Women with Disabilities' Experiences of Gender-Based Violence in Cape Town, South Africa

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For Dad, who supported me in everything I do.

For Vyvyan, who supported me after Dad passed away.

For Helen, who continues to support me in everything I do.

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PREFACE

This doctoral thesis includes work presented in peer-reviewed publications as per general provision 6.7 in the General Rules for the Degree of Doctor of Philosophy (PhD) of the University of Cape Town. The Doctoral Degrees Board approved the submission of the thesis in this format on 17 September 2018.

The publications included in this thesis all relate directly to the thesis topic and contribute to answering the aims and objectives of the study.

The following publications are included in this thesis:

Aim / objective	**Chapter**	**Publication citation**
How to conduct ethical gender-based violence research with women with disabilities?	4	Van der Heijden, I., Harries, J., & Abrahams, N. (2018). Ethical considerations for disability-inclusive gender-based violence research: Reflections from a South African qualitative case study. *Journal of Global Health,* 1–13.
What are the nature and forms of violence against women with disabilities in South Africa?	5	Van der Heijden, I., Abrahams, N., & Harries, J. (2016). Additional layers of violence: Intersections of gender and disability in the violence experiences of women with physical disabilities in South Africa. *Journal of Interpersonal Violence,* 1–22.
How do disability stigma and sexuality influence women with disabilities' intimate partnerships?	6	Van der Heijden, I., Harries, J., & Abrahams, N. (2018). In pursuit of intimacy: Disability stigma, womanhood and intimate partnerships in South Africa. *Culture, Health & Sexuality.* 1-14.
What are the barriers to gender-based violence service provision?	7	Van der Heijden, I., Harries, J., & Abrahams, N. (under review). Barriers to gender-based violence services and support for women with disabilities in Cape Town, South Africa. Manuscript submitted for publication September 2018.

DECLARATION

By submitting this thesis electronically, I, Ingrid van der Heijden, hereby declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (or, in the case of multi-authored published papers and manuscripts prepared for publication, constitutes work for which I was the lead author) and that the reproduction and publication thereof by the University of Cape Town will not infringe on any third-party rights and that I have not previously, in its entirety or in part, submitted it for obtaining any qualification.

Ingrid Jeanne van der Heijden

Signed by candidate

20 June 2019

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I am a woman living with a congenital disability who has experienced both disability-based and gender-based violence. During the research project, my experiences of chronic pain, fatigue, depression, work pressures, personal grief and vicarious trauma were eased by friends, family, colleagues and therapists. I acknowledge them all.

I acknowledge the participants and gatekeepers who showed enthusiasm for the research and voluntarily shared their stories and participated in the study.

Throughout the process of working on this thesis I have had the opportunity to undertake and lead research on disability and gender-based violence under the supervision and mentorship of colleagues in the disability and gender-based-violence research fields – specifically under the supervision and mentorship of Professor Naeemah Abrahams, Professor Rachel Jewkes, and Dr Kristin Dunkle at the Gender and Health Research Unit (South African Medical Research Council). The funding and support of the South African Medical Research Council towards this research project is hereby acknowledged. Any opinions expressed and conclusions drawn in this thesis are those of the author and are not to be attributed to the organisation.

Supervision and mentorship from my supervisor at the University of Cape Town, Professor Jane Harries, was indelible to producing the final research project.

ABSTRACT

Background: Little is known about violence against women with disabilities in South Africa. Given that South Africa has a high prevalence of gender-based violence (GBV), especially intimate partner violence (IPV), there is a need to highlight the violence experiences of women with disabilities within their communities, intimate partnerships, and other settings.

Aims: The aim of the thesis was to investigate how South African women with disabilities experience GBV. In doing so, the study's objectives were to highlight the nature and forms of violence they experience, the social constructions of women with disabilities' intimate partner relationships, and the barriers and enablers to GBV support they may encounter.

Methods: This thesis takes the form of a qualitative research study that was conducted with 30 women with physical and sensory disabilities, and 19 disability and GBV service providers in Cape Town, South Africa. Repeat in-depth interviews and focus groups followed a narrative approach that was used to elicit participants' stories, perspectives and lived experiences. Thematic analysis was conducted on the data, and interpretation of the data used an intersectional framework, with an emphasis on social approaches to disability and resistance theories.

Findings: Published or submitted papers included in the thesis reveal how women with disabilities in South Africa may experience additional layers of GBV because of their disability status, and consider how gender inequality, disability stigma, and disability-specific forms of abuse shape participants' lives and experiences of violence (Paper 1). The thesis claims that, while women with disabilities are vulnerable to GBV, particularly IPV, some women have agency and are able to manage disability stigma and intimate partnerships to avoid acts of

violence (Paper 2). The thesis finds that, while women with disabilities do seek help after IPV and sexual violence, they encounter unique barriers to GBV service-provision. Service providers and women with disabilities acknowledge various limitations to providing inclusive and accessible services to women with disabilities who experience violence (Paper 3). The thesis also makes a series of recommendations for undertaking ethical GBV research with women with disabilities, and argues for the need to review current ethical guidelines to facilitate future disability-inclusive GBV research (Paper 4).

Conclusion: The thesis recommends that violence prevention efforts should address the role of disability stigma, facilitate economically empowering opportunities for women living with disabilities in the country, and provide a range of accessible mental health services and GBV care and support services to facilitate better intimate partnership outcomes. Strengthened pathways to violence prevention and post-violence care and support should be coordinated by both disability and GBV sectors. The thesis calls for population data to reveal the prevalence and adverse public-health outcomes of GBV against women with disabilities in South Africa and other low-middle income countries (LMICs). Future epidemiological research should include validated disability measures and measures of disability-specific forms of violence that may compound GBV. Understanding the magnitude of violence against women with disabilities is the first step in the public-health approach to GBV prevention and requires collaborative research and surveillance efforts.

LIST OF ABBREVIATIONS

CRPD	Convention on the Rights of Persons with Disabilities
DPO/s	disabled people's organisation/s
EDR	emancipatory disability research
HIV	human immunodeficiency virus
ICF	International Classification of Functioning (WHO)
IPV	intimate partner violence
GBV	gender-based violence
HMICs	high-middle income countries
LGBTQ	lesbian, gay, bisexual, transgender, and questioning (or queer).
LMICs	low-middle income countries
UN	United Nations
WHO	World Health Organisation

DEFINITIONS

Gender-based violence (GBV) includes the spectrum of gender inequality and psychological, physical, economic and sexual abuse experienced disproportionately by women and perpetrated predominantly by men: i.e. intimate partner violence (IPV), rape and sexual violence, child sexual abuse, stalking, commercial sexual exploitation, psychological violence, financial control or exploitation and harmful practices such as forced marriage and female genital mutilation.

Intimate partner violence (IPV) refers to behaviour by an intimate partner or ex-partner that causes physical, sexual, or psychological harm, including physical aggression, sexual coercion, psychological abuse and controlling behaviours such as isolating one's partner from friends and family, monitoring their movements, or restricting access to financial resources, employment, education, and health care.

Persons with disabilities are defined in the Convention of the Rights of Persons with Disabilities as those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Sexual violence is any sexual act, attempt to obtain a sexual act, or other act directed against a person's sexuality using coercion, by any person regardless of their relationship to the

victim, in any setting. It includes rape, which is defined as the physically forced or otherwise coerced penetration of the vulva or anus with a penis, other body part or object.

CHAPTER 1. INTRODUCTION, RATIONALE AND THESIS OVERVIEW

1.1 Introduction

There are limited studies and data concerning gender-based violence (GBV) against women with disabilities living in low-middle income countries (LMICs), and there are several gaps in the existing literature. There is some evidence from the global North that the maltreatment and abuse of women with disabilities far exceeds that of men with disabilities, and of women without disabilities (Platt et al., 2015; Krnjacki, Emerson, Llewellyn, & Kavanagh, 2016; Rich, 2014; Schröttle & Glammeier, 2013; Mitra, Mouradian, & Diamond, 2011). Yet very little is known about the violence experienced by women with disabilities in South Africa. Given that South Africa has some of the world's highest levels of GBV, particularly intimate partner violence (IPV) (Abrahams, Mathews, Jewkes, Martin, & Lombard, 2012; Seedat, Van Niekerk, Jewkes, Suffla, & Ratele, 2009; Krug, Mercy, Dahlberg, & Zwi, 2002), it is important to understand how and why women with disabilities living in the country may be at higher risk for violence, and what their GBV experiences may be.

1.1.1 Gender-based violence in South Africa

The evidence that violence and assault are regular features of women's lives in South Africa reflects the unequal gender relations between men and women in the country (Jewkes & Morrell, 2012). Be it at home, in the community, within institutions, or on the streets, a woman living in South Africa's Gauteng province has an approximately one-in-four chance of ever experiencing GBV (Machisa, Jewkes, Morna, & Rama, 2011). Interviews with men in the KwaZulu-Natal and Eastern Cape provinces reveal that nearly a third of South African men

disclose having raped a woman during the past year (Jewkes, Sikweyiya, Morrell, & Dunkle, 2009). Other findings from South Africa show that between 25% and 55% of women have experienced violence in the past year at the hands of their intimate partners (Jewkes et al., 2006; Dunkle et al., 2004; Jewkes, Penn-Kekana Levin, Ratsaka, & Schrieber, 2001). At the extreme end of the spectrum of IPV, a national study on femicide (men's killing of their intimate female partners) estimated that every eight hours in South Africa a woman is killed by her intimate partner – six times the global average (Abrahams et al., 2012).

Violence against women in South Africa is a public health issue as it causes physical injuries, co-morbid mental health conditions, and adverse sexual and reproductive health outcomes (Tsai, Tomlinson, Comulada, & Rotheram-Borus, 2016; Norman et al., 2010). In addition, injuries and other adverse outcomes from GBV can result in additional disabilities or exacerbate existing disabilities (Thomas, Joshi, Wittenberg, & McCloskey, 2008).

1.1.2 Global prevalence of violence against women with disabilities

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) definition of disability highlights the marginalisation and socio-economic disadvantage that people with disabilities experience (Krnjacki et al., 2016). All over the world, people with disabilities are excluded from schooling, public life, housing, employment and health services. Thus, disability is increasingly being viewed as a public health and human rights issue (WHO & World Bank, 2011).

However, women with disabilities face particularly high levels of marginalisation and disadvantage because of the double discrimination based on their disability *and* gender. Their status as a woman renders them vulnerable to GBV, including sexual abuse, neglect and IPV compared to men with disabilities (Mays, 2006; Abu Habib, 1995). The perceived

powerlessness of a woman with a disability and their perceived physical and economic dependency on perpetrators put them at further risk of violence within the home and their community (Oktay & Tompkins, 2004). Stereotypes of women with disabilities as "non-sexual" can also contribute to their increased risk to GBV (Plummer & Findley, 2012). Added to these risk factors are physical and communication barriers that prevent the disclosure and reporting of abuse, putting these women in even further jeopardy (Swedlund & Nosek, 2006; Chang et al., 2003; Anderson & Kitchin, 2000; Nosek et al., 1995).

Prevalence research in HMICs has established that women with disabilities experience increased violence compared to women without disabilities and to men with and without disabilities. Various studies show that intimate partners are the most common perpetrators of violence against women with disabilities, and illustrate that women with a broad spectrum of disabilities have a greater chance of experiencing IPV than women without disabilities (Scherer, Snyder & Fisher, 2016; Ballan et al., 2014; Hahn, et al., 2014; Rich, 2014; Schröttle & Glammeier, 2013; Anderson & Leigh, 2011; Barrett, O'Day, Roche, & Carlson, 2009; Armour, 2008; Barranti & Yuen, 2008; Smith, 2008; Brownridge, 2006).

A systematic review published in the Lancet found that adults with severe intellectual and mental health disabilities living in the United States are at the highest risk for violence (Hughes et al., 2012). While the review neglected to disaggregate the findings by gender, other international studies show that women with disabilities, when compared with women without disabilities, experience more violence by a wider range of perpetrators (Plummer & Findley, 2012; Martin et al., 2006).

In Canada, a national cross-sectional survey found that heterosexual women with various disabilities were two to three times more likely to report IPV when compared with women without disabilities five years prior to the survey. The findings revealed that women

with disabilities were more often subject to severe forms of physical IPV, including being kicked, punched, or bitten (Brownridge, 2006).

Evidence from the United States reveals that women who experienced some form of abuse in their current relationship were more than two times more likely to also have a disability associated with chronic pain or mental health than women not reporting IPV (Coker, Smith, & Fadden, 2005). Using data from a 2006 Behavioural Risk Factor Surveillance System survey, Armour (2008) found that 37% of women with disabilities reported experiencing emotional, physical, or sexual abuse by an intimate partner, compared with 21% of women without disabilities. Schröttle and Glammeier (2013) found that 25%–45% of women with disabilities had experienced IPV, which is two to five times the rate for women in the general population. Amongst students attending high school or college in the United States, females with diverse disabilities were approximately twice as likely than their male counterparts and non-disabled peers to experience IPV (Scherer et al., 2016; Anderson & Leigh, 2011). Using a nationally representative sample, a study by Hahn et al. (2014) confirms that women with physical and mental disabilities were at increased risk of IPV than those without disabilities and those who were men. However, the authors reaffirm the vulnerabilities of adults with intellectual and mental health impairments, regardless of gender; men with mental disabilities were reported at higher risk of IPV than men without disabilities (Scherer et al., 2016; Hahn et al., 2014; Anderson & Leigh, 2011). Contrary evidence from a cross-sectional survey in the United States shows that, while women with diverse developmental impairments were at higher risk than men with similar disabilities, the minority of perpetrators were intimate partners (Platt et al., 2015).

The argument that intimate partners are the overall main perpetrators of GBV against women with disabilities is yet to be solidified In LMICs. In Cambodia, for example, other

household members contributed to violence against women with disabilities. Astbury and Walji (2014) found Cambodian women with disabilities had significantly higher rates of all types of household violence compared with non-disabled women. Lifetime prevalence for physical violence by a household member was 25.4% for women with disabilities compared with 11.4% for non-disabled women. Puri, Misra and Hawkes (2015) conducted a cross-sectional survey in Nepal of 475 women with disabilities and showed that 57.7% of women with disabilities experience violence from immediate family or local community members during their lifetime, including emotional violence (55.2%); physical violence (34%); and sexual violence (21.5%).

In some LMICs, the emerging evidence of violence against women with disabilities compared to women without disabilities shows increased odds for IPV – approximately two to four times higher for women reporting disability (Dunkle, Van der Heijden, Stern, Chirwa, 2018). In evaluations of global programmes to address violence against women and girls with disabilities, over one-third of women across 15 LMICs reported experiencing physical and sexual IPV in the past year at baseline, and over 40% reported experiencing emotional IPV in the year prior. Risk for IPV increased with severity of disability reported (Dunkle et al., 2018).

One limitation of the existing evidence is that many population-based studies do not disaggregate by or mention the types of disabilities included in their samples. Other limitations are the inconsistent use of disability measures in population-based studies, inconsistent reporting of types of disability (using various terms), and an absence of data from diverse samples of women, i.e., women of colour and women living in LMICs like South Africa.

1.1.3 Disability in South Africa

The prevalence and nature of disability in South Africa are difficult to establish due to inconsistent definitions and measurements of disability in census surveys (Heap, Lorenzo, & Thomas, 2009). Census data from 2011 found that more than 7.5% of the South African population have a disability (Statistics South Africa, 2014), while a National Income Dynamics Survey conducted in 2008 revealed that 18% of the population are living with some form of disability (Moodley & Ross, 2015).

A history of apartheid segregation by race means that most of the South African population live in impoverished environments, increasing the risk of disability and chronic illnesses, and exacerbating existing disability (Emmett, 2006). Education, employment, and income outcomes for people with disabilities from a South African national survey show how intersections of poverty, gender and race have compounding effects on disability, due to processes of marginalisation and disadvantage arising from all identities (Emmett & Alant, 2006). Over two-thirds of the disabled population in South Africa is made up of black African women[1], and they are more likely than men and women without disabilities to have adverse socio-economic outcomes (Moodley & Graham, 2015; Moodley & Ross, 2015). Extreme racial inequalities in the distribution of income in South Africa are compounded by gender inequality, which means disabled women in general live in poverty, with black African disabled women needing the most economic empowerment and access to basic services (Moodley & Graham, 2015; Jelsma et al., 2008; Loeb et al., 2008; Emmett, 2006).

[1] In the thesis, the term “black” is used for people of colour in general, and “black African” to distinguish between “African” and “coloured”, which are the two largest communities in Cape Town. Socio-economic conditions and discourses in South Africa are still largely shaped by the legacy of apartheid laws that divided the population into four racial categories – white, black (African), coloured (diversely mixed ethnicity) and Asian.

Furthermore, there is a small amount of evidence that women with disabilities in South Africa have fewer options available to them for accessing HIV- and sexual-and-reproductive health care services (Kritzinger, Schneider, Swartz & Braathen, 2014; Eide et al., 2011; Rohleder, 2010; Mgwili & Watermeyer, 2006; Philander & Swartz, 2006) and post-violence support (Meer & Combrink, 2017, 2015) – potentially increasing their risk for violence and disability.

1.2 Rationale

Women with disabilities remain a neglected group in South African GBV research, and we do not know how similar or different their experiences may be to their non-disabled counterparts – meaning their rights to safety, violence prevention, and justice are unrealised. Assuming women with disabilities experience just as much (if not more) GBV than their non-disabled counterparts, this thesis recognises that women with disabilities in South Africa have experiences of violence to share.

Because they have largely been left out, to include women with disabilities in GBV research requires a lot more effort and additional ethical considerations. To date, studies on GBV and disability in other LMICs do not acknowledge the sensitive nature of GBV research overall, nor how women with disabilities living in LMICs may require disability-specific strategies and additional resources to protect them and ensure their equal participation in GBV research. If efforts to include women with disabilities in GBV studies are not approached with care and adaptations made for participants, the assurance of quality and robust evidence of prevalence and violence experiences of all women in the country cannot be reached.

Building on existing global and South African studies on GBV and disability, and taking into account the need for inclusivity in GBV research, the thesis aims to contribute to existing

qualitative data about women with disabilities' experiences of GBV and what is needed to protect them. Qualitative exploratory data will place value on the lived GBV experiences of women with disabilities, and highlight in a multi-dimensional manner why and how they are vulnerable to violence in their everyday lives. An intersectional lens will help explore how poverty, gender and disability intersect to render women with disabilities more likely to be victims of violence than their non-disabled and male counterparts (Cramer, Choi & Ross, 2017; Meer & Combrinck, 2017, 2015; Moodley & Graham, 2015; Coleman-Fountain & McLaughlin, 2013; Wickenden, Nixon & Yoshida, 2013; Shaw, Chan & McMahon, 2012; Hague, Thiara, & Mullender, 2010; Pal, 2011; Winker & Degele, 2011).

While the small and qualitative nature of the study cannot help to fill the gap in prevalence data on GBV against women with disabilities, the findings can contribute to existing data and may inform more inclusive GBV research, services and prevention efforts and responses in the country.

1.3 Research aim and objectives

The aim of this thesis is to generate qualitative evidence (presented in the form of journal articles) and highlight the experiences of GBV by women living with disabilities in South Africa. The objectives are:

1. to describe the nature and forms of violence women with disabilities experience in South Africa;

   Chapter 5 (published journal article): Van der Heijden, I., Abrahams, N. & Harries, J. (2016). Additional layers of violence: Intersections of gender and disability in the violence experiences of women with physical disabilities in South Africa. *Journal of Interpersonal Violence*, 1–22.

2. to describe participants' experiences of intimate partnerships in lieu of identifying how they may be at risk of intimate partner violence;

   Chapter 6 (published journal article): Van der Heijden, I., Harries, J. & Abrahams, N. (2018). In pursuit of intimacy: Disability stigma, womanhood and intimate partnerships in South Africa. *Culture, Health & Sexuality,* 1–14.

3. to explore the disability-inclusivity of GBV services, and what an appropriate response should be;

   Chapter 7 (under review): Van der Heijden, I., Harries, J. & Abrahams, N. (2018) Barriers to gender-based violence services and support for women with disabilities in Cape Town, South Africa. Manuscript submitted for publication.

4. to consider how to promote ethically safe GBV research with women with disabilities;

   Chapter 4 (published journal article): Van der Heijden, I, Harries, J. & Abrahams, N. (2018). Ethical considerations for disability-inclusive gender-based violence research: Reflections from a South African qualitative case study. *Global Public Health,* 1-7.

5. to discuss the implications of the findings and provide recommendations to prevent and respond to violence against women with disabilities in South Africa (**Chapter 8**).

These objectives are presented together and emerge through the chapters and published qualitative papers included in this thesis.

1.4 Thesis overview

Chapter 1 Background, objectives, and thesis overview

Chapter One gives an introduction, rationale, the aims and objectives, and an overview of the thesis.

Chapter 2 Literature and conceptual framework

By presenting both international and local literature on the intersections between disability, gender and violence, Chapter Two lays out the relevant evidence and theory required for exploring the experiences of GBV for women with disabilities. The chapter states that disability is academically and socially constructed. The ways in which disability is understood in academic and scientific theoretical frameworks is different than the ways it may be defined and experienced in other contexts. Firstly, the complexity of disability and the various models that espouse its complexity is presented. Secondly, the problem of violence against women with disabilities is revealed, exploring risk factors and prevalence of violence against women with disabilities, as well as the adverse health consequences of GBV, and pathways to GBV care and service provision. Thirdly, the context of disability, poverty and GBV in South Africa is discussed and various theoretical options for understanding and conceptualising violence against disabled women in South Africa are debated.

Chapter 3 Methodology

Chapter Three comprises an account of the research processes used to answer the research question. It justifies the use of a qualitative approach to the study and shows how narrative inquiry is appropriate for eliciting participants' stories of GBV. A detailed description of the way in which data were collected, managed and analysed is provided. The chapter also describes the sensitive way in which participants were accessed and interviewed, and this leads into the findings, which are presented over four chapters.

Chapter 4 Ethical considerations for disability-inclusive gender-based violence research: Reflections from a South African qualitative case study

Women with disabilities experience heightened and unique forms of violence compared to men with disabilities, and women without disabilities. “Unique” refers to the additional forms of violence that may be specific to these women because of their disability status. However, there is a lack of formalised guidelines for their inclusion in GBV research. Chapter Four, which is also a published journal article, draws on the existing gaps in international ethical guidelines for researching violence against women to advocate for the inclusion, safety and well-being of women with disabilities in future GBV research. It argues that concepts of reasonable accommodation, accessibility, and equal participation should be integrated into existing ethics guidelines and inform the planning and conducting of ethical and inclusive GBV research.

Chapter 5 Additional layers of violence: The intersections of gender and disability in the violence experiences of women with physical disabilities in South Africa

Chapter Five, which is also a published journal article, explores how gender and disability intersect in South African women’s experiences of violence, reveals that women with disabilities are exposed to various forms and additional layers of violence, and considers how their impairments may shape their violence experiences.

Chapter 6 In pursuit of intimacy: Disability stigma, womanhood and intimate partnerships in South Africa

Chapter Six, also a published journal article, highlights the stigmatised construction of sexuality for women with disabilities and illustrates how this shapes intimate partnerships and may put them at risk of intimate partner violence.

Chapter 7 Barriers to gender-based violence services and support for women with disabilities in Cape Town, South Africa.

Chapter Seven, also a journal article (under review), explores services for post-violence care and support by asking:

1. Are disabled women able to access the services and support they need?
2. What limits or enables their ability to access these services and supports?
3. At what levels should violence prevention occur?

Chapter Seven provides dual perspectives on violence against women with disabilities in South Africa by considering both those who experience it and those who work to prevent and respond to it.

Chapter 8 Discussion, limitations, recommendations

Chapter Eight contains the integrative narrative of the project and explores links between the findings from the thesis and those from other international and South African publications. The chapter provides recommendations based on the findings and reflects on future research questions that may contribute further knowledge to women with disabilities' experiences of GBV. Chapter Eight also expounds on the limitations of the study.

1.5 Terminology

For the purposes of the thesis, the term “impairment” refers to a person’s functional limitations, and “disability” is used to refer to the various environmental, economic, social and cultural interactions that play a role in their exclusion. Women with physical disabilities include those whose impairments are visible to others, and which restrict their mobility or dexterity. Women with sensory disabilities refer to those women with impairments of the senses, i.e., visual or hearing disabilities.

The terms “disabled women” or “disabled people” are used interchangeably with “women (or people) with disabilities” because there is no consensus on the preferred terminology. Global North literature favours people-first terminology while some disability activists argue that the phrase “disabled people” also has its advantages in that it names a marginalised, identifiable social category in binary opposition to able-bodiedness (UN, 2006). These critics also argue that changing terminology will not change the reality of disabled people’s lives and that negative connotations continue to be attached to functional limitations or bodily difference. Some reject the term “people with disabilities” as it implies that the disabling effect rests within the individual person rather than society (Abberley, 1987). While reviewers and editors of the journal articles included in this thesis had personal preferences on what terminology to use, I do not favour either one over the other. Participants used a variety of terms to describe themselves.

I have included a description of the nature of participants’ impairment (e.g., physical, visual, hearing) and in some cases have included a description of the nature of their diagnosis as it was described to me during the interviews (e.g., para- or quadriplegia, epilepsy, cerebral palsy, spina bifida). I do not feel that classification per type or severity of impairment and relating disability is particularly important in this study. It is rather the interplay of personal

and social interpretations of disability, along with the ways in which these are mediated through context and culture, that appear to be defining factors within the individual narratives of participants.

In this thesis, cognitive impairment refers to, and is interchangeable with intellectual, developmental, communication or mental health impairments, and does not refer to co-morbid or secondary conditions resulting from disability.

Also, I use the terms “violence against women,” “gender-based violence,” “violence,” “abuse,” and “maltreatment” interchangeably.

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CHAPTER 2. LITERATURE REVIEW

2.1 Introduction

This literature review aims to describe and appraise the published literature on disability and gender-based violence (GBV). The objective of the chapter is to identify evidence and theory that can inform understandings of women with disabilities' GBV experiences in South Africa and other low-middle income country (LMIC) contexts.

Models of disability are introduced, followed by an overview of how disability stigma is pertinent to understanding women with disabilities' experiences of GBV. Building on conceptualisations of disability, the pathways to violence against women with disabilities are discussed. Thereafter, the chapter focuses on how intersectionality provides a framework for understanding the interrelated risk factors for, and public health impacts of, violence against women with disabilities in South Africa. Finally, the chapter debates alternative theoretical options for understanding violence against disabled women in South Africa and presents a conceptual framework that may be more useful in understanding those experiences.

2.2 Conceptualising disability

From the outset, it is important to iterate that definitions of disability are multidimensional, contested and controversial. It is not a static term but one that can oscillate in breadth and severity over a lifetime (Mitra, 2018; Madans, Loeb, & Altman, 2011; World Health Organisation [WHO], 2001). Following a description of three main disability models, this section outlines how social and biopsychosocial models of disability may provide suitable

frameworks for conceptualising disability in the thesis, as well as arguing for a recognition of disability stigma as a concept to bear in mind when understanding women with disabilities' vulnerability to violence.

2.2.1 Medical model

Traditionally, disability was a problem or impairment located within a person – a kind of "personal tragedy". The "medical model" of disability (also referred to as the deficit, charity or welfare model) purports that disability results from intrinsic or biological deficits inherent in a person's body or brain. The medical model defines disability in terms of functional limitations and bodily restrictions: i.e., a person who "cannot walk, see or hear," is "homebound," "confined to a wheelchair," "sick," and needing medical intervention. Such terms define those living with disabilities as ailing and malfunctioning citizens in need of looking after and fixing. As disability scholar Liz Crow (1996) notes, this medical model of disability holds that "a person's functional limitations (impairments) are the root cause of any disadvantages experienced and these disadvantages can therefore only be rectified by treatment or cure" (p. 3). People with disabilities are thus viewed through the prism of impairment and assumed dependency (Hague, Thiara & Mullender, 2010). This model was used to ascertain levels of care and rehabilitative services for people with disabilities in population-based surveys. Welfare states and health-care administrations were thus able to categorise people in terms of being eligible for treatment and support.

With the rise of the civil rights and women's movements, medical model discourses became heavily criticised for portraying disabled people as disempowered citizens without independence, choice and control, and the model has been criticised for not taking cognisance of the ways in which disability and illness are mediated by other societal

inequalities such as classism, racism, sexism, patriarchy and heteronormativity (Haegele & Hodge, 2016; Coleman-Fountain & McLaughlin, 2013).

2.2.2 Social model

In opposition to this medicalisation, disability was conceptualised as a form of systemic societal exclusion, as a result of which "disabled people occupy a position of lesser citizenship" (Thomas, 2004, p. 23). The social model differentiates between impairment and disability and argues that the two are not equivalent. Impairment becomes a disability because of disabling political, social, and environmental factors and contexts that compound impairment and block people from participating effectively in society (Shakespeare & Watson, 1997; Oliver, 1996).

The social construction of disability refers to the meanings and responses that society attributes to a person's impaired functioning. Social change, in this context, seeks the eradication of oppression and the removal of barriers in the environment. Finkelstein (1980) writes, for example, that, "once social barriers to the reintegration of people with impairments are removed, the disability itself is eliminated" (p. 33).

The social model has been influential in redirecting attention to the environment (Oliver, 2013). In their book, *Disability and Social Change: A South African Agenda,* Watermeyer et al. (2006) recognise the systematic exclusion of, and discrimination against, disabled citizens. The authors elaborate on the environmental and social barriers that cause disability: the inaccessibility of buildings, toilets, transport, and social and health services; segregated education and institutional living arrangements; hostile and patronising attitudes and behaviours (namely, disability-related stigma and discrimination), and the socialisation

of the “abled” world that serves to reproduce the disadvantages that disabled people already have.

While the social model has become a regular feature in disability scholarship and political discourse – particularly in the United Kingdom – it is also critiqued for sidelining the role of impairment in disability. This takes several forms. Morris (1991) objects to “a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created” (p. 10). Similarly, Sally French (1993), a visually impaired scholar, notes that her impairment directly restricts some of her daily functioning, and that this would persist no matter what societal barriers might exist or be removed. Reeve (2002) notes Carol Thomas’s concern that the social model highlights “the public experiences of oppression such as social barriers, at the expense of the more personal experiences of oppression which operate at the emotional level (Thomas, 1999a)” (p. 495). By focusing on socio-structural barriers, the social model tends to ignore the internalised personal aspects of a disabled identity, and defines disability in terms of its consequences but not as an embodied experience (Owens, 2015). Shakespeare and Watson (2001) further argue that the social model replicates the medical model’s dualism of impairment versus society; that it dismisses the continuum and spectrum of disability; and that disability is not universal and not dichotomous.

The above critics argue that the social model tends to ignore the diversity of disabled people, thereby ignoring intersectionality and the social relativity of disability. This has been taken further by critical and feminist disability scholars. In that critique, the social model is seen as a creation of white, male wheelchair users that therefore overlooks the varying experiences and needs of people with diverse impairments who are also people of colour, women, lesbian, gay, bisexual, transgender or questioning/queer (LGBTQ), or part of any

other marginalised group, thus ignoring different forms of oppression and power (Owens, 2015).

Thomas (2004) brings further attention to the unequal power relations that exist between people with and without disabilities, and within the disabled population. She claims that the social model needs to be linked with theories of what *generates* unequal social relations and disabling social barriers – that is, to explore the material forces of socio-economic status, class, gender and race relations that contribute to what constitutes impairment and how these are related and responded to. Her argument for a more social-relational perspective of disability may offer scholars in non-western and developing societies opportunities to understand the ways that excessive marginalisation, lack of technology, and unequal economic opportunities influence experiences of disability.

Furthermore, feminists like Thomas (2006, 2004), Reeve (2002), Mays (2006) and Morris (1991) recognise that theory that draws on the social model of disability does not adequately explain the gendered nature of disadvantage and social exclusion, nor how impairment and disability are experienced and reacted to differently by men and women. Specifically, the social model "limits the understanding of the way disablism is produced and shaped by other dimensions, such as gender.... It is the interrelations between differing forms of oppression (sexism and disablism) which provide insight into the way women with disabilities experience domestic violence and consequences of marginalization" (Mays, 2006, p. 150).

Cautious to align with the social model of disability, the World Report on Disability (WHO & World Bank, 2011) recognises that the diversity of disability encompasses the varying interactions of health conditions and personal and environmental factors, and that generalisations about people with disabilities, or about disability, are misinformed. The tenets

of the Report tend to favour an intersectional lens for understanding disability as a social, developmental and human rights issue. There are wide ranges of type, onset, severity, temporality[2], and visibility of impairments, and differences in gender, age, socio-economic status, sexuality, ethnicity or cultural heritage mean that each person's experience of, and reaction to, disability, is different. Significantly, the report is loath to equate disability with disadvantage. It argues that combined advantages of wealth and status may help overcome activity-limitations and participation-restrictions. Conversely, the combined disadvantages associated with gender inequality and disability for women with disabilities mean that they experience more oppression than their male counterparts. Persons with mental-health or intellectual impairments are found to be more disadvantaged than those with physical or sensory impairments, and those with greater impairment at a greater disadvantage (WHO & World Bank, 2011).

The World Report on Disability also recognises that disability is not just a societal issue. When considering the need to prevent and treat health conditions and injuries, and to dismantle barriers to accessing health care, disability becomes a developmental issue, too. The prevention of health conditions implies equal access to health care – which makes disability a human rights issue as well (WHO & World Bank, 2011).

Degener (2016) specifically argues that the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (2006) helped to endorse disability as a human rights issue and builds on the social model's attempt to make society more inclusive. For instance, the CRPD recognises persons with disabilities as equal before the law (Article 12), having rights to independent and community living (Article 19); to inclusive education (Article 24),

[2] Impairments differ in temporality or permanence; some are degenerative, others static.

accessibility (Article 9) and reasonable accommodations (Articles 2 and 5); and to protection from all forms of exploitation and violence (Article 16). Harpur (2012) argues that the CRPD has added a disability rights paradigm for scholars in the disability field. The CRPD provides detail on what is required from signatory states to ensure rights are realized and how to substantially improve the lives of people with disabilities.

2.2.3 Biopsychosocial model

The social model has come under fire by some because of its separation of impairment from the personal experience of disability. Consequently, a more holistic model was developed that accounts for the considerable inequalities that disabled people experience through social, economic, political, cultural, interpersonal, and psychological barriers (Goodley, Hughes & Davis, 2012).

The biopsychosocial model advances the notion that the impacts of disability are physical (pain, fatigue), psychological (attitude, depression), and social (access to resources, social networks, isolation, stigma). The model further recognises that impairments are often due to illness or injury that cause pain and discomfort to individuals, and how a person's response to their own disability affects his or her overall experience of disability. It recognises the significant contribution of psychosocial factors to disability and, in doing so, amalgamates biological, social, cultural, emotional, and environmental issues on health, well-being, and functioning in society (Jette, 2006).

The biopsychosocial model may include personal aspects of stress and coping with impairments, and emphasises disability as a personal experience that differs from person to person and from context to context. All these factors contribute to how a person with an impairment may respond or react within their environments.

For instance, disabled women differ in terms of their physical functioning and personal identity, which influences their experiences of sexuality. Impairments may restrict functioning or appearance, as well as the attainment of sexuality norms (Shakespeare & Watson, 1997). Communicating sexual wants and desires or making eye contact with partners may be difficult for women with visual or hearing impairments. Mobility impairments may restrict sexual positions and accomplishing sexual desires. Paralysis means that women may experience little or no bodily sensations, affecting their sexual satisfaction. It is not only the body that complicates sexuality; the psycho-emotional aspects of disability also contribute to how women with disabilities may repress their sexuality (Watson, 2002).

Potential inability to fulfil traditional gender roles, problems in interpersonal relationships, and deformed body image become internalised and can be major stressors for women with disabilities, and lead to psychological distress. There are various manifestations of the psycho-emotional dimensions of disability. Reeve (2002) explains how people with disabilities respond emotionally to social exclusion and physical barriers and may deal with anger and frustration at not being able to access buildings or having to rely on others. They also react to disability stigma. Negative reactions to the disabled body, being stared at or mocked, and rejection from partners and family may cause shame, self-loathing, and humiliation, which “are among the hardest aspects of being a disabled person” (Barton, 1996, p. 42). These psycho-emotional dimensions of disability are created and maintained by various structures and oppressions and differentially affect disabled people on a personal level (Reeve, 2002; Watson 2002). In various ways, external oppression becomes internalised oppression – which is a common feature of any marginalised group within society (Reeve, 2002)

However, the biopsychosocial model has been criticised by disability activists for advocating a definition of disability imposed by "professional" (non-disabled) individuals. Furthermore, disability scholars say the biopsychosocial model is largely unexamined within academic literature, and too much emphasis is placed on the subjective meaning of impairment, thus undermining the real and disadvantageous dimensions of disability and other oppressions that contribute to the exclusion of disabled people from participation in society (Shakespeare, Watson & Alghaib, 2017).

2.2.4 Disability-related stigma and discrimination

American disability scholars emphasize stigma and discrimination as significant social factors attributing to disability (Coleman-Fountain & McLaughlin, 2013; Susman, 1994). In social science research, stigma is defined as a discrediting label: an undesired differentness gleaned from social expectations. Individuals who characterise difference acquire a "spoiled identity" and are socially devalued (Goffman, 1963; Campbell & Deacon, 2006). Social-interactionist Goffman (1963) argues that there are two types of stigmatising conditions. The first relates to discrediting conditions which are readily obvious to others, such as visible impairments. The second kind is discreditable conditions that are not visible to others or which can easily be concealed: impairments like epilepsy, HIV or depression. Thus, the visibility of impairments is more likely to violate appearance norms and trigger social responses, whereas invisible impairments may not (Susman, 1994).

Goffman's analysis of stigma explores the power relations that are embedded in cultural constructions of "normalcy". The "normal", Goffman argues, is a prized cultural status ascribed to those "who do not depart negatively from...expectations" (1963, p. 15). Stigma thus describes the negative reaction that a person experiences when they fail to

realise “a particular norm” (Goffman, 1963, p. 6). Stigma involves social power, inequality and exclusion (Campbell & Deacon, 2006). Link and Phelan write that “[we] apply the term stigma when elements of labelling, stereotyping, separation, status loss and discrimination co-occur in a power situation that allows them to unfold” (2001, p. 367).

Disability is a mark of difference that sets people out as “other” to the “normal” (Coleman-Fountain & McLaughlin, 2013). Disability-studies scholars such as Friedman and Owen (2017) describes the discrimination that people with disabilities experience as “ableism”. Ableism can be defined as systemic discrimination based on disability. It may incorporate social encounters that make a person embarrassed about their disability or other barriers that prevent a person from having their needs or desires met. In essence, ableism incorporates able-bodied attributes and ideals as highly socially accepted and valued – i.e., it is preferable, for instance, to read print rather than Braille, to walk rather than use a wheelchair (Wolbring, 2008). Ableism values normative or socially desirable attributes such as engaging in play with one’s siblings or performing duties associated with marriage, child-bearing, sex and employment. This means that those who cannot attain such attributes are often socially marginalized (Friedman & Owen, 2017).

Globally, negative attitudes towards, and beliefs about, disability shape the daily experiences of those living with impairments. Those with physical disabilities “depart from normative images of human physique and fail to meet prescribed standards of physical attractiveness” (Hahn, 1988, p. 41). Persons with physical disabilities are often represented as being without gender, as non-sexual creatures other to the social norm (Milligan & Neufeldt, 2001; Tepper, 2000). Straying from ableist standards of beauty and mobility means that women with physical disabilities may be unable to achieve sexuality norms of physical performance and attractiveness (Shah, Tsitsou & Woodin, 2016; Esmail, Dally, Walter &

Knupp, 2010; Crawford & Ostrove, 2003; McCabe & Taleporos, 2003; Abu-Habib, 1995). Regardless of the context, type, or severity of physical disability, the visibility of the impairment and limited mobility becomes the central focus of negative reactions (Taub, Blinde & Greer, 1999).

Evidence reveals that women with physical impairments may be perceived as undesirable and unable to reproduce, preventing them from fulfilling normative or ableist gender roles of reproduction and motherhood, and resulting in increased difficulty to form healthy intimate relationships (Iglesias et al., 1998). Begum cites that "the idea that these 'damaged' bodies could have sexual feelings, the mere thought that they may engage in sexual behaviour is considered unwholesome, repulsive and comical" (1992, p. 78), and that, with the social "tendency to reduce their bodies to an asexual object, disabled women learn very early on that their bodies can be objects which are manipulated and controlled by others" (Begum, 1992, p. 76–77). Assumptions of non-sexuality mean women that with disabilities are less likely to get married, and more likely to get married later in life or to divorce, than those without disabilities (Asch, Fine, Perkins & Rousso, 2001; Abu Habib, 1995). Women with physical disabilities also experience limited opportunities to establish romantic relationships compared to women without disabilities; in addition, they encounter more obstacles in attracting dating partners, and date less often (Asch et al., 2001). In South Africa, Potgieter and Khan (2005) concluded that entrenched disability-related stigma and discrimination appears to limit the opportunities for spinal-cord-injured adolescents to express their sexuality more than the limitations caused by their impairments.

Traditional opportunities to be nurtured and to nurture or to be mothers are also constrained. Societal stigma around the body of women with physical disabilities erroneously

claims that disability negatively affects a person's parenting ability. Fears that they would produce children with similar conditions, and assumptions that they would harm, deprive or burden their children have been documented (Ortoleva & Lewis, 2012). Their deviation from sexual norms means that women with disabilities may have a lesser likelihood of marriage, raising a family or engaging in sexual or intimate partnerships, while restrictions to sexual and reproductive health education and care are experienced, too (Asch et al., 2001).

Disability-related biases are not universal, yet disability research shows that people who identify as disabled report negative social and psychological effects of living in a world that is created for non-disabled people (Bell, 2013; Ostrove & Crawford, 2006). Goffman (1963) writes that members of stigmatised groups may also internalise negative representations of themselves. The internalisation of stigma is a psychological and social process where social perceptions become entrenched in an individual's psyche. This may lead to a loss of confidence and self-esteem, and undermines the likelihood that individuals may challenge their devalued status (Campbell & Deacon, 2006). Zhou (2016) argues that the stigmatization of people with disabilities in Namibia goes beyond external and internal oppression: it impedes the general socio-economic development of a social group. By inhibiting the positive formation of self, stigma inhibits the formation of social capital, such as social networks, access to resources and opportunities.

Disability scholars show how negative reactions and the invalidation of women with physical disabilities becomes a central process underlying their maltreatment and experiences of violence (Hassouneh-Phillips, et al., 2005). In recognising the significant role of societal and internal personal responses that shape disability, the next section describes the bi-directional pathways of violence against women with disabilities.

2.3 Bi-directional pathways and vulnerabilities for violence against women with disabilities

The causes and consequences of violence against women with disabilities are bi-directional. Exposure to violence can be associated with new injuries or mental health conditions, or exacerbate existing impairments, making disability more severe (Thomas et al., 2008). A study by Coker, Smith, & Fadden (2005) showed that women reporting current intimate-partner violence (IPV) were more than twice as likely to report having a disability as compared to non-abused women. In the same study, almost 42% of those women with past IPV histories, compared to 24% of those without, reported that a violence-related injury caused their disability. Using Behavioural Risk Factor Surveillance System (BRFSS) data, Martin et al. (2006) found that the odds of reporting impairments were almost three times greater among women who had experienced physical and sexual violence. It is unclear whether Martin and colleagues were able to determine whether the impairment or the violence occurred first.

Despite prevalence indicators of increased violence against women with disabilities, they have generally gone unrecognised as potential and actual victims of violence. Consequently, there have been few studies exploring risk factors, vulnerabilities, prevalence, experiences of and impacts of violence for women with disabilities, nor of their use of and barriers to GBV services.

The type and severity of impairments are said to affect women with disabilities' defences and/or vulnerability to violence. Research conducted in the United States has found that visual impairments may hamper the identification of perpetrators, hearing impairments may cause communication difficulties in disclosure, and immobility may thwart their ability

to escape violence or seek help. Women with cognitive and mental health impairments were found to encounter compounded barriers to identifying and disclosing and reporting violence – from not comprehending acts of violence to experiencing communication difficulties and lacking credibility as witnesses (Shuttleworth & Mona, 2002). Additionally, their physical, economic, and social dependency on caregivers may increase vulnerability to intimate partner, family, or caregiver violence, and perpetuate powerlessness to end the cycle of violence (Curry et al., 2009; Oktay & Tompkins, 2004; Crawford & Ostrove, 2003).

From a young age, girls with disabilities experience abuse because they are perceived as undesirable and without sexual desires of their own – and this continues into adulthood. Women with disabilities are less likely than women without disabilities to be married, and it is assumed that disabled women don't have intimate partners, so IPV often goes undetected (Barnett, Miller-Perrin, & Perrin, 2005). The stigma and discrimination that questions the desirability of women with disabilities and their eligibility for marriage may provide male perpetrators with opportunities to present themselves as "martyrs", thus perpetuating their use of violence against their female disabled partners (Iglesias et al., 1998). Moreover, such assumptions of unmarriageability and non-sexuality may give women with disabilities a sense of "relationship unworthiness" (Barranti & Yuen 2008, p. 118). Internalised disability-stigma and low sexual and body esteem are widely known contributing factors to women with disabilities' experiences of IPV (Astbury, 2012; Hassounah-Phillips & McNeff, 2005; Hassounah-Phillips et al., 2005). Moreover, invalidation creates an avoidance of sex education and reproductive health care, further hampering knowledge and agency for healthy, appropriate, and consensual sexual encounters (Hassounah-Phillips & McNeff 2005; Hassounah-Phillips et al., 2005). Internalised stigma can prevent women with disabilities from recognising abuse and violence as inappropriate when it occurs in a relationship (Jones, 2007).

Furthermore, their ignorance of maltreatment can become a means for intimate partners to justify their abusive actions as expressions of love (Iglesias et al., 1998).

Assumptions of the non-sexuality, powerlessness, and lack of mental capacity or communication ability of women with disabilities also perpetuate the stigmatised attitudes of service providers, such that these women are often shown a lack of respect and acknowledgement of their violence experiences (Chang et al., 2003). Assumptions of non-sexuality also lead to guardians and health-care providers assuming control over their reproductive health-care needs, often denying them options of divorce, contraception or abortion (Asch et al., 2001). All these contributing risk factors for GBV are exacerbated in LMICs (Chouinard, 2012).

Evidence shows that women with disabilities may experience other forms of abuse because of their disability (Nosek et al., 2001). These added violations have come to be termed “disability-specific violence”. Disability writers argue that violence against women with disabilities encompasses not only physical, sexual and emotional abuse, such as hitting, rape and verbal abuse, but also incorporates other forms of disability-specific violence such as physical or drug-induced restraint, medical exploitation, institutional abuse and harassment. Women with disabilities who experience neglect and abuse at home or in an institution may be subjected to financial exploitation, or subjected to physical or drug-induced restraints, or prevented from using a wheelchair or other assistive device (Lund, 2011; Curry et al., 2009; Oktay & Tomkins, 2004; Nosek et al., 2001; Howe, 2000; Sobsey & Doe, 1991). Ridicule about their impairments can present added psychological abuse (Nixon 2009). In addition, women with disabilities may experience violence by carers, disability service providers, or transportation employees (Oktay & Tomkins, 2004; Saxton et al., 2001). Because of added disability-related violations that women experience on top of GBV, women

with disabilities around the world experience much higher levels of physical, sexual, and psychological violence, for longer periods of time, and with worse physical and mental health outcomes than women without disabilities (Nosek, et al., 2001).

These impairment-related restrictions and reduced defences may be further compounded by the social context of disability, i.e., poverty, isolation, and lack of access to education, employment, services, and assistive devices. A lack of accessible preventative information and interventions adds to women with disabilities' risk of violence (Dunkle, Van der Heijden, Stern, & Chirwa, 2018).

2.4 Intersectionality: A framework for understanding GBV against women with disabilities

> In an equal society, disabled people would be no more susceptible to abusive situations and relationships than would any non-disabled person. (Calderbrank, 2000, p. 521)

This thesis responds to a need to look at the intersecting effects of various social inequalities and attitudinal and environmental barriers that compound and heighten the risk of women with disabilities, and to investigate how disability is "influenced by historical/situational contexts and internal and external mechanisms" (Asch et al., 2001, p. 345).

Intersectionality theory suggests that multiple biological, social and cultural categories, such as gender, socio-economic status, class, race, disability, sexual orientation and other identities, can interact on multiple and often simultaneous levels to contribute to systemic injustice and social inequality (Dutta, 2015). Thus, intersectionality provides a lens

for understanding mutual processes of marginalisation and exclusion. It acknowledges that multiple and interactive identities of an individual result in various experiences of disadvantage or advantage (Moodley & Graham, 2015; Cho, Crenshaw & McCall, 2013).

Given that over 80% of the world's disabled population live in extreme poverty in LMICs, where resources and services are severely limited (WHO & World Bank, 2011), the importance of an intersectional perspective for disability and gender studies is emerging. In recent years, disability scholars have used intersectionality more frequently to understand how poverty, gender and disability intersect to render women with disabilities more likely to be victims of violence than their non-disabled and male counterparts (Cramer, Choi & Ross, 2017; Meer & Combrinck, 2017, 2015; Moodley & Graham, 2015; Coleman-Fountain & McLaughlin, 2013; Wickenden, Nixon & Yoshida, 2013; Shaw, Chan & McMahon, 2012; Hague et al., 2010; Pal, 2011; Winker & Degele, 2011).

Using intersectionality theory, the next part of this chapter describes how poverty, race, disability and gender inequality, entrenched violence, disability-related stigma, and environmental restrictions may put women with physical disabilities at heightened risk of GBV in South Africa.

Despite South Africa's progressive human rights constitution, it remains a society marked by glaring inequality. In South Africa, exclusion and oppression are closely connected with the entrenched racial and gender inequalities and socio-economic divisions of the apartheid system (Swartz & Watermeyer, 2006). For those who live with disabilities, South African society is a particularly "disabling society".

2.4.1 The relationship between race, poverty, gender and disability in South Africa

Disability intersects with various aspects of social disadvantage in South Africa. During apartheid, access to health and education services was disparate, based on racial grounds (Emmett & Alant, 2006). As a result, black (African and Coloured[3]) people with disabilities are less likely than other population groups to have high levels of education, which lessens their employment possibilities (Emmett, 2006). Thus South Africa's entrenched segregation by race has left an indelible culture of poverty among the majority of the black African populations living in South Africa, and poverty rates are especially high among those living with disabilities (Moodley & Graham, 2015; Moodley & Ross, 2015; Ataguba, Akazili, & McIntyre, 2011; Jelsma et al., 2008; Loeb et al., 2008; Emmett & Alant, 2006). While South African researchers warn that robust data regarding the social and economic status of people with disabilities is still lacking – due to the variability of disability definitions and measures – there are indications of the ways that disability, race and poverty compound each other. With the majority of the population living in impoverished households and harsh conditions in rural areas and informal urban settlements, where people's basic needs of water, sanitation and access to health care are often unmet, the risk of acquiring disability and chronic illness is increased (Emmett, 2006).

Disability also worsens poverty. A household member with a disability is often unable to work, either due to lack of opportunity, social stigma, or facing barriers due to impairment-related restrictions, i.e., difficulty of mobility or a lack of specialised transport to get to work. Disability has a further impact on already poorer households because of costs incurred by medical care, special education and rehabilitation needs, on top of supporting other

[3]Coloureds are an ethnic group composed primarily of persons of mixed race. They are a minority group within South Africa, but are the predominant population group in the Western Cape. They are generally bilingual, speaking Afrikaans and English, though some speak only one of these languages.

household members and children. The 2011 South African census (Statistics South Africa, 2014) reported a dire lack of assistance and assistive devices among those living with disabilities. Social development programmes such as disability and child care cash transfers/grants do little to alleviate economic hardships (Hanass-Hancock & McKenzie, 2017; Jelsma et al., 2008; Emmett, 2006). Those with disabilities living in poor households are thus highly unlikely to be able to pull themselves out of poverty.

The interface of poverty and disability makes it extremely difficult to fully participate in society, both socially and economically, causing people with disabilities to remain on the margins of society. Black African and coloured women with disabilities are hardest hit by poverty and disability, as they face the compounded disadvantage of gender inequality, poverty and increased social exclusion (Emmett & Alant, 2006).

2.4.2 Gender-based violence and disability in South Africa

Many South African women will experience more than one form of GBV in their lifetimes. Vulnerability to GBV is increased by the patriarchal authority the perpetrator has over the victim, poor social support structures and poverty, disability, lack of ability or opportunity to report on experiences of violence, financial or emotional dependence on the perpetrator, or repeated exposure to violence over the course of a lifetime (Ward et al., 2012).

On a societal level in South Africa, discriminatory patriarchal attitudes that favour men over women are further said to be the root causes of GBV (Jewkes & Morell, 2010; Jewkes, Dunkle, Nduna, & Shai, 2010; Jewkes, 2002). Hegemonic ideas of masculinity prescribe that men be independent, successful, unemotional and strong; however, most masculinities are bound up with their domination of women (Morrell, 1998). In South Africa, the concept of manhood is linked to toughness, male honour, strength, sexual risk-taking and

conquest, and makes violence against women an everyday occurrence. A man may be expected to lead and control sexual relations, and his female partner to comply. Male sexuality is consequently associated with multiple partnerships, forced or unprotected sex with women, and increased risk of HIV infection (Morrell, Jewkes & Lindegger, 2012; Jewkes & Morrell, 2010). The term "toxic masculinity" in South Africa encapsulates the harmful interpretations and enactments of masculine norms that perpetuate GBV and sexual violence.

Connell (1987) famously coined the term "emphasised femininity" for socially constructed feminine roles for women as dependent, passive, and weak. Women may sustain harmful masculinity by embracing powerlessness, compliance, and dependency, putting them at risk of unrelenting male violence (Morrell, Jewkes & Lindegger, 2012; Jewkes & Morrell, 2010). Both constructions of "emphasised femininity" and " hegemonic" or "toxic" masculinity put South African women at a disadvantage in terms of negotiating safer sex or refusing unwanted sex (Morrell, Jewkes & Lindegger, 2012; Jewkes & Morrell, 2012). These constructions may also serve to place women with disabilities at an even far greater risk of GBV. A study in Canada corroborates the ways in which patriarchal domination and male sexual propriety – in addition to impairments and disability-related stigma – increase the likelihood of IPV against women with disabilities. As Brownridge writes, "women with disabilities are perceived by men who espouse a patriarchal ideology as being less difficult to dominate, which may include domination through violence" (2006, p. 809).

Studies from other high-middle income countries (HMICs) attest to how the socialization of women with disabilities, with an emphasis on female vulnerability and powerlessness and the need to be agreeable to receive care, puts them at risk of violence from personal caregivers (Saxton et al., 2001). Women with disabilities are also likely to be

deemed less able to defend themselves or seek support, making them extremely vulnerable to coercion and limiting their options to escape violence. The consequences again place them at higher risk of sexual violence and IPV (Gerschick, 2000).

At the community or neighbourhood level of risk factors for GBV in South Africa, all women are vulnerable in neighbourhoods where violence against women and the use of alcohol and gun ownership are celebrated as markers of hegemonic masculinity. Experiences of childhood abuse predispose survivors to early sexual behaviour, multiple partnerships, and other high-risk activities. In addition, witnessing violence perpetrated by a father against a mother normalises GBV and the abuse of partners later in life. An absent father, or a father who is not a positive role model, also influences men towards harmful masculine behaviour and intimate partner perpetration (Gass, Stein, Williams, & Seedat, 2011; Matthews, Jewkes, & Abrahams, 2011; Abrahams & Jewkes, 2005). There is also evidence that childhood disability increases the likelihood of childhood abuse and neglect (Leeb, Bitsko, Merrick, & Armour, 2012). Allowing that sexual and physical violence against children is extremely high globally (Jones et al., 2012), girls with disabilities in South Africa may be at even higher risk, and their experiences of GBV may start from an early age. However, research evidence does not yet exist to support this.

The wide acceptance of abuse within relationships and marriage in South Africa means that women tend not to frame their experiences as abuse. Between 59% and 36% of women interviewed in three provinces in South Africa agreed that, once a man has paid *lobola* (marriage dowry), it is “culturally accepted that if a wife did something wrong her husband had the right to punish her” (Ludsin & Vetten, 2005, p. 24). Multiple other reasons prevent South African women from reporting abuse or leaving abusive relationships, engendering a

complex psychosocial perpetuation of violence. Many are limited in their agency to change or leave violent relationships because they remain profoundly economically disempowered and rely on their partners for financial support (Jewkes & Morrell, 2012). Pregnancy and having children with an abusive partner further compounds women's dependency (Shamu et al., 2011). A woman's ability to report intimate partner violence is also influenced by intimidation and threats of abandonment, the loss of child custody, or the loss of a child welfare grant. Learned helplessness, traumatic bonding with a partner, and psychological entrapment also serve to perpetuate violence (Rhatigan, Street, & Axsom, 2006). A lack of awareness of human rights instruments and legislation, such as South Africa's Domestic Violence Act, along with poor knowledge about – or faith in – the legal system, also contribute to a deficit in agency to resolve situations of GBV and IPV (Gordon, 2016).

Furthermore, access to medical and legal services is restricted by cost or distance of travel, or dismissive attitudes by service providers (Gordon, 2016; Chang et al., 2003). The cycle of IPV prevents women from negotiating the circumstances of sex, resulting in more frequent sex, less condom use, and increased likelihood of HIV-infection (Jewkes et al., 2010).

Women with and without disabilities in South Africa share vulnerabilities to, and experiences of, different forms of GBV. However, to date there is limited understanding of the lived experience of disability and GBV in South Africa, and how GBV experiences for women with disabilities may differ from the experiences of women without disabilities.

One of the few studies in South Africa that have considered this research gap is a small qualitative study conducted in the Gauteng province to understand how women with disabilities' experiences of GBV may differ from non-disabled women (Naidu et al., 2005). The study had a small sample size, comprised of two women with physical and sensory disabilities, and ten civil society and justice service providers. The study identified disability-specific abuse

against women with disabilities in South Africa, largely relating to the caregiving relationship, which many women with disabilities depend upon. In the study, women with physical disability reported how partners removed assistive devices or deliberately injured functional parts of their bodies to restrict independent movement (Naidu et al., 2005). Compared to literature from the global North, the study recognises how disability-related dependency puts South African women with disabilities at increased risk of staying in abusive relationships. However, the glaringly small sample of the study means that evidence of disability-related dependency and vulnerability to violence remains unverified.

Further evidence of women with disabilities' unique experiences of GBV in the country emerges from a study in three South African provinces. The study reveals the role played by isolation and family neglect in creating conditions where opportunistic sexual violence can easily occur because predatory family members, family friends, and neighbours have unchecked access to women with disabilities (Meer & Combrink, 2017, 2015). Participants reported that, in many families, women with disabilities are vulnerable to violence because they are devalued or conceived of only in terms of their value to men. Family resentment about investing resources, including money and care work, also encourages violence against women with disabilities. Due to family neglect and the burden of care[4], the institutionalisation of women with intellectual disabilities renders them vulnerable to neglect or assault within these institutions. Stigmatised community and service-provider attitudes play a further role in perpetuating the GBV experiences of women with intellectual disabilities in South Africa (Meer & Combrink, 2017).

[4] Burden of care is a concept emerging in the literature that describes the physical, emotional, social, and financial problems that can be experienced by family caregivers.

Other South African studies highlight myths about the non-sexuality of people with disabilities. Because non-sexuality may signify virgin status, some findings reveal a relationship between high HIV incidence and prevalence in South Africa, GBV against women with disabilities, and high incidences of rape because of virgin cleansing myths (Mall & Swartz, 2012; Hanass-Hancock, 2009; Groce & Trani, 2004).

Overall, various cultural, community and socio-economic factors increase South African women's risk for GBV. Those women with disabilities may be at increased risk of GBV given that these factors are exacerbated because of their disability status. With greater risk may come greater health impacts. This warrants urgent recognition if we are to understand the consequences of violence against women with disabilities in the country. The next section examines the public health impacts of violence against women with disabilities and pathways to care and prevention.

2.5 Public health impacts of violence against women with disabilities and pathways to care and prevention

Overall, GBV is a major public health issue and has profound consequences on the health and well-being of women by negatively affecting their physical and mental health, curtailing mobility and decreasing their productivity (Campbell, 2002; Thomas et al., 2008). The World Report on Disability recognises violence and associated injuries as a contributor to disability worldwide (WHO & World Bank, 2011). Pooled analysis of all sites in a global study on violence against women found significant associations between lifetime experiences of IPV and self-reported poor health problems, including difficulty walking, difficulty with daily activities, pain, memory loss, dizziness and vaginal discharge (Ellsberg et al., 2008). Negative sexual and

reproductive health outcomes like HIV and unintended pregnancy are also likely to increase the severity of IPV (Shamu et al., 2011; Taillieu & Brownridge, 2010). IPV has also been shown to increase the likelihood of women's substance abuse (Thomas et al., 2008). Overall, strong evidence suggests the vicious cycle of IPV influencing HIV-positive outcomes, mental illness, reproductive health, childhood development, health behaviours and chronic disease, all of which lead to numerous injuries, disability, and death (Seedat et al., 2009; Thomas et al., 2008; Garcia-Moreno et al., 2006; Coker et al., 2005).

For women with existing disabilities, the consequences of GBV pose even greater threats to health and well-being. Dembo, Mitra and McKee (2018) examined data from a National Crime Victimization Survey in the United States and found that women with disabilities are at higher risk of negative psychological consequences resulting from violence compared to other gender–disability groups, and had higher odds of experiencing anxiety and depression compared to men and women without disabilities. However, very few studies in LMICs have estimated the health consequences of violence against women with disabilities. One study conducted in Cambodia on the impact of disability and IPV on women's mental health revealed a strong relationship between disability and symptoms of severe psychological distress. The presence of IPV further aggravated this relationship (Astbury, 2012).

Barriers to care are also exacerbated by disability. The most often cited obstacles to health care, family planning, and post-violence services for women with disabilities are financial cost; lack of transport; lack of physical access to buildings and transportation; lack of appropriate sexual and reproductive health information and knowledge; and lack of appropriate training and communication skills among service providers (Chang et al., 2003; Anderson & Kitchin, 2000). Even where care and services do exist and are accessible, women

with disabilities are often met with insensitive attitudes and behaviours by service providers (Gordon, 2016; Chang et al., 2003; Swedlund & Nosek, 2006; Nosek et al. 1995). Thus, the uptake of GBV services and disclosure of abuse by disabled women is generally low (Radford, Harne & Trotter, 2006).

Evidence on the role and effectiveness of health services in preventing intimate partner violence mostly comes from developed countries. From the existing evidence, studies evaluate the access to sexual and reproductive health services. This is significant as sexual and reproductive health services are often the first points of care for women experiencing GBV (Garcia-Moreno et al., 2006; Heise, Ellsberg, & Gottmoeller, 2002). As discussed earlier, various factors influence the provision of sexual and reproductive health services and GBV support and care, all contributing to under-reporting. Furthermore, Heise et al. (2002) indicate that health providers often miss opportunities to help survivors by being unaware, indifferent or judgmental. Asking about and identifying violence and related injuries has to be done with sensitivity and, with enough training and support, health professionals can provide medical treatment, document injuries and provide counselling and referrals. Heise et al (2002) also found that empathy and support for survivors is a facilitating factor to GBV support and care. In South Africa's North-west province, a study showed that 40% of nurses themselves reported having experienced domestic violence, and how their personal experiences of GBV helped foster empathy and facilitated higher-quality care and support for clients (Christofides & Silo, 2005).

There is little data on the response to, and protection of, IPV or domestic violence survivors with disabilities. A small qualitative study in the Philippines included 14 in-depth interviews and two focus groups with a total of 32 sexual and reproductive health service providers. The study shows that service providers have little understanding of human rights

for all women – irrespective of disability. Service providers also receive very little training in relation to disability and have limited access to resources that would enable disability-inclusive services. Significantly, service providers are often unaware of factors undermining the health of women with disability, especially violence and abuse (Lee et al., 2015).

Universal and equitable health-care services are restricted for many people in South Africa, especially those living in poor and rural communities. Disabled people bear the brunt of restricted services (Moodley & Ross, 2015; Harris et al., 2011). Disability-inclusive and accessible health-care services and information are limited, and popular beliefs about the sexuality of women with physical disabilities curtail their sexual and reproductive health rights and undermine the benefits they may derive from sexual and reproductive health services (Hunt et al., 2017). In South Africa, evidence reveals that sexuality education and HIV-prevention services are not an integral part of the lives of many young people with physical disabilities in South Africa (Wazaliki, Mpofu & Devlieger, 2009). A small-scale research project on persons with visual disabilities in South Africa and their risk of HIV and access to HIV prevention and care showed that social exclusion and an ignorance of blind peoples' sexuality limited their linkages to information and health care, which may lead to sexual violence or perpetuate the cycle of violence. The study also reported a lack of accessible and formatted HIV information and programming for blind persons (Philander & Swartz, 2006).

Evidence from a South Africa study on women with physical and sensory disabilities reveals further difficulties accessing health care services. In Cape Town, deaf people experience communication barriers when accessing health care services (Kritzinger, Schneider, Swartz, & Braathen, 2014). Deaf clients' shyness, lack of knowledge of their medical history, and strong dependency on caregivers and interpreters compound impairment and communication barriers. Furthermore, health care providers are not trained

in using interpreters and thus end up talking directly to the interpreter and not directly to the patient.

To date, only one study has focused on the accessibility of post-GBV services in South Africa. Meer and Combrink (2017, 2015) describe obstacles to accessing these services among intellectually disabled women and their caregivers in three South African provinces. From the perspective of service providers, intellectually disabled women's and their caregivers' utilisation of services is hampered by ingrained poverty, ostracism, lack of social support structures, and fear and shame associated with the sexuality of people with disabilities. Comparable to studies focusing on physical and sensory disabilities, the authors agree that stigma-related barriers are among the most widely reported obstacles to post-violence care and support (Meer & Combrink 2017, 2015).

2.5 Invisibility in GBV research and prevention

The unique forms and impacts of GBV against women with disabilities call for inclusion in research, support and prevention interventions. Nevertheless, challenges in estimating prevalence, such as under-reporting of violence, and the lack of standardised instruments used to measure disability status may undermine data comparability in research and interventions. Research that neglects to report types of disabilities in uniform terms also poses challenges for comparability. Existing standardised measurements, such as the WHO Disability Assessment (WHODAS) (see Madans, Loeb & Altman, 2011) often neglect the social and environmental barriers that inform disability and may not capture the diverse personal and social experiences of disability. Furthermore, disability-related violence is often not measured in conjunction with the existing measurements and remains under-estimated. Moreover, there is a lack of gender disaggregation and longitudinal follow-ups on self-

reported violence. Robust studies are absent in most regions of the world, particularly in low-income and middle-income countries. Considering that 80% of people with disabilities live in low middle-income countries (WHO & World Bank, 2011), this is a huge limitation.

Few violence- and abuse-prevention efforts exist that include or are tailored towards people with disabilities, and none of these prevention interventions (all of which have subsequently been conducted in developed countries) demonstrates decreased incidences of violence or mitigation of risk factors for violence. Existing initiatives also lack rigorous planning, implementation, and evaluation (Van der Heijden, 2014).

Mikton, McQuire and Shakespeare's (2014) review of violence prevention and victim support programmes for people with disabilities, for example, included only one study from an LMIC. No meta-analysis was conducted due to small study samples, and the authors used a narrative synthesis. The content of the interventions varied from training programmes for service providers, survivor support groups and relief care through to educational workshops for carers of survivors. Included studies mainly focused on intellectual and developmental disabilities, limiting the generalisation of findings. All of the included studies were evaluated as being at high risk of bias. Moreover, Mikton and colleagues (2014) did not perform a gender analysis on the data, hence its inappropriateness for adding to the evidence of prevention of GBV for women with disabilities.

Reviews of prevention of violence against women with disabilities remain limited and offer no evidence of effectiveness. Thus, there remains an urgent need for the inclusion of women with disabilities in high-quality GBV research. The invisibility of women with disabilities in GBV prevalence and prevention research further attests to a lack of ethical guidelines and quality-assurance measures for inclusive GBV research.

2.6 Critical and feminist disability theory for understanding disability and GBV

The multi-faceted nature of disability means that multiple frameworks exist to understand it. Former models for understanding disability have been criticised for their use in LMICs, and they lack emphasis on the junctures of discrimination and affirmation of disabled identity, as well as people's resilience, capabilities and agency (Mitra, Posarac & Vick, 2013; Mitra, 2006). While this thesis uses a blend of the social and biopsychosocial models of disability, and an intersectional framework to understand GBV in South Africa, it draws on other theoretical approaches not only to highlight the interactions of factors that make women with disabilities more vulnerable to violence, but also to make sense of how disabled women's agency and resistance may shape their resilience to GBV experiences.

The role of physical impairment is as important as other barriers, as the visibility of impairment on the body may mean that the body becomes a site of discrediting and stigma. However, scholars often fail to highlight the individual embodiment of gender and disability; they neglect to investigate how women's bodies are part of violent experiences, and do not take into consideration the fact that bodies can also be sites of resistance to hegemonic oppressions (Scheper-Hughes, 1993).

Contemporary feminist and critical-disability theorists espouse intersectional theorising about embodiment and resistance (Garland-Thompson, 2005, 2001). Feminist-and critical-disability scholars call for transformative conceptualisations of disability that avoid conceptions of women with disabilities as passive victims of oppressive social conditions, stigma and low body- and self-esteem (Wehbi & Lakkis, 2010). These scholars claim that conceptualisations of disability should include representations of the ways in which women

cope with or resist stigma and oppression in its multiple forms (Nario-Redmond, Noel & Fern, 2013).

There is evidence that women with physical and sensory disabilities use strategies to protect themselves from negative characterisations and acts of violence. They can shuffle between disabled and non-disabled identities to suit their needs and, in doing so, protect themselves. They may conceal impairments, assert independence, decline or not ask for assistance, or utilise rehabilitative or medical intervention to eliminate impairments, "thereby escaping disability" (Nario-Redmond et al., 2013, p. 470). Women with visible disabilities are also able to manage, deflect, resist, or renounce public scrutiny (Garland-Thomson, 2001). In accepting impairments as part of themselves and not being ashamed of their limitations, disabled women can challenge or reject constructions of normalcy, shed dependent roles, and assert themselves in different ways, even as non-disabled people (Watson, 2000).

The affirmation model of disability holds that disability can be a benefit and not merely a form of oppression. For example, a specialised school may provide better education for some disabled women, while social grants may benefit those living in poor communities. There may also be lower societal expectations to live up to – women with disabilities are not expected to marry, get a job, or raise children. Moreover, body limitations may result in more innovative lovemaking strategies and therefore a better sex life (Swain & French, 2000). Thus, resistance theorists argue for the *embodiment* of disability, which includes experiences of pain, sexuality, relationships and violence, while recognising positive actions taken in the face of adversity and disability (Chappell, 2017).

The thesis may argue that the ways in which external and internal oppressions (the psycho-emotional dimensions of disability) can be challenged by disabled women may

provide an additional analytical and conceptual framework with which to explore and understand disabled women's experiences of GBV in South Africa.

Already, a few studies in southern Africa describe how women with disabilities confront disability stigma and assertions of "culture" that perpetuate gender norms and IPV. One study examined how women with disabilities in Zimbabwe challenge disability and sexuality stereotypes by demonstrating sexual prowess, by including themselves in sexual initiation rites, and by attaining reproduction and motherhood ideals (Peta, McKenzie, Kathard & Africa, 2017; Peta, McKenzie & Kathard, 2015). In South Africa, Chappell (2015) argues that resistance to normativity can occur by "queering" disability and disrupting normative constructs of sex, gender race and disability. He writes that "disabled people can queer their identity and open new social spaces in which to challenge normativity" (p. 55). In his study on black South African youths with physical and visual disabilities in rural KwaZulu-Natal, Chappell (2017) revealed that adolescents downplay their disability and affirm heteronormative sexuality; they do not perceive their relationship experiences to be any different to their non-disabled peers. Disabled young people, he argues, can either reinforce or subvert gender stereotypical roles and cultural norms in relationships. The study affirmed that disability is only one component of their identity and that disabled youths in South Africa are exposed to dominant discourses of hegemonic ableist ideals of marriage, sexual risk-taking, multiple partnerships, and the normalisation of IPV. Chappell underlines the danger that comes with assuming both disabled and heteronormative sexualities and identities. The study shows that, by minimising disability and overstating their sexuality, disabled youths remained at risk of HIV and GBV. Therefore, he argues, while resistance and agency may be central components of a disabled identity, they can further perpetuate disabled women's experiences of GBV.

A focus on resistance theories of disability may help to unpack the divergent discourses, processes, contexts, and power relations of disability and GBV in South Africa (Gabel & Peters, 2004). Recognition of the fluidity of the social model has led to this postmodern paradigm shift. And while resistance has been defined as “critical self-reflection coupled with action” (Davis, 2016, p. 184), resistance theory still neglects to examine or document the influence that resistance has on social change, and GBV prevention, for women with disabilities.

2.7 Emancipatory disability research for social change

The topic of social change has dominated rationalisations for disability-inclusive research in recent years. Both feminist and critical disability scholars acknowledge that emerging theories and models are still unable to improve living conditions for people with disabilities and create social change in the disability world (Bone, 2017, Mitra, 2018).

The emancipatory disability research (EDR) paradigm is purported to have a transformative agenda and is strongly linked to feminist and resistance objectives. The paradigm potentially heralds the possibility of inclusion and independence for people with disabilities, and advocates that any research be used for social change and include policy or practical implications (Stevenson, 2010; Barnes, 2008). The instrumentality of emancipatory research is closely tied to ethics and the ways in which research is conducted with and for people with disabilities.

The argument for the use of qualitative methodologies in emancipatory disability research, particularly those conducted in LMICs, pertains to their flexibility, and how they can elicit the psycho-emotional experiences of disability (Hartley & Muhit, 2003).

Thus the thesis will argue that formative qualitative investigations alone, or at the beginning of any research endeavour, may help to capture the political nuances of disability, and to ensure that multiple and heterogeneous understandings, definitions and experiences of disability are included in the research, and that all participants' needs can be reasonably accommodated. Moreover, including participants' own perspectives helps to facilitate an analysis of the complexities of knowledge and experience, which can, in turn, inform appropriate and inclusive GBV intervention.

2.8 Conceptual framework for understanding women with disabilities' GBV experiences in South Africa

No single model can fully explain disability (Mitra, 2018; Pfeiffer, 2001). Instead, various conceptual models reflect diverse ideological positions of disability, while other critical disability theories highlight agency, resistance, capability, and resilience. These may all serve to provide an understanding as to how women with impairments may differentially experience disability and GBV.

For the purposes of this thesis, disability is understood as socially and personally constructed. It is both a form of oppression and resilience. Both social and biopsychosocial models and theories of resistance and emancipation are useful for understanding the interactive causes of disability, but also for investigating how disability stigma, both external and internal, may further marginalise women with disabilities in South Africa, exacerbate their disability, and undermine their individual agency for resilience and inclusion. In saying this, the thesis makes use of intersectionality theory as a central analytical tool for understanding disabled women's experiences of GBV. The conceptual framework will guide

the interpretation of findings and provide a framework through which to present the evidence in the thesis as a composite body of knowledge. Combining the models and theories suggests that:

1) A spectrum of physical impairments (biology) is part of the disability experience. Physical impairments cause personal discomfort, pain and fatigue that add to their GBV experiences (embodiment).
2) Impairments lead to social discreditation and stigma that elicit disability-based violence in addition to gender-based violence.
3) Stigma may disrupt intimate relationships or become internalised and cause low self-esteem, which increases vulnerability to GBV. Thus, for the purposes of this thesis, disability stigma will require ongoing analysis regarding how it shapes the lives and violence experiences of women living with disabilities in South Africa.
4) Societal reactions to impairment will be exacerbated by environmental barriers, restricting participation and access to services, and increasing women's vulnerability to GBV.
5) Disability and GBV experiences are mediated by societal violence and social norms, e.g., the widespread acceptance of GBV, poverty and marginalisation in South Africa.
6) Their strategies to cope with personal pain, violence and disability stigma may show that women with disabilities are resilient.
7) By acknowledging the exclusion of women with disabilities' in GBV research, inclusive, ethical, and emancipatory research may help to chart participants' vulnerability, agency, and vision for social change.

The discussion (Chapter 8) will tie the qualitative findings to the existing literature and conceptual frameword presented above.

2.9 Conclusion

For all people with disabilities, the human right of freedom from violence and exploitation remains unrealised (Bartlett & Schulze, 2017). Thus, for the purposes of this thesis, the definition of disability sits at the intersections of biology and society and of agency and structure. The thesis attempts to draw on the social and biopsychosocial models of disability as well as emancipatory and resistance approaches. In doing so, it endeavours to highlight the gendered, personal and social experience of disability and to add knowledge about the lived experiences of disability and GBV in South Africa and other LMICs.

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CHAPTER 3. RESEARCH METHODOLOGY

3.1 Introduction

The aim of this study is to understand women with disabilities' experiences of GBV from their own perspectives, illustrating how a group of participants in similar contexts co-constructed the concepts and findings in this thesis. This chapter outlines how the research was conducted, the research paradigm, design and ethical principles, and the processes of selecting participants, along with the strategies used to collect, analyse, store and disseminate data. The chapter also discusses the role of potential biases and care for the researchers' own well-being.

3.2 A phenomenological paradigm

Morris (1991) argues that no single model or epistemology can serve disability research, because doing so treats participants as objects. By ensuring that both the personal experience and social construction of disability are included in interpretation and analysis, the thesis draws on the epistemology of the social and biopsychosocial models of disability, intersectionality, and critical disability studies within a broader phenomenological paradigm. The exploratory nature of phenomenology is suitable to this study's focus because it echoes these models and theories of disability insofar as the researcher is expected to describe the phenomena as they exist within the reality of a social location. Philosophical principles of phenomenology focus on discovering, describing, and understanding phenomena as they are experienced and given meaning from the point of view of several individuals, and representing participants' own perspectives (Creswell, 2012).

3.3 Research design

Both qualitative and quantitative projects, if done robustly, can help to fill evidence gaps on GBV against women with disabilities. However, there are strengths to designing and implementing a qualitative study. Qualitative research relays the experiences and perspectives of participants, and the dynamics of participants' interaction with the social world (Mays & Pope, 1995). Qualitative methodologies with persons with disabilities can approach "the complex interrelationships between physical impairments, barriers and [services]" (O'Day & Killeen, 2002, p. 9). Qualitative methods can reveal varying accounts of disability, different perceptions and themes around GBV, and intersections between historical, social, and personal factors that shape experiences of disability and GBV (Stone & Priestley, 1996). The participatory nature of qualitative methodologies "ground" IPV-research studies in the voices of participants, using their perspectives and language, and reflect the lived realities of women who experience intimate partner violence (Allen, 2011). However, practical measures and accommodations are needed to address the health, impairment and linguistic needs of participants with disabilities (Harris & Roberts, 2003). Identifying and removing physical and communication barriers posed by research processes is still under-researched.

There are some limitations to qualitative research. While interaction with participants and listening to their stories in their own words may strengthen the quality and validity of data, there are inherent challenges of bias in the researchers' interpretation of the stories of others. In addition, while face-to-face interviews, focus groups, and participant observations are deemed flexible and accessible qualitative-research tools when working with vulnerable populations (O'Day & Killeen, 2002), it may be that participants are less likely to disclose

violence or to be guaranteed anonymity, which makes data-collection on GBV challenging. Quantitative research has particular advantages where self-completed surveys may provide women more privacy to disclose violence.

Doing research with people with disabilities is not a straightforward process (Barnes 2008). Nind (2008) discusses the difficulties presented by the use of traditional qualitative methods with people with learning or communication disabilities who may have trouble understanding abstract questions or expressing their stories, and with whom establishing rapport and gaining informed consent may be challenging. She includes ways in which qualitative methodologies can be adapted to help with decision-making and communication, and suggests that accommodation and adjustment be ongoing throughout the research process. However, there is still little formal research and guidance on how to conduct qualitative research with people with a range of impairments, or with women with disabilities' experiences of GBV.

3.3.1 Narrative research approach

This qualitative research study aimed to gain a holistic understanding of GBV and disability through a narrative approach. Narrative research is a qualitative methodology to study embodied experiences and the ways in which participants make sense of the world around them, and to understand the process of personal identification (or lack thereof) with being disabled (Valeras, 2010). Narratives are not direct representations of a person's "individual experiences, but are shaped by the larger social, cultural and institutional narratives within which they live and have lived" (Clandinin, 2006, p. 51). Narratives are formed by using qualitative data collection tools to capture stories from participants about their individual lives and social experiences (Clandinin, 2006).

In this study, interviews and focus groups employed an “open-ended questioning and probing” technique to enable participants to share their own experiences and perceptions. Asking open-ended and probing questions can allow various interpretations of violence to emerge and provide opportunities for participants to formulate their own conceptualisations concerning lifetime experiences of disability-related and gender-based violence.

Having discussed the phenomenological paradigm, qualitative design, and narrative approach of the research, the next section identifies the strategies employed to ensure the inclusion of participants in the project.

3.4 Ethics for inclusive research

Research on GBV that includes women with disabilities requires special ethical attention. On the premise that participating in research can, under the right conditions, be therapeutic or cathartic (Ramjan et al., 2016), several measures were put in place to ensure the protection of women with disabilities in the study. Ethical principles of confidentiality, anonymity and informed consent were discussed with all participants. Participants were given information about the nature and process of the research, the potential risks and benefits involved in participation, and what outcomes could be expected, and that findings from the research would be available to participants if they asked for it. The study incorporated guidelines on conducting GBV research with women (Ellsberg & Heise, 2005). During the research process, however, it became clear that additional ethical considerations needed to be put in place to facilitate the inclusivity and protection of women living with disabilities. The combined ethical issues around participants’ disability-related needs and vulnerabilities and the sensitive

nature of violence-related research provoked ethical debate, which is discussed below (see Chapter 4).

The researcher (PhD candidate) was present at all interviews to conduct informed-consent procedures. Before any interviews took place, adequate information about the study processes was given to participants. “Informed consent” means that all participants are told exactly what is expected of them during each interview; are made aware of the potential risks involved; are informed of their rights to withdraw. The researcher made sure that participants could acknowledge all this and agree to participate. All participants were provided with a typed information sheet and information was shared with them orally in their preferred language (English, Afrikaans or isiXhosa) with the research assistant helping with isiXhosa translation. After participants asked questions and were satisfied with answers, they consented to participate, in writing or verbally. Verbal consent was audio recorded and noted on the consent form and signed by a witness – in this case, the interviewer. Verbal consent is considered an appropriate measure to ensure the anonymity of GBV survivors and can compensate for any literacy or impairment-related issues that make written consent difficult.

The information sheet and consent form appear together in Appendix 6. However, the accessibility of consent from women living with physical and sensory disabilities is another area that needs special attention and appropriate facilitation. This is covered in depth in Chapter Four.

Voluntary participation is a universal ethical issue but this is heightened for women with disabilities because of the power hierarchy between researcher and participant. World Health Organisation (WHO) guidelines state that women participating in violence research must be assured that their participation is voluntary and that they can withdraw from the

study at any time, and their withdrawal must not negatively affect them in any way (Ellsberg & Heise, 2005).

The interviewer gave participants several clear decision points during the interview to decide whether to go on – particularly when the participant was upset or reluctant to answer. Furthermore, probes were used to anticipate more difficult questions, e.g., "The next few questions relate to times when you have been hurt or abused. Do you want to continue?" Private spaces were identified for conducting interviews, such as a quiet room at the disabled people's organisation (DPO), at participants' homes, at the community library, outside under a tree at the residential care facility, or sometimes in the researcher's car. This helped to open discussions, ensure privacy, and facilitate disclosure of GBV.

It was anticipated that the duration of the interviews might cause some participants discomfort – for example, if their impairments create fatigue – potentially affecting the quality of the data collected. The time required to collect the data was explained to participants (approximately 1.5 hours per interview) and they were assured that they could stop or rest during the interview, if required, and continue when they were ready.

After interviews, participants were given a pamphlet of referral services with expertise in disability and GBV for their use. They were encouraged to contact the services they felt comfortable with, and to ask social workers to help facilitate access to a service if needed. The extent to which these referral services were accessible to participants with a range of impairments and different accommodation needs is unknown and may be considered a limitation of this study. The scope of the study did not allow for follow-up with participants to determine access to services recommended after the research.

The study was approved by the South African Medical Research Council's (SAMRC) Ethics Committee (EC034-11/2012) and the University of Cape Town's Human Research Ethics Board (HREC: 477/2013). This research study was reviewed and approved annually by the South African Medical Research Council (SAMRC) until study close-out.

3.5 Selection of study participants

A range of selection strategies was used in the study. Selection of participants was a collective effort facilitated by the researcher, research assistant and representatives of DPOs in Cape Town.

In qualitative research, the exact number of participants cannot be specified before the study is conducted, as the number of participants is informed by the extent to which the research question has been addressed (Marshall, 1996). Qualitative research is largely informed by the idea that ongoing data collection and interpretation may indicate missing voices or other persons who must be included to gain a more holistic understanding of the phenomena. Considering this, data from women with disabilities were supplemented with interviews and focus groups with a range of service providers in order to triangulate the participants' perspectives on violence against women living with disabilities in South Africa. A protocol amendment to include service providers was approved by the University of Cape Town and the SAMRC Ethics Committee in March 2015 (Appendix 1). Overall, 30 women with disabilities and 19 service-provider representatives participated in the study.

3.5.1 Selecting women living with disabilities

The inclusion criteria for participants with disabilities determined that the women had to be over 18 years old and had to have been living with long-term physical or sensory impairments for at least ten years prior to being interviewed. The ten-year impairment onset criterion

ensured that long-term perspectives of women living with disability who had histories of violence would be captured. Participants with co-existing severe cognitive impairments or requiring substantial physical or communicative assistance were excluded. The exclusion of more-severely disabled women and those with cognitive impairments is recognised as a limitation to the study's representivity and inclusivity, especially considering that they are often perceived as less able to speak for themselves and are more likely to be victims of violence (Hughes et al., 2012). Capri and Coetzee (2012) intimate that including research participants in study samples on the basis of their type of impairment could be seen as discriminating, unethical, and a contravention of their human rights. They further argue that the exclusion of people with intellectual disabilities means that their health and services needs remain unrecognised and unmet. While Northway, Howarth & Evans's (2015) research reveals that people with intellectual disabilities can discuss their feelings around abuse and recognise the impact this has on their lives, the small nature of the present study and the limited capacity of the researcher to facilitate communicative accommodations and assistance for these women may undermine its inclusivity.

For this study, women with physical or sensory disabilities were identified and selected from DPOs in Cape Town, including protective workshops[5] and residential rehabilitation facilities. There is a benefit to recruiting participants from services in that they may already have access to the support and counselling that might be called for during and after the research. At the same time, there may also have been a bias, as women who are involved with DPOs are likely to self-identify as disabled, and are already accessing services –

[5] Protective workshops are day-programme facilities set up in urban and rural communities by the Department of Social Development. The aim of the workshops is to provide skills-building and income-generating opportunities to persons with disabilities whose functionality does not necessitate institutional care but is too severe to qualify for employment.

thus excluding women who did not similarly self-identify or access services. Furthermore, using DPO representatives for recruitment may have jeopardized the representivity of the sample. DPOs may have coerced women into volunteering or, conversely, barred them from volunteering in fear that the services might be jeopardized or negatively evaluated (McDonald & Kidney, 2012).

The inclusion criteria were explained to service providers who invited women to be informed about the study. With permission from a senior manager of each organisation, the researcher and research assistant visited protective workshops (n=6) and residential care facilities (n=5) and introduced the study to groups of women who met the inclusion criteria.

Participants were introduced to the study as a research project on the lives of women with disabilities and the challenges and abuse they face and have faced. Although participants were not required to disclose whether they had previously experienced violence, service providers, such as social workers, often invited women they knew to have had previous cases of abuse or violence to participate. Service providers also typically invited women with disabilities without age-related impairments, given the ten-year onset criterion. As another limitation, the study thus has a relatively younger-aged sample and may not be representative of older women with disabilities.

Snowball sampling was also used a few times. This is an approach to locating information-rich informants by taking recommendations from participants about who the researcher should speak to (Heckathorn, 1997). Participants in the study referred the researcher to other women they thought would be interested in participating. The research assistant, who works as a qualified occupational therapist, was also instrumental in helping to identify former clients who would be willing to be interviewed.

3.5.2 Selecting service providers

Nineteen representatives from national and regional non-governmental organisations working in disability and GBV sectors in Cape Town participated in the study. Using email or telephone, and a database of organisations in Cape Town, the researcher invited service-provider representatives to participate in the study. Service providers were selected based on their knowledge or experience of working with women with disabilities or women experiencing GBV, as well as their willingness to participate.

DPOs in disadvantaged communities in Cape Town include protective workshops and residential care facilities for community members with disabilities. The DPOs provide disability awareness, and advocate and facilitate access to rehabilitation services, residential care facilities, counselling, individual case management and referrals. Some DPOs provide social development services, such as assistance with accessing government disability grants and housing programmes, and also assist with the procurement of specialised transport and assistive devices. Others provide life skills and economic empowerment strategies through job training, employment internships, and daily skills-building protective workshops.

GBV service providers include rape crisis centres, domestic violence shelters and Thuthuzela Care Centres (TCCs)[6]. The services provided by these centres included post-rape medical care and forensics, criminal justice system referrals, procedural assistance in reporting violence, 24-hour hotline services for victims, suicide-prevention hotline services, and trauma counselling for survivors of sexual assault and domestic violence.

[6] Thuthuzela Care Centres are one-stop facilities that were introduced as a critical part of South Africa's anti-rape strategy, aiming to reduce secondary victimisation and improve conviction rates. Fifty-one centres have been established since 2006. The centres are located in close proximity to hospitals and police stations and link up with sexual offences courts, prosecutors, social workers, magistrates, police officers and non-governmental organisations working with women and children.

3.6 Data Collection

3.6.1 Women with disabilities

Data was collected over a period of ten months in 2013–2014. The narrative approach employed repeat interviews with women with disabilities conducted by the researcher (PhD candidate) and research assistant. Overall, 52 interviews were conducted.

Interviews included open-ended questions with a semi-structured scope of inquiry (Appendix 2). The scope of inquiry covered topics such as living with a disability, childhood, family, community perceptions of disability, interpersonal relationships, and sexuality; experiences of violence, violence prevention, help-seeking, and access to post-violence care and services. Acknowledging that the experiences and aspects of women's lives cannot be pre-known or pre-defined, the study aimed to allow participants to determine their own definitions and characterisations of violence by posing indirect, open questions like, "Tell me about a time when you felt scared of being hurt or were hurt". This provided an opportunity for participants to speak about their own experiences and events and actions that were abusive from their personal perspective. Participants were encouraged to express knowledge, opinions, and feelings through further open-ended enquiry (probes). Modified questions from the Adult Abuse Assessment tool were incorporated into the scope of inquiry and used to probe for information on disability-specific violence experiences (McFarlane et al., 2001). Participants were given an opportunity at the end of interviews to share reflections on their participation in disability-related violence research.

Since the study explored experiences of stigma, gender inequality, sexuality, and violence, it was not expected that participants would be forthcoming and recount or

remember all their experiences, meaning that follow-on interviews allowed issues to be explored in stages across interviews. Returning for subsequent interviews helped to build rapport between the researcher (PhD candidate) and the participants. It allowed the researcher to come back to sensitive issues that were raised in a previous interview, depending on the readiness and willingness of the participant. Furthermore, questions about violence were regarded as sensitive and were therefore planned for discussion once rapport was established between participants and the researcher, i.e., during the latter part of the interview or during follow up interviews.

Repeat interviews were conducted until data saturation was achieved (Fusch & Ness, 2015; O'Reilly & Parker, 2013; Guest, Bunce, & Johnson, 2006). The number of interviews conducted with each participant varied, with some participants having one interview, and others having up to three. At the end of the initial interview, participants could agree to be contacted again. Translation and data analysis took place alongside data collection to allow questions to be refined and new avenues of inquiry to develop and be incorporated into follow-up interviews until saturation was reached in the emergence of new information and themes (Patton, 2002; Pope, Ziebland, & Mays, 2000). Interviews that were analysed and found saturated on the first visit were not followed up.

The number of interviews conducted with participants varied for different reasons: some participants were uncomfortable or distressed and did not wish to volunteer for a follow-up interview. Some were not inclined to extensive sharing, whereas others shared detailed histories and narratives about their life experiences, making follow-up interviews imperative. Although the researcher facilitated access to transport and venues, follow-up interviews in some cases were prevented by difficulties such as the participant's inability to meet at the venue at the scheduled date and time due to personal or family-related reasons,

terrible weather conditions, or lack of specialised transport. Overall, it was up to both participant and researcher (PhD candidate) to measure the attainment of data saturation and to make alternative meeting dates in order to fully represent their perspectives and ensure their ongoing participation in the study.

Women with disabilities who volunteered to participate nominated the time and date of the interview and a preferred, accessible venue, either at a nearby service-provider venue or at home. It can be problematic for a researcher to visit a participant's home. Home-visits may subject participants to further discrimination and/or violence if other household members learn of their participation in the study (Jewkes et al., 2000). Also, the presence of a caregiver or partner in the home may inhibit participants' responses (Jewkes et al., 2000). Thus, it was critical to identify interviews settings where participants felt safe, and where confidentiality and anonymity could be ensured.

The researcher (PhD Candidate) conducted interviews in English or Afrikaans, with a research assistant conducting interviews in isiXhosa. The research assistant was a black African female isiXhosa- and English-speaking occupational therapist with experience in rehabilitation and participation in the disability sector, as well as significant experience conducting qualitative research. Since the majority of participants generally spoke little English, it was recognised that the complexity of their stories could be lost through translation (Temple & Young, 2004) and that the process of translation in research is never neutral. Studies from South Africa show that translations and interpretations of languages and dialects may include various forms of identity and cultural politics, which introduces potential biases. Swartz (2015) and Drennen, et al. (1991) argue that the characteristics of translators – such as age, gender, and where they live – means that there may not be a single, ideal translation.

As insider knowledge is also key to good translation, it is important that the translator's life and situation are as close as possible to that of participants.

While the researcher (PhD candidate) was familiar with English and Afrikaans, it was difficult to follow the isiXhosa conversations. Not wanting to interrupt the participants' storytelling during interviews, the researcher (PhD candidate) allowed the assistant to use her own discretion to pause for translation or to let the participant carry on speaking. Serving as the translator during isiXhosa interviews, the assistant used her insider knowledge of the participants' communities and her disability scholarship and occupation to assist in interpreting the isiXhosa data. The audio-recorded interviews were transcribed verbatim by an employed transcriber and translated into English.

3.6.2 Socio-demographics and context of participants with disabilities

Socio-demographic information was collected during interviews with women living with disabilities, including age; onset, type and nature of impairment; race, living arrangements; type of housing; residential location: marital status; number of children; and employment status (see Appendix 2).

Thirty women with physical and sensory disabilities volunteered to participate in the study. Participants were majority black African (n=21) and Coloured women (n=9), residing in eight different lower and middle-class communities in the Cape Town metropole. The racial make-up of the participants means that they are more likely to experience social and economic disadvantage, and indicators of poverty and race have been consistently tied to differential experiences of disability in South Africa (Emmett, 2006).

The communities where participants resided were largely characterized by poverty. Common social conditions included informal housing, "shacks" and backyard dwellings; lack

of infrastructure and poor access to basic services; high unemployment rates; and high levels of crime, alcoholism, and substance abuse. The uneven and unpaved terrain, congested housing, and communal sanitation facilities of the informal settlements were often described as “inaccessible” to people with physical disabilities. Challenges associated with access to sanitation, education, and services highlight the relationship between poverty and disability in the country, and how restricting environments prevent people with disabilities from participating in community life and protecting themselves from violence.

Nineteen women had congenital impairments and eleven had acquired impairments, with the time of onset ranging from approximately 10 to 43 years. The relatively young age of the participants was surprising, but could be due to the 10-year onset criterion for inclusion. Congenital impairments include cerebral palsy or spina bifida at birth; conditions acquired in childhood or later in life include poliomyelitis, transverse myelitis, meningitis, diabetes, stroke, or injuries due to motor vehicle accident, fire, or gun-related violence that resulted in mobility or dexterity restrictions, paralysis, limb amputation or disfigurement. Some participants were wheelchair-users, others used alternative assistive mobility devices or moved independently. Hearing (n=7) and visual (n=4) impairments were either genetic, congenital or resulting from trauma, autoimmune conditions, cataracts, glaucoma, or chronic conditions associated with albinism or diabetes. Assistive devices included hearing aids or a probing cane. Generally, participants experienced a range of social and health problems and were often accessing some type of support from health- and rehabilitative-care providers, social workers, mental health providers, or protective workshops.

Living arrangements varied, with the majority of participants co-habiting with a partner or husband (n=14) or living with parents or siblings (n=7). Nine participants were resident in care facilities at the time of the study. Only half of the participants had ever

partnered. Twelve participants had children. Most participants had been enrolled in mainstream schools where they received little to no rehabilitation and where they struggled to keep up with their non-disabled peers. Most of the participants had not completed secondary school education and only two women had enrolled in tertiary education.

Participants reported that formal employment was a struggle due to the already high rates of unemployment in the country, lack of education, or barriers produced by impairments, which limited employment opportunities. Seventy percent were unemployed or working for a stipend at a protective workshop. Those in residential care facilities were the least likely to be employed or have an income other than their disability grant. Most women were eligible recipients of disability grants[7]; however, some reported challenges in accessing them, despite being dependent on the grant for their monthly income (see Appendix 3 for socio-demographic information of participants with disabilities).

3.6.3 Reasonable accommodations during the research process

Because of the social model's emphasis on dismantling barriers and assisting people with disabilities to participate in society, one central tenet of the data collection process is "reasonable accommodation", which requires facilitation throughout the research process. Reasonable accommodation means any action, behaviour or modification made to the immediate environment to eliminate barriers or increase access, participation or advancement of a person with a disability, or from another disadvantaged group (United Nations, 2006). It encompasses the principle of accessibility. Reasonable accommodation was inseparable from the research methodology.

[7] The South African government disability grant is available to those with certified impairments who are medically unfit to work. At the time of the study, grantees were receiving USD103monthly.

Participants in the study were reasonably accommodated according to their *self-defined* needs: the aim was to ensure they were physically comfortable, able to communicate effectively, and protected from adverse events precipitated by their inclusion in a study on violence. DPO representatives and the research assistant used their rehabilitation experience to gauge the comfort and accommodation needs of participants. Specialised transport was arranged with assistance from service providers for three participants requiring transport to interview venues. A South African Sign Language (SASL) interpreter was used twice during the study to assist with communication with hearing-impaired participants. Participants were encouraged to nominate an interpreter with whom they had established rapport and trust. The SASL interpreter translated the questions and probes from the researcher and responses from the informant.

3.6.4 Service providers

Nineteen representatives from seven DPOs and three GBV services agreed to participate in interviews or focus groups. In order to include various representative levels and role players, persons interviewed included senior managers, counsellors, and social workers.

Service providers were contacted by telephone or email and invited to participate. With informed consent, seven individual interviews and three focus-group discussions with three to five representatives were conducted in private venues and lasted between one and two hours. When more than one representative agreed to participate, focus groups were conducted to include a diversity of opinions, values and concepts. Service providers were offered refreshments after discussions. The scope of inquiry for service providers included perceptions of the magnitude of the problem; sources of support; perceptions of the

effectiveness of services; and recommendations for responding to violence against women with disabilities (Appendix 5).

All service-provider participants were given information about the study, were made aware of the potential risks involved, and told of their rights to withdraw. All participants were provided with a typed information sheet that was shared with them orally in their preferred language (English, Afrikaans, or isiXhosa). After participants asked questions and were satisfied with answers, they consented to participate in writing or verbally. Verbal consent was voice-recorded and noted on the consent form and signed by a witness – in this case, the interviewer (See Appendix 7 for the information sheet and consent form).

3.7 Data generation and management

Qualitative analysis is an iterative process and findings are generated inductively (Mays & Pope, 1995). From demographic information and notes taken during interviews, descriptive summaries were collated for each interview. Each summary was placed into participant case folders on the computer, along with the typed-up field notes and transcribed interview/s. Case folder information was managed and collated using ATLAS.ti 7.5.6.

3.8 Data analysis and coding

In the phenomenological paradigm, narrative analysis has become the common practice for interpretation of qualitative data (Silverman, 2015; Rapley, 2011; Riessman, 2011; Ollerenshaw & Cresswell, 2002; Mattingly & Lawlor, 2000). In this research project, narrative inquiry was used to analyse abstract constructs and experiences of GBV from the participants' viewpoint rather than providing an absolute answer to the problem. Furthermore, by showing

relationships between themes embedded in narratives, narrative analysis can move across structure and context to reveal the processes through which gender is produced (Silverman, 2015, p. 130).

Thematic coding

Thematic coding (i.e., single coding) was conducted by the PhD candidate. Through a close reading of the transcripts, key or striking fragments of the texts were identified and labelled with a code that was attached to categories and themes. Initially, thematic coding was deductive and drew from the main themes that emerged from the scope of inquiries.

Subsequent themes were identified through inductive analysis of emerging issues, ideas, and patterns. Relationships and connections between labelled codes were identified and grouped together. Sub-grouping was guided by the repetition of concepts or experiences, similar phrases, patterns, themes, relationships, and differences.

Then transcripts were re-read, and selective coding was used to identify core concepts that included all similar or categorised data. Selective codes with related information could be compiled into empirical findings or arguments, while connections, complexities, and contradictions within and between narratives were documented in memos, to be integrated later into the presentation of findings. Memos further noted aspects of interviews that were of significance to new research questions or for future research inquiries. Emerging codes shaped ongoing decisions about how to proceed and which further recurrent and new themes could be added to the scope of inquiry.

3.9 Data storage

All participants were given pseudonyms in all public reports and manuscripts. The audio recordings, field notes, signed consent forms and transcriptions were stored at the SAMRC's offices in Cape Town in locked cabinets and on a password-protected computer. All data will be kept in a secure storeroom for at least five years after the thesis has been approved. After this period, the recordings, transcripts, and notes will be destroyed.

3.10 Data dissemination

Bearing in mind the fundamental ethical responsibility to disseminate research findings and share findings with participants, it is hoped that the outputs from this thesis may be used (and be useful) to inform the development of knowledge in the field of GBV research, as well as to have future impact on the prevention of violence against women with disabilities. In Chapter 4, the accessibility of research dissemination and translation that is relevant and suitable for people with disabilities is discussed. It is hoped that the published peer-reviewed papers that are part of this thesis are accessed by both the GBV and DPO sectors, and broader academic community. The findings have and will be presented at academic conferences and used to train fieldworkers in how to conduct ethical and inclusive research with women with disabilities. It is envisaged that a summary of findings from the thesis will be developed into a format such as a pamphlet (available in all languages) and made accessible (in large print or Braille) for use by DPOs and the GBV sector for dissemination to women with disabilities.

3.11 Data validity and potential biases

Ensuring the validity of qualitative data is a contentious issue. Research findings in the thesis are conceptualised as representations of participants' experiences. Since disability is socially constructed, so, too, participant narratives are partial and situated. Research biases in qualitative research include respondent and researcher bias that may affect data validity. Acknowledging that some participants with disabilities are vulnerable to exclusion and violence, and may be less able to independently meet their needs or overcome problems, those participants living in facilities, or recruited from DPOs and protective workshops that are meant to "serve their needs", may have provided more socially desirable stories that would not potentially affect the help and services they received. Women with disabilities may have also underplayed or under-reported their experiences of violence for fear of exposure or retribution by perpetrators at home or at DPOs. To help minimize desirability bias, questions were presented in a manner that attempted to make the participant feel accepted and unjudged, no matter what answer they gave. If it was suspected that they felt fear or were not forthcoming in sharing a story, indirect questions about what a third party would do in a particular or similar situation were asked. This may help the participant to project his or her own feelings onto others and provide accurate and more representative answers.

It is also likely that, due to the disability status of both the researcher and the participant, there may have been acquiescence bias or friendliness bias. This occurs when the participant simply agrees with the researchers' directions for study participation or interpretation of participants' stories. This may have occurred due to participants' feeling that they had something in common with the researcher (namely disability status). This bias escalates if fatigue sets in; some people will agree just to complete the interview. To avoid

this, the researchers tried to replace questions that imply a “right” answer with those that focus on the respondent’s true point of view.

To enhance the trustworthiness of the study, open-ended questions and probes were used, and leading questions were to be avoided. Participant quotes are used to reflect their personal experiences and perspectives. Combined viewpoints from both service providers and women with disabilities further validate the data. Also, the keeping of notes and memos throughout the work of data collection and analysis helps to jog researchers’ memories and encourage “truthfulness” (Silverman, 2013). The culmination of interview transcripts and codes also increased the credibility of what is being represented (Silverman, 2013).

Member checks, in which participants review their interview transcripts and edit them as needed, were not conducted. It was decided that member-checking could be difficult due to literacy challenges or impairments, and might potentially re-traumatise participants. However, in follow-up interviews, summaries of the participant’s previous interview data and the researcher’s understanding of the data were presented to participants by the researcher or assistant to re-centre the data collection process. This was also done to try to avoid confirmation bias by the researchers. A more participatory approach to the data collection may have enhanced data quality and interpretation (Chappell et al., 2014).

The validity of this study may also be based on how well the knowledge generated from the overall analysis could facilitate the prevention of violence against women with disabilities in South Africa, or improve the provision of GBV and other health services for them. One of the central concerns of emancipatory disability research is that the research can improve the lives of people with disabilities (Barnes, 2003, 2004, 2008). Chapter Four considers the potential of the study to achieve social change.

Narratives are interpretations of peoples' social worlds. Interpretations made by the researcher are themselves construed within an institution of academic theorising, reporting and peer review, and thereafter presented as findings. Thus, interpretations of qualitative data are partial and situated. Findings are valid insomuch as they are discursive and situated within power relations or rules of *how* data must be analysed.

3.12 Positionality and reflexivity

Validity is further enhanced if the positionality of the person analysing the narratives is considered. "Positionality", a central component in the process of qualitative data collection, constitutes a reflexive approach that recognises the relevance of social divisions and power hierarchies between the researcher and participants. The thesis acknowledges that a multitude of biases and identities might have affected the researcher's interaction with participants, interpretation, analysis and summation of the research – culminating in potential researcher bias.

The involvement of the research assistant needs to be mentioned. The assistant's professional, cultural, racial and personal filters had an influence on the data collection process. The research assistant was a black African woman living with a physical disability, who had grown up in one of the informal communities in Cape Town that were visited for recruitment. As a trained occupational therapist, she had the advantage of tertiary education and training that a woman living with a more severe disability may not have had due to limitations in accessibility. Her established links with DPOs and rehabilitation centres in Cape Town helped facilitate the recruitment of potential participants with disabilities and service providers. Moreover, her knowledge of the sociocultural context of informal settlements and

disability-related issues was crucial to the interpretation and probing done during the interviews.

The researcher's position was somewhat different from those of the participants and the research assistant. This is reflected in her position as an academic, and as a white middle-class woman living with a congenital physical impairment (cerebral palsy). Living in an affluent suburb in Cape Town, having training and experience in GBV research, and having access to multiple resources, meant that her life experiences were different from participants. On the other hand, being a disabled researcher may have assisted in building rapport with the participants, despite other differences in identities. Chapter Four discusses this in more detail.

3.13 Looking after the researcher's well-being

Feminist and emancipatory paradigms emphasise the consequences of "doing research" on the researcher. Although preventing harm to participants is of primary importance, the emotional toll of listening to women's stories of despair, degradation, and physical pain and violence can have an impact on the researchers and intermediaries involved in conducting research on GBV. Acknowledging the potential for vicarious trauma in studies of this nature, the researcher and research assistant conducted a maximum of two interviews per week, as these could be long and traumatic. After each interview, the researcher and assistant discussed the fieldwork experiences together, including the distressing issues that emerged.

The researcher experienced some overt and other subtle signs of vicarious trauma during the data collection and writing process of the project. Her first interview with a young participant with cerebral palsy was particularly emotional and stirred up many feelings that would re-emerge throughout the research process. The collection of sensitive data can evoke

emotional reactions and researchers may have difficulty distancing themselves from personal stories. Debriefing can address the emotional effect of gathering sensitive qualitative data (Ramjan et al., 2016). The researcher's supervisor had many years' experience and training in GBV research and was thus able to facilitate debriefing. Furthermore, the researcher sought personal counselling many times during the years of data collection and interpretation.

3.14 Conclusion

There are strengths and limitations to a qualitative study on GBV against women with disabilities. There may also be ethical challenges to overcome when involving women with physical and sensory disabilities, of which there is little discussion or guidance in the existing literature on GBV research. The next chapter details the ethical dilemmas of including women with disabilities in a study on GBV.

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CHAPTER 4. ETHICAL CONSIDERATIONS FOR DISABILITY INCLUSIVE GENDER-BASED VIOLENCE RESEARCH

REFLECTIONS FROM A SOUTH AFRICAN QUALITATIVE CASE STUDY

Citation:

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Conceptualisation:

The conceptualisation of this paper emerged from the research process. I conceptualised and conducted the data analysis for this paper and wrote the full draft and all revisions of the paper. Both supervisors approved the final draft of the paper before it was submitted for publication (revisions currently under review at *Global Public Health*).

Authors' contributions:

I. van der Heijden – protocol development, data analysis, writing full draft and all revisions of the paper.

N. Abrahams – review of protocol, mentoring of data analysis, critical review of all drafts of paper.

J. Harries – review of protocol, mentoring of data analysis, critical review of all drafts of paper.

Motivation for inclusion:

This chapter addresses the fourth objective of the thesis: to consider how to promote ethically safe GBV research on women with disabilities and is presented in the format of a journal article.

Abstract

Globally, women with disabilities experience heightened and unique forms of violence compared to men with disabilities and women without disabilities. Yet formalised guidelines for their inclusion in gender-based violence (GBV) research is lacking. This paper draws on ethical guidelines for researching violence against women and disability studies on the ethicality of including people with disabilities in research to advocate for women with disabilities' inclusion and safety in GBV research. Reflecting on lessons from a qualitative study on violence against women living with disabilities in South Africa, the paper considers what could be of value for violence researchers and ethics review committees in low-middle income countries. It aims to stimulate debate around the integration of reasonable accommodation, accessibility and equal participation in planning and conducting ethical and inclusive GBV research. The paper recommends that considerations are practically applied and tested in other low-middle income countries (LMICs) and thereafter critiqued in consultation with a range of stakeholders and women with disabilities to enhance best practice and form a basis for developing a guideline for undertaking ethical and inclusive GBV research in LMICs.

4.1 Background

Eighty percent of the world's disabled population are living in low-middle income countries (LMICs), humanitarian and conflict settings and various institutions (WHO & World Bank, 2011; WHO, 2007). These contexts heighten vulnerability, and people living with disabilities are more likely to experience violence during their lifetime than their non-disabled counterparts (Hughes et al. 2012). Focus on women with disabilities and gender-based violence (GBV) research in South Africa and other LMICs is emerging (van der Heijden & Dunkle, 2017; Puri, Misra, & Hawkes 2017; van der Heijden, Abrahams, & Harries, 2016; Meer & Combrink, 2015; Neille & Penn, 2015; Astbury & Walji, 2014; Kvam & Braathen, 2008). However, a central ethical dilemma for scholars is how to include women with disabilities in GBV research and protect them from harm.

Researchers have developed a set of ethical guidelines for GBV and primary violence prevention studies (Ellsberg & Heise, 2002; Ellsberg & Heise, 2005; Hartmann & Krishnan, 2016). Ethical recommendations have also been produced for studies on perpetrators of violence (Jewkes, Dartnell & Sikweyiya, 2012), trafficked women (Zimmerman & Watts, 2003), women in conflict settings (WHO, 2007) and violence against children (CP MERG, 2012). These guidelines try to ensure quality data collection and protection of participants. Guidelines address privacy and confidentiality, safety of participants and research staff, researcher training and informed consent procedures. However, attention to the unique ethical complexities of research with women with disabilities who may have experienced GBV is missing.

Ethical guidelines tell us that vulnerable research participants should receive special attention as they experience heightened stigmatisation, limited power, lower education,

increased poverty, limited resources, live in settings of conflict, and have inadequate physical strength and/or other necessary attributes to protect and defend their own interests; i.e. they may be at risk of being exploited or harmed during research (WHO, 2016). Notwithstanding, there are ethical contradictions for including vulnerable groups, particularly in violence related research. Disability scholars acknowledge how ethics relates to weighing agency and vulnerability of disabled participants and consider how ethics can be both a tool for protection and exclusion in research. Disability studies largely focus on the susceptibility of people with intellectual disabilities to coercion and give arguments supporting intellectually disabled people's capacity to give informed consent. Researchers also debate the benefits of inclusive research that uses accommodations and assistive devices, and ensures the time is taken to ensure full understanding and ongoing consent (Northway, Howarth & Evans, 2015; McDonald & Kidney, 2012: Nind, 2008, Iacona 2006; Iacona & Murry, 2006).

For people with intellectual disabilities, disclosure of violence is not easy given communication difficulties; disclosure is not always taken seriously; and inadequate psychological support for the impact of violence is not always available or timeous (Northway, Howarth & Evans, 2015). Benefits of inclusion are typically de-emphasised (McDonald & Kidney, 2012) or undermined when participants remain in abusive scenarios, perpetrators are not prosecuted, or participants find that they are not empowered through self-defence strategies or prevention intervention (Northway, Howarth & Evans, 2015). While there is widespread contention over the conservative and over-protectionist ethics surrounding disability inclusive research, there are increasing calls for direct participation of people with disabilities in all research that affects their lives (McDonald & Kidney, 2012; Barnes, 2004, 2008).

While not particularly addressing GBV studies, the positions and arguments pertaining to the ethics of disability inclusive research are worth considering. Drawing from disability and GBV ethics literature and lessons from a qualitative study, this paper considers what could be of value for violence researchers and ethics review committees in LMICs. It aims to stimulate debate around the integration of reasonable accommodation, accessibility and equal participation in planning and conducting ethical and disability inclusive GBV research. The paper recommends that considerations should be practically applied and tested in other LMICs and reviewed in consultation with a range of stakeholders and women with disabilities to enhance best practice. The idea is thus to form a basis for developing guidelines for undertaking ethical and inclusive GBV research.

The case study

A qualitative study undertaken in Cape Town, South Africa, between 2013-2015 revealed the precursors to recommendations made in this paper. The study protocol attempted to be inclusive and applied an emancipatory disability research stance (Barnes 2003, 2004, 2008). The South African Medical Research Council and the University of Cape Town ethics committees approved the research. The study included 30 adult women with a range of physical and sensory disabilities, who participated in in-depth interviews about lifetime violence and interpersonal relationships.

Participants' impairments ranged from immobility caused by cerebral palsy, Spina Bifida, para- and quadriplegia, amputation, deformity, muscular dystrophy, and transverse myelitis. participants were wheelchair-users and others used alternative assistive mobility devices or moved independently. Hearing and visual impairments were either genetic, congenital or resulting from trauma, autoimmune conditions, cataracts, glaucoma, or chronic condition associated with Albinism or diabetes. Assistive devices included hearing aids or a

white cane. However, participants generally had limited access to assistive devices or prostheses.

Participants were recruited from protective workshops and residential rehabilitation facilities and were mostly poor black African and Coloured individuals living in informal settlements, and were eligible to receive a monthly disability support grant (see Appendix 3 for sociodemographic characteristics of participants with disabilities). It is important to note that ethical considerations in the paper are specific to participants who reported no cognitive or intellectual impairments and whose context is comparable to women with disabilities living in other LMICs.

While the study protocol stipulated additional sensitivity in undertaking GBV research with women with disabilities, the research process provided a further opportunity to identify lessons learned from the field, and limitations in existing GBV research ethics guidelines that undermine protection and equal participation of women with disabilities prompted further debate.

4.2 Considerations for disability-inclusive GBV research

The research process revealed several additional ethical considerations to foster inclusivity: defining disability and inclusive recruitment; reasonable accommodation and accessibility of consent and referral services; confidentiality and disability intermediaries; acknowledging power hierarchies and disabled researcher positionality; additional researcher training and skills; benefits and compensation for marginalised participants; promoting positive social change for participants (i.e. dismantling stigma and barriers) and ensuring accessibility of knowledge, research translation and uptake.

4.2.1 Defining disability and inclusive recruitment

How disability and (gender based) violence are defined depicts how inclusive GBV research and methodologies can be. Endorsed by the World Health Organization, the International Classification of Functioning, Disability, and Health (ICF) framework recognises that disability is not defined or measured by personal impairment or level of functioning. Rather, disability is socially constructed, i.e. social factors or environmental barriers hinder an individual's full participation in society on an equal basis with others (WHO, 2001).

Impairment severity, age, gender, race, sexual orientation, ethnicity, socio-economic status, refugee status, etc, interact and marginalise people with disabilities (Oliver, 2013; Haegele & Hodge, 2016). Social and biopsychosocial models of disability concur that if barriers are removed and people with disabilities are given suitable accommodations, equivalent rights and access to equal opportunities and resources, they can participate in and contribute to society (WHO, 2001). That said, models of disability are evolving, severity of impairments are varied and the extent of barriers people with disabilities face are diverse and subjective. To dissuade the use of medical model conceptualisations of disability, ethical guidelines can recommend the incorporation of the WHO's definition of disability and measurement tools (WHO, 2001) to ensure that inclusive GBV studies are comparable.

The severity of impairments and extent of barriers women face are varied and subjective; disability is not a homogenous concept in Southern Africa (McKenzie, Mji, & Gcaza, 2014). Methodologies and research processes therefore should be flexible and responsive to a broad spectrum of impairments, but more importantly they should reveal the disabling and enabling factors that impact on inclusive participation.

The qualitative and flexible nature of the case study meant that stringent sampling processes did not apply. Purposive sampling occurred whereby women with disabilities were

recruited from a range of protective workshops and residential rehabilitation facilities that work directly with women with disabilities in disadvantaged communities in Cape Town. Gatekeepers at DPOs were contacted to gain permission to introduce the study to participants. Managers and social workers at these establishments helped identify those women they knew or expected had experienced violence and helped identify participants' mental state or readiness to participate in a study of this nature. A research assistant also helped facilitate recruitment as she had experience in the disability sector and was familiar with the contexts of the workshops and care centres, and lived in one of the communities these organisations served.

Like GBV researchers, some disability researchers suggest placing recruitment in the hands of service providers working directly with women with disabilities and whose interest is in the protection of and benefit of participants (Nind, 2008). Others argue that this kind of gatekeeping or use of intermediaries can be selective and biased (Iacona & Murry, 2006). During the study it was suspected that one participant had a severe cognitive or learning difficulty. This incident revealed the challenge of relying on gatekeepers to access suitability of participants to inclusion criteria. It further highlights how some service providers in South Africa may have little knowledge or awareness of clients' capacity to participate or may be complicit in coercing their participation. Other possibilities to understanding this recruitment dilemma is acknowledging that women with cognitive disabilities are at higher risk for violence than those with other impairments (Hughes et al., 2012), and perhaps the service provider was less focused on cognitive capacity than increased vulnerability to GBV.

For our study, we recognised that women with disabilities are frequently excluded from research or are spoken for by other stakeholders. Further, understanding that many people with disabilities are isolated and have no contact with service providers or

researchers, recruitment strategies needed to focus on finding those most hidden and at risk of marginalisation and abuse. Recruiting participants from protective workshops[8] and residential rehabilitation facilities captured participants that were unemployed and had little access to resources but were accessing disability-related services. Additionally, participants who volunteered were encouraged to act as informants to help identify women with disabilities they knew had experienced violence. Some of these participants, who were identified by snowballing, were isolated, and had no contact with service providers, thus their recruitment facilitated the study's inclusivity. We argue that in future GBV inclusive studies, inclusion and exclusion criteria must be justified and compensate for the isolation of women with disabilities, especially those who are home-bound, institutionalised or lack communication faculties to reveal experiences of GBV.

4.2.2 Reasonable accommodation and accessibility of consent and referrals

Reasonable accommodation is a tenet of the Convention on the Rights of People with Disabilities and refers to any action, behaviour or modification to the immediate environment that has been made to eliminate barriers or increase access, and encourage the equal participation or advancement of a person with a disability in society and in research (UN, 2006). It encompasses the principle of accessibility. The protocol of this study anticipated additional and unintended barriers and planned to consult with managers and social workers of DPOs to facilitate disability-specific needs and minimise barriers before commencing research. Further to this, participants were given opportunities at the beginning of the study to self-identify supports required to facilitate their participation.

[8] Protective workshops are day-programme facilities set up in urban and rural communities by the Department of Social Development. The aim of the workshops is to provide skills building and income-generating opportunities to persons with disabilities whose functionality does not necessitate institutional care but is too severe to qualify for employment.

This paper argues that letting participants define their needs improves the quality of inclusive GBV research. That said, reasonable accommodations may be dependent on specific cases and resources available. In the study, provisions were made for specialised transport, interpreters and included both oral and written informed consent procedures to facilitate equal participation. Participants were encouraged to nominate an interpreter with whom they had established rapport. Having a trusted interpreter may facilitate disclosure and help put participants at ease that their words would be correctly translated. It was anticipated that the length of the qualitative interviews might cause some participants discomfort, as they may tire due to impairments, potentially affecting the quality of data collected. Accordingly, data collection was put on hold if participants were fatigued, uncomfortable or distressed and interviews resumed at a later stage (Ellsberg & Heise, 2005).

WHO guidelines on violence against women research recommend that researchers have an ethical obligation to provide participants with information or services that can respond to their needs (Ellsberg & Heise, 2002, Ellsberg & Heise, 2005). Thus, accessibility of referral services is an additional recommendation for planning inclusive GBV research. The study envisioned that researchers help facilitate access to protection and justice, given that women with disabilities have been historically marginalised from accessing services and are often unaware of resources and services that exist in their communities (Baart & Taaka, 2018). It was the responsibility of the researchers to facilitate accessible referrals, in consultation with DPOs and GBV service providers.

Disability studies acknowledge the mental health effects related to violence against women with disabilities (Dembo, Mitra & McKee, 2018; Joseph, Soletti & Basumatary, 2017; Astbury & Walji, 2014). This study focused on sensitive topics relating to stigma, discrimination, and violence, which had the potential to invoke embarrassment, fear, sadness

or anxiety for participants. This applied to researchers as well, who could potentially feel distressed after hearing traumatic stories. While researchers were given de-briefing opportunities (Ellsberg & Heise, 2005) it was important that participants experiencing trauma directly from violence or through talking about it be offered accessible services of professionals for onward referral. However, many participants were unaware whether they could utilise these services, a lesson learnt for future research. Thus, ethical guidelines should indorse using a service access checklist to ensure the accessibility of such services, i.e. guidelines should recommend checking for ramps, lifts, toilet access for inclusive GBV research and prioritise collaborative referral processes between GBV services and DPOs. Furthermore, researchers offered to initiate contact with professionals for participants and it was stipulated that costs would be covered for transport to these services if needed, taking into consideration the obstacles associated with getting to and receiving health care (Baart & Taaka, 2018).

Accessibility of study information and informed consent is an area that needs special attention and appropriate facilitation if GBV research is to be inclusive. Inclusive communication is a methodology for ensuring that information can reach all participants regardless of the nature or severity of impairment or level of education, such as speaking slowly or using inclusive communication tools such as Braille (Nind, 2008). Furthermore, while it is common practice to request written consent, Silverman (2013) states that highly formalised ways of securing consent should be avoided in favour of fostering relationships in which on-going ethical regard for participants is sustained.

It was anticipated that participants living in the poorer communities of Cape Town were more likely to have literacy limitations and unequal access to communication alternatives, making accessible informed consent important. Moreover, GBV research

guidelines acknowledge how written consent may be problematic for ethical research as it may be viewed as a risk by respondents or may be difficult for illiterate participants, and how verbal consent is an appropriate alternative (Jewkes, Dartnall & Sikweyiya, 2012). What is less agreed upon regarding these ethical guidelines is how verbal consent should be obtained and documented.

Understanding that people with sight impairments rely heavily on speech communication, an option for verbal explanation of consent was important for this study. Talking one-on-one with participants, sharing study information, and asking participants to state their name, acknowledge comprehension and agreement to participate on audiotape facilitated verbal consent in the study. For those few participants who used South African Sign Language (SASL) a nominated sign language interpreter ensured accessibility and facilitation of either signed or verbal informed consent process.

To date there is little to no research that has been conducted on the power dynamics of including a third party or intermediary in GBV research procedures such as informed consent – an exception being the dynamics on guardianship for minors (CP MERG, 2012) and a brief consideration of including caregivers (Hartmann & Krishnan, 2016). The ethicality of using proxies for consent of participants with intellectual disabilities has been covered (Carey & Griffiths, 2017; McDonald & Kidney, 2012). However, while guardian consent is required in the case of minors and those who lack mental capacity to provide consent in South Africa (Republic of South Africa, 2005; Republic of South Africa, 2002), GBV ethical research guidelines should consider diverse and often ambiguous roles and standards of intermediaries used to facilitate inclusivity, across different settings.

4.2.3 Confidentiality and intermediaries

Respecting anonymity and protection of vulnerable research participants is fundamental to the ethical principle of 'do no harm'. International guidelines on VAW research clearly identify privacy and confidentiality as essential to women's safety and data quality (Ellsberg & Heise, 2002; Zimmerman & Watts, 2003; Ellsberg & Heise, 2005) and recommend confidentiality be reaffirmed throughout the research process (Hartmann & Krishnan, 2016). Confidentiality requires additional attention in the case of intermediaries who aid women with disabilities. The presence of an intermediary can severely limit equal participation and confidentiality and may expose women to disclosure-related violence and other harmful repercussions (Jewkes, Watts, Abrahams, Penn-Kekana, & Garcia-Moreno, 2000). To minimise harm and ensure their safety, their disability-specific needs should be accommodated for, and confidentiality be ensured.

In the cases where intermediary assistance was needed for communication difficulties with participants with hearing impairments, participants were made aware of the potential risks in their involvement so that they could make an informed decision about being included in the study. Participants identified intermediaries with whom they had established rapport to ensure their trustworthiness. Where participants were not able to identify an assistant, an alternative was using proxy interpreters or assistants selected by DPOs and de-briefed by the research team. In the study, sign language interpreters signed a pledge agreement that acknowledged their respect of participants' confidentiality. Equally, participants had to agree to their assistants' involvement in the interviews and acknowledge the risks involved. These agreements were dealt with before each interview.

4.2.4 Acknowledge power hierarchies and researcher positionality

The spectrum and diversity of disabilities and intersections with other social categories within a study will play a role in creating power differentials. Inclusive and ethical approaches to GBV research should reflect on power differentials and researcher positionality and the impact they have on the collection, interpretation, and representation of data.

Regardless of variations in appropriate data collection methodologies, hierarchies between a non-disabled researcher and disabled participants or the vastly different socioeconomic opportunities between different participants with disabilities may be amplified (McKenzie, Mji & Gcaza, 2014).

In the study, power differentials were made more complex by the interaction of disability status and socioeconomic and historical racial divisions entrenched by apartheid. While the advantage of having a black African female research assistant with a disability from one of the included communities helped facilitate rapport and deeper sociocultural understanding, participants' background contrasted largely from the primary researcher. The white female researcher was from a historically privileged background, with a high level of education and formal employment. She is also a woman living with a congenital physical disability. While disability research does not necessarily require that disabled researchers collect data (Barnes, 1992, p. 122), the disability statuses of both researchers helped break the disability divide and facilitated rapport and empathy with participants. Participants were more likely to include researchers in their narratives by saying "people like us" or "you know how difficult it is?", despite racial and socio-economic differences. That is not to say that other identities such as same gender, nationality, ages or race (of the research assistant) may have facilitated rapport and empathy.

Researchers in LMICs show how participatory research strategies facilitate reasonable accommodation, alleviate power hierarchies and foster representation of participants and socio-cultural interpretation of findings (Chappell, Rule, Dlamini, & Nkala, 2014; Harris & Roberts, 2003). To minimise power differentials, South African disability researchers advocate involving participants as co-researchers. Chappell et al. (2014) argue that participants' training and inclusion in research processes reinforces the agency of participants and allows them to build identities as co-researchers other than as passive participants with disabilities. Chappell and colleagues' study particularly helped rural black South African youth gain self-worth and recognise their potential for inclusion in social and health care opportunities (Chappell et al., 2014).

While including people with disabilities as researchers can close the gap between researcher and participant, this strategy was deemed unsuitable for an exploratory study on GBV, where survivors with disabilities may experience re-traumatisation by interviewing participants. Furthermore, vicarious trauma in the field of GBV research with women with disabilities may be exaggerated by a researchers' personal experience of disability and marginalisation and/or experiences of GBV. While Swartz (2014) advocates training uneducated and unqualified persons with disabilities in research in LMICs, further considerations and evidence of participatory research in GBV-specific research is needed.

4.2.5 Additional researcher training and skills

The World Health Organization's ethical recommendations argue that interviewer skills, competence and training are key quality measures for GBV research and recommends two weeks of training to be included in protocols (Ellsberg & Heise, 2005). The emancipatory disability paradigm suggests that disability-specific training of research staff should be

emphasised and budgeted for (Barnes, 2003). Accordingly, training needs for inclusive GBV studies will vary across a spectrum of impairments, setting and research population, all of which should be ethically mandated. Despite living with a disability and having skills in conducting qualitative and GBV-related research, the researcher required disability awareness and disability sensitisation as it was her first experience conducting disability-specific GBV research. The research assistant was a trained occupational therapist with experience in working in the disability sector and could provide mentorship on disability-related issues, inclusive communication, and challenging disability stereotypes during the research process. The research assistant was instructed on GBV ethical mandates, such as respecting confidentiality, ensuring safety during the fieldwork and referring participants after disclosure.

4.2.6 Benefits and compensation

The emancipatory paradigm stipulates that all research must benefit participants (Barnes, 2003, 2004, 2008). gestures of reciprocity and the provision of feedback to the study population should serve as measures to enact beneficence, a universal ethical research requirement (Beauchamp, 2003). Scholars define reciprocity as the act of presenting participants with a token of appreciation for participating in research projects, whilst is may act as a form of coercing vulnerable participants to take part in research studies (Marshall & Rossman, 2011).

Considering that poverty is a contextual factor hindering women with disabilities' equal participation in life (Mitra, Posarac et al., 2013), the contentious issue of compensation being coercive should be suspended, as involving women with disabilities in research may provide relief from abject poverty and social isolation, especially where access to resources

and services is limited, as in South Africa. Considering the socioeconomic demographic of the study sample, fiscal payments of R150 (USD10) to participants were likely to have compensated for time and energy spent participating in interviews, but also complemented disability cash transfers, assisted in family financial obligations, or have gone towards purchasing assistive devises or rehabilitation. Monetary compensation can also make women feel like valuable contributors to knowledge generation (Kruger, Ndebele, & Horn, 2014) In the Cape Town study, participants asked for more money than had been originally stipulated because of poverty, financial exploitation, and theft of their personal monies from family members and other caregivers (van der Heijden, Harries & Abrahams, 2016).

Participants also benefited from intangible compensation (Fontes, 2004). Participants' involvement inadvertently raised self-awareness of their own trauma and problems and awareness of rights to freedom from violence. Raising awareness is likely to increase access to existing health and violence prevention services and interventions.

Women with disabilities may have differing needs in terms of benefits and compensation. The length of the research and contribution expected from participants, as well as the variation in participants' socio-economic needs and assistance requirements, can determine the argument for how much monetary compensation should be given. Compensation and the potential benefits of the research should be a thoughtful process in the protocol, guided by input from local DPO who could assess or were aware of participants' needs. Both compensation and benefits should be discussed during recruitment and informed consent processes. The benefits of inclusion in research must extend beyond compensation for it to be emancipatory (Barnes, 2004, 2008). In the next section the benefits and expectations of research, as well as the importance of knowledge generation for and feedback to participants and the disability sector is discussed.

4.2.7 Emancipatory research for positive social change?

From an ethical perspective, it is important to consider why and how we include women with disabilities in GBV research. One of the reasons for qualitative research to be used in conducting disability research is that it allows participants' expectations and perceptions of social change to be explored (O'Day & Killeen, 2002). Qualitative methodologies that illicit in-depth knowledge and perceptions are best placed to get a sense of how social change is understood, perceived, and experienced. For violence-related research, disability-specific risks and forms of violence, as well as unique contexts of abuse can be elicited to inform appropriate prevention programmes and interventions that are inclusive of disability experiences. Emancipatory research that puts participants with disabilities in control of the research process can suspend stigma and assumptions that women are passive victims of violence. Moreover, existent gaps and accessibility issues in service delivery can be uncovered and provide opportunities to dismantle barriers to GBV care and support services for women living with disabilities in LMICs. Engaging women with disabilities in their perspectives on their inclusion in GBV research and its risks and benefits will also ensure autonomy and participant perspectives that are emancipatory and participatory.

Violence against women research should only be collected if done correctly and used for violence prevention and social change (Ellsberg & Heise, 2005; Ellsberg & Heise, 2002). Similarly, the premise of emancipatory disability research is that research be used for social change and findings should include policy or practical implications (Stevenson, 2010; Barnes, 2008; 2003). The politics of ethics research, and who it serves has elicited much scholarly debate, particularly when including participants with disabilities. There is often an implicit paternalism around the inclusion of disabled participants; this is even more so where issues of sexuality or violence are included.

Vulnerability and agency should be considered in relation to what the study offers or is perceived to offer (Hartmann & Krishnan, 2016). The belief that participation will mitigate violence and/or improve lives may be especially likely in contexts where the perpetration of violence is often left unaddressed, as is so often the case with women with disabilities. In the study, participants were informed they would not directly benefit from participating but that their contributions may help to define the needs and priorities for women living with disabilities in similar contexts. Informing participants that data may benefit the future lives of women living with disabilities was a key ethical step taken in the study. Participants' were also informed that their inclusion might help dismantle barriers to services and social stigma around disability (McDonald & Kidney, 2012; Iacona, 2006). Despite no tangible benefit, women expressed positivity about being invited to participate and found it a rare or first opportunity to talk about their lives and violence experiences.

Furthermore, there is advantage for inclusion in GBV research in that it alters the ways in which agency is expressed and stimulated through the research process. Participants were not passive in any way; they demanded inclusive societal change, asked for assistance and referrals to GBV services, and requested research incentives and study feedback. A mainstay of emancipatory disability research echoes GBV research ethical guidelines, in that it calls for empowering participants through research processes. A robust argument is that to achieve empowerment, disability should be eradicated; meaning research must impact on non-disabled society too (Barnes, 2004, 2003).

4.2.8 Accessibility of knowledge and research uptake: Research for who?

For ethical and inclusive GBV research, contributions from research should be disseminated for beneficence and impact (Barnes, 2008). However, there is great paucity of data on

accessibility and inclusivity of knowledge uptake and research translation in GBV research agendas. Expertise in augmenting and disseminating disability-friendly research materials and findings, particularly findings that can be integrated into policy and violence prevention measures, is lacking. Involving disabled women and disability sector in knowledge translation and uptake can ensure that findings have appropriate dissemination and uptake strategies to help prevent violence against women with disabilities.

While publishing of academic papers exposes the inaccessibility of majority knowledge generation, it can lead to wider awareness of violence against women with disabilities and provide an impetus for further research, research translation and uptake, which will benefit both disability and GBV sectors. Involving disabled participants in GBV research means that research findings should be accessible and appropriately communicated to all stakeholders, including participants. Furthermore, the formative nature of this study has potential to stimulate future ethical and inclusive GBV studies, contributing to knowledge on violence against women with disabilities.

4.3 Limitations

The qualitative nature and small sample of participants in the study means recommendations in this paper may require modifications for quantitative or population-based GBV research. A limitation is the types of impairments included in the sample. GBV research undertaken with women with psychosocial, cognitive or severe communication impairments will require additional considerations. While existing disability studies engage with the ethics of research inclusion, it is critical that contributions be made to existing ethical guidelines on GBV research to protect women with a range of disabilities from harm while simultaneously

including them in the research process – both globally and especially in LMICs. Moreover, conflict and institutional settings will need specific recommendations extrapolated where violence is exaggerated (Kett & van Ommeren, 2009), and additional ethical issues may apply to violence-related studies including men and children with disabilities.

4.4 Conclusion

Ethics committees are notorious in promoting over-protectionist or paternalistic frameworks for research with vulnerable populations, especially concerning children and people with disabilities; more so when violence or sexuality topics are covered. However, the CRPD (UN, 2006) underlines the importance of mainstreaming disability in all spheres. Inclusive ethical research recommendations may be diverse, and may be characterised by a lack of consensus, divisive value orientations and gaps in knowledge and practice. The heterogeneity of disability in research populations also dictates diverse accommodations required for achieving inclusive GBV research. Proposing and approving GBV inclusive research in a wide range of settings where women with disabilities are at higher risk of violence will encompass multi-stakeholder collaboration and additional ethical precautions.

The study formed the groundwork for thinking about mediating factors that undermine inclusivity and which may pose ethical limitations for inclusive GBV research. Thus, in looking toward formalising ethically strong guidelines, GBV research with women with disabilities should not be constrained; it must be conducted with sensitivity and expertise with on-going reasonable accommodations and safeguards put in place. The extrapolation of these and future inclusive ethical issues should be tested, with reflections from the field and include contributions and advice from disability experts, GBV researchers, ethics committees

and stringent peer review processes. In doing so, we can encourage higher quality GBV studies that leave no one behind.

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CHAPTER 5. ADDITIONAL LAYERS OF VIOLENCE: INTERSECTIONS OF GENDER AND DISABILITY

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The PHD candidate conceptualised and conducted the data analysis for this paper and wrote the full draft and all revisions of the paper. Both supervisors approved the final draft of the paper before it was submitted for publication.

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I. van der Heijden – protocol development, data analysis, writing full draft and all revisions of the paper

N. Abrahams – review of protocol, mentoring of data analysis, critical review of all drafts of paper

J. Harries – review of protocol, mentoring of data analysis, critical review of all drafts of paper

Motivation for inclusion:

This chapter addresses the first objective of the study: To describe the nature and forms of violence women with disabilities experience in South Africa and is presented in the format of a journal article.

Abstract

South Africa has unprecedented levels of violence and many South African women are exposed to violence during their lifetime. This article explores how gender and disability intersect in women's experiences of violence during their lifetime. Repeat in-depth qualitative interviews with 30 physically disabled women in Cape Town reveal that women with physical disabilities are exposed to various forms of violence, and show how their impairments shape their violence experiences. The most common forms of violence women with disabilities experience are psychological violence, financial abuse, neglect, and deprivation, with disability stigma playing a central role and contributing to how women with disabilities are exploited and dehumanised. Constructions of women as non-sexual shape their sexual relationships and experiences of sexual violence. This article identifies that women with disabilities are more at risk and experience additional layers of violence than women without disabilities. These additional risks and layers of violence must be recognised and inform interventions to prevent and respond to violence against women with disabilities in the country. Prevention of violence against women with physical disabilities in South Africa needs to address the role of disability stigma that shapes the types of violence they experience, change gender norms, and create accessible and safe environments and economic empowerment opportunities.

5.1 Introduction

Disability is now defined not by impairment, but by how society and the physical environment isolates, restricts, and bars people from full participation in everyday social, political, cultural, and economic life. The social model of disability no longer defines disability as the tragic medical problem of unfortunate individuals but rather as a form of social oppression and exclusