templates for knowledge production.

In addition to its autoethnographic orientation, this article draws on critical theory in its discussion of non-disabled ableism, not least the insight provided in 'the social model' of disability. The Western discourse on disabled people had been dominated for a long time by what is now referred to as 'the biomedical model' when Oliver (1983) theorised these concepts. In the biomedical model, disability is understood primarily as pathology that yields impairment in individual bodies. Consequently, disabilities are first and foremost health problems in need of medical attention, and disabled persons are measured against cultural ideas of normality. The ideal trajectory for a disabled person is, in turn, one that will render her 'cured, treated, trained and changed' (Barnes 2003, 9–10). In the social model, disability is socially created instead of being located as a problem in the body itself (Oliver 2013). Here, disability is the consequence of the gap between individual functioning and society's facilitation. For instance, 'an inability to speak is an impairment but an inability to communicate because appropriate technical aids are not made available is a disability' (Morris 1993, ix in Barnes 2003, 14). Hence, disability may be seen as a manifestation of discrimination that might be treated with equal rights and social justice.

<sup>1</sup> Fürst does not explicitly position herself as an autoethnographer, but the article has many autoethnographic characteristics.



### ***Concepts and the risk of exotification***

Let me point out that I find it somewhat challenging to write about encounters with disabled bodies from the position of a non-disabled body. Firstly, this entails a risk of cementing the same discourses of norms and deviance that I aim to critique, because it may easily reproduce the dualistic imaginary in which certain types of bodies are deviant while other are normative. When I choose to describe myself as non-disabled, rather than able-bodied, the aim is to avoid reproducing a non-disabled starting point as norm. I must emphasise, however, that it is still a matter of utterly simplified categorisation when I refer to myself as non-disabled and to study participants as disabled. Both the participants and I have unique functional abilities, histories of injury, and experiences of living in our bodies. The way I use these concepts, therefore, is both imperfect and problematic, and must be understood as a form of 'strategic essentialism' (Petersen 1998, 28) through which the researcher with critical awareness refers to what is understood as a group-level essence in order to enable theorisation. A body as a being in the world is not reducible in the same manner. Disabled persons, just as non-disabled persons, are clearly not a uniform group of people who share the same experiences of disability (Couser 2005; Lid 2013). Moreover, disabilities are diverse and make up a complex field consisting of different groups, identities and struggles for political, economic and social rights (Solvang 2000). For example, diagnostic criteria are continuously being negotiated (Bowker and Star 2000), and the same individuals may have status as non-disabled and disabled in different periods of their lives (Lid 2013). Some theorists rely on a more radical understanding of disability that considers everyone (or a majority) of the population as impaired, highlighting the body's general capacity for illness, exhaustion, ageing and dysfunction (Shakespeare 2014, 51).

Secondly, there is a risk of reproducing a pattern in which disabled people are yet again exotified through a non-disabled gaze, or even a 'non-disabled stare' (Garland-Thomson 2009). Disabled people have been marginalised, objectified and at times colonised (Goffman 1990 [1963]; Stiker 1997), and it is important to maintain critical awareness of this history as part of the effort to avoid reproducing such ideas and practices. In this article, my non-disabled gaze is still a non-disabled gaze, but I hope that it may work to significantly challenge rather than to reproduce exotification when the vantage point is one of conscious self-reflection that takes a critical perspective on normative ideas. Through confrontations with disabled bodies, the gaze may be thrown back towards the non-disabled body, which is revealed as complicit in the production of ableism and thus loses its upper hand. In this way, the non-disabled gaze may take on a different function, as an analytic tool that can help provide access to cultural assumptions, understandings, norms and unspoken scripts that shape society's takes on disabilities. This kind of self-critical gaze will hopefully contribute to discussions of ableism that may encourage so-called non-disabled people to reflect on their own relationship to disability (Campbell 2009; Ellis 2010) and contribute to nuances and knowledge of potential benefit in the field of disability studies.

### ***From individual to society***

I seek to say something about the general, that is, trends at the collective level, by using the particular as a starting point. I do not in any way claim to capture the only perspective,<sup>2</sup> and it is of course not possible to generalise data in qualitative research in the same manner as in quantitative research (e.g., Moen and Middelthon 2015). Though I cannot rule out the possibility that some of my reactions and experiences may be particular to me, I primarily understand them as formed and mediated by ideas and trends in the cultural contexts I am part of. Like Geertz, I understand cultural context here as 'a system of inherited conceptions expressed in symbolic forms by means of which men communicate, perpetuate, and develop their knowledge about and their attitudes toward life' (Geertz 1993, 89). Turning the gaze from the individual to the collective is key to understanding ableism. Doing so enables the capturing of complexities that are overlooked when ableism is only interpreted as prejudices at the individual level. Like racism (Blumer 1958), ableism is to a large extent about group-based positioning since

'the sense of group position is the very heart of the relation of the dominant to the subordinate group. It supplies the dominant group with its framework of perception, its standard of judgment, its patterns of sensitivity, and its emotional proclivities' (Blumer 1958, 4).

What follows is based on this very understanding of ableism. While it is unpacked from the standpoint of the researcher as an individual, that individual is understood to be part of and draw on discursively produced understandings of both disabled and non-disabled bodies. While this may not render my own prejudices any 'better' or less alarming, it clearly expands the scope of the critical analysis.

<sup>2</sup> For example, it has been shown that disabled people are subject to verbal harassment (Ahlvik-Harju 2016) and staring (Garland-Thomson 2009) by non-disabled people. My contribution is not meant as a counterpoint to this, but as a supplement to the ongoing academic debate about the different expressions of ableism by non-disabled people.

## Findings

During fieldwork, I had several experiences that revealed ignorance about disabilities and a propensity to generalise about disabled people based on rather unconscious preconceptions informed by the biomedical model of disability. In the following, I present this discovery and my process towards a more nuanced understanding.

### *Stumbling over wheelchairs*

In my interaction with the study participants, I had several awkward encounters with wheelchairs. The first revelatory wheelchair moment occurred early on in fieldwork, when for the first time I was to have a study-related conversation with a person using a wheelchair, Åge.<sup>3</sup> I had been in touch with him on the phone to schedule the interview, and I knew that he was paralysed. When I stood outside his door and knocked, my heart was racing. This was not so much because I was going to do an interview as I had done that before, but because I was going to interview a paralysed person and was not sure how to behave in this unfamiliar situation. According to my field diary, our encounter started like this:

I heard him call 'come in' and opened the door. I entered a room with no furniture other than a bed and two wheelchairs. A manual wheelchair was parked next to the bed, and a large, motorised wheelchair stood along one wall. Åge was lying in the bed and was looking at me while I – with a growing sense of confusion – pondered whether and where to sit down. There were no chairs in the room! Should I get one? Or wait until he explained where I could find one? Or sit down on the edge of his bed? I waited for him to help me, tell me what to do, when he calmly said: 'Do you not want to sit down?' and made a gesture with his hand. Had I understood him right – that he gestured towards the wheelchair next to the bed? He could not mean that I was to sit there? This turn of events was both surprising and uncomfortable. I felt resistance towards sitting in the wheelchair. I was not sick. There was nothing wrong with me. Uncertainly, I walked towards the wheelchair and gripped its back. I tried to turn it towards me, but it would not move. 'It is the brakes', he said. I think I smiled and said 'oh, ok'. I hoped my voice sounded calmer than I felt. I leaned down and started to mess with the brakes. It did not go well. Bright red and despairing, I pushed and pulled on buttons and levers. Something finally happened, a click could be heard as the brakes were released. I moved the chair a bit back and forth and finally sat down in it. It was awkward. I felt small and uncomfortable, but I smiled at him and pretended that I felt like I had a handle on the situation. He nodded back. I conducted the interview, but did not for one second forget that I was sitting in a wheelchair.

In retrospect, when reflecting on what happened in this situation, it is obvious that I oriented myself in the room from a distinctly non-disabled perspective. I had seen a room entirely without chairs. My preconceptions were made apparent in the encounter with someone who oriented himself based on a different understanding. To Åge, this was a room with two chairs. This was just as obvious to him as it was to me that the room did not have any chairs at all. Åge's gentle gesture towards the wheelchair filled the social situation with this basic insight. At the same time, it both revealed a cultural difference between us and made his understanding of the wheelchair accessible to me. Before his intervention, I had not seen the chair in the wheelchair because wheelchairs were something *other* than chairs to me.

Another significant difference in the way Åge and I saw the wheelchair also emerged in this situation. His vision was richer than mine because where I first and foremost saw what the wheelchair could *not* be used for, Åge saw what it *could* also be used for, namely to sit in. For anyone. I did not associate wheelchairs with their use but with a group of users: a clearly delimited 'them'. I also associated wheelchairs with being 'sick' or having something 'wrong with you'. With anthropological astonishment, I had to acknowledge that these were not characteristics I primarily associated with wheelchairs, but with disabled people, and that these were characteristics I was distancing myself from when I considered wheelchairs as objects I should and could not use.

As my fieldwork continued, my limited view of wheelchairs and wheelchair users continued to be challenged and developed on several other occasions, including in this situation when I met with Hans-Egil:

He sat in a wheelchair and waited for me when I stepped off the bus. He lived some distance from the bus stop, and we headed towards his place together. Or, not quite together – that was not really how it happened. He sped ahead in his wheelchair, and I followed as best as I could. It felt strange, because I have always thought of wheelchairs as a disadvantage. Exhausting, slow, and difficult to manoeuvre, rendering places cumbersome to get to. That is how I had imagined it. Instead, now I was suddenly taking up the rear. Hans-Egil outmanoeuvred the red light and sped across the pedestrian crossing, while I was left on the other side. He had to wait for me several times. Most of the time, he was many metres in front of me. I was jogging along, trying not to lose sight of him. Unlike Hans-Egil, I was sweaty and out of breath when we finally rounded the corner to the building where he lived. Phew. I wish I had a wheelchair.

<sup>3</sup> Åge is a pseudonym, as are all names used on study participants in this article.

In the example above, my immediate assumptions about wheelchairs were shaped by culturally prevalent ideas that represent wheelchair users as being only at a disadvantage. Instead, I found that Hans-Egil unquestionably had the more convenient form of transport for the situation, and that he was quick, strong and mobile. With anthropological astonishment, I realised how I had not attributed such characteristics to him, at least not there and then. On the contrary, I had stereotypically reduced him and his window of opportunity to act in the world in line with a pathology-focused biomedical framing of disability. Hence, I had pictured Hans-Egil as sick and lacking in strength.

Two insights emerged from this revelatory moment: first, I came to realise that there are other ways of handling disability than I had access to in my cultural repertoire. Here, this was demonstrated when Hans-Egil operated the wheelchair in a manner I had not predicted. Secondly, I realised how an ableist worldview might make wheelchair users disabled – rather than their bodies or their wheelchairs. The insights of the social model were demonstrated for me as I witnessed Hans-Egil's skilled handling of his wheelchair. Here, the wheelchair user created and experienced a highly favourable interaction between body and terrain. At the same time as Hans-Egil became non-disabled, I emerged as disabled, for I had lagged behind, sweaty and out of breath.

### ***Colliding with sexualities***

Recent research demonstrates that disabled people encounter significant prejudice related to their sexuality (Rogers 2009; Kim 2011; Grønningsæter and Haualand 2012; Sparkes, Brighton and Ingle 2014). For example, disabled people are often assumed to be asexual by staff in health and social service organisations (Grønningsæter and Haualand 2012). With anthropological astonishment, I discovered that I was drawing on similar cultural notions. I will illustrate this with an excerpt from the field notes I wrote after a conversation with Jonas. He had both cognitive and physical injuries.

I talked with Jonas on the phone today and was taken aback when he said he had been separated [from his wife] since we last spoke. It had seemed like he and his wife were doing so well. I was even more surprised when he told me why. He had 'had dessert somewhere other than at home', he explained. It was not the first time he had been unfaithful, but now his wife had had enough. This really hit me, because I must admit that it had simply not occurred to me that this man, who had sustained such major injuries, had a sex life. And it certainly had not occurred to me that he was having sex with women behind his wife's back. How on earth could I have assumed that he was not having sex? The feeling I got during this telephone conversation reminded me of the embarrassing situation I experienced on another occasion when I heard myself saying to Jonas that he was lucky to have married. The look his wife gave me made me realise what I had said. She patiently went on to explain to me that many people with traffic injuries are married. She had a friend with a traffic injury who was a great charmer, she said. He could have whoever he wanted. I remember how utterly foolish I felt. I got defensive right away and tried to cover up my mistake. Said of course I didn't mean it like that, so sorry.

Stereotypical expectations about the sexuality of a disabled person emerge in the excerpt above. I was surprised that Jonas was unfaithful. Unfaithfulness – and actually even a sex life in the first place – was a capacity I did not immediately attribute to a person with 'such major injuries'. My presumptions were clearly reflective of a pathologising view of disability. Also, it echoed the hegemonic, cultural idea that sex is a privilege that belongs to non-disabled, normatively attractive bodies. The wide circulation of notions like these creates barriers for the bodily and sexual expressions of disabled people, in part because exclusionary sexual ideals are imposed on them, and in part because their own entanglement in the same cultural imaginary renders disabled persons themselves at risk of accepting and reproducing those very norms (Sparkes, Brighton and Ingle 2014). Conversely, moving away from ideals that exclude give room for a re-articulation of pleasure (ibid).

During fieldwork, the barriers of sexual exclusion, and the potential of a re-articulation of pleasure, was illustrated for me during a conversation between myself and a study participant with a spinal cord injury. An excerpt from the field diary illustrates how ableism was made apparent, and confronted, in one of our conversations:

I asked Håkon how he felt about not being able to have sex any more. He was quiet for a while. Then he said: 'So ... what is sex?' This simple question overwhelmed me, and for good reasons. It revealed how I had automatically invoked the idea that sex equals penetration. I had basically assumed that he did not have sex because he was paralysed and could not get an erection. In that moment, I realised what an incredibly limited view I had produced of him moments earlier. And of sex. How embarrassing! He said he would open up to me about this topic even though it was a sensitive issue for him, because it is so important that it comes out. He has good sex. He gets pleasure from the visual. Lying near another body is just as pleasurable for him as it was before. He can get an erection when he uses vibrators. He can ejaculate. He does not feel orgasms as before, but he feels desire, pleasure and satisfaction. He said it might well be that he has a better sex life than someone without functional impairments, even though he is paralysed.

In this conversation with Håkon, I realised with anthropological astonishment how I had unconsciously invoked a core aspect of a heteronormative<sup>4</sup> understanding of sex. Unconsciously, I had expected sex to mean penile-vaginal penetration. In such a conceptualisation of sexual practice, some men with spinal cord injuries are excluded from the possibility of a sex life as are lesbians, for example. The discovery that I had mobilised such a conservative and ignorant view of sex was surprising, given that I had been reading queer theory for years and had worked politically for the recognition of women's sexual agency. Queer theory is a theoretical approach that problematises heteronormativity and views sexuality as dynamic, fluid and culturally shaped. My sudden regression to a heteronormative, penetration-focused understanding of sex in my conversation with Håkon suggests that the cultural understanding that defines disabled people as outside of sex is so firmly entrenched that it can trump even a strong academic basis for knowing better.

When my surprising assumptions about sex – and disabled people – were revealed in the question I had asked Håkon, he patiently corrected them. He pointed out to me that sexual pleasure can be actively and creatively explored and enjoyed regardless of other functional abilities. What the social model of disability articulates is exactly this insight: whoever is sexually non-disabled depends on the interplay of bodies and terrain. In other words, it is not a given, but continuously negotiated. To free body and sexuality from narrow normative ideals allows transcendence of imposed limitations, and the discovery of new sexual practices (Sparkes, Brighton and Inle 2014).

### Conclusions

When I started fieldwork for this study, I was unwittingly enmeshed in a web of ableistic notions and non-disabled normative ideals. The cultural taken for grantedness of non-disabled privilege and superiority regularly came to the fore in my encounters with study participants. I saw them as people in a rehabilitation *process* where the ultimate goal was to strive for a return to the body and life they had had before their motor vehicle accidents. It is striking how it did not occur to me at the time that being in the world *with* a disabled body could also be a satisfactory possibility. Furthermore, I was leaning heavily on the culturally shared 'knowledge' that disabled bodies cannot be used as well as non-disabled bodies. For example, it did not immediately occur to me that a body in a wheelchair can function more effectively than a body not in one.

Clearly, my way of seeing disability was largely the result of a gaze through the pathology-focused lens so characteristic of the biomedical project. Far from being limited to the clinic, this lens has helped to shape the overall take on disabled bodies throughout the society in which I grew up. The point here is not that medicine has not been enormously important for the treatment of impairments, but that the biomedical way of knowing has come to dominate our overall take on disabilities and 'the disabled' (Stiker 1997). The understanding of 'them' as infirm sets them apart as different, subordinate and underprivileged (Goffman 1990 [1963]), and allows for the consequences that follows in terms of ableism.

In the field, I found again and again that my focus and my preconceptions were out of touch with the perspectives and experiences of the study participants. These situations were filled with bewildered astonishment and the unique kind of cultural insight which may occur when what is commonly taken for granted by 'us' is questioned through a different approach from 'them' (Hastrup 1992). Some of these moments were quite alarming to me because they revealed that my core values of equality were not always as present in my attitudes as I had thought and wished for them to be. Had it been up to willpower, I would not have been an ableist, but I was in the grip of something stronger than my volition, or rather: that did not provide me with the resources that were needed to break out of the ideational framework that boxed me into the biomedical model of disability.

It is remarkable that I did not have better access to the notions that have challenged, nuanced and critiqued the reliance on the biomedical lens in our ways of viewing disabilities. Various alternative articulations and framings have now been promoted by disability scholars for decades (see e.g., Oliver 1983; Moser 2005; Gibson 2014; Grue 2014). Nevertheless, alternatives are not culturally accessible to the point where they provide non-disabled people with the resources needed to encounter unusual bodies without drawing on ableistic conceptualisations. Hence, we must keep addressing cultural prejudices towards different bodies, and continue to explore and promote alternative ways of knowing to extend our imaginations.

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<sup>4</sup> Implicitly, this entails being based on a traditional and heterosexual worldview, which means that other alternatives are obscured (Grønning-sæter and Haualand 2012).

## Competing Interests

The authors have no competing interests to declare.

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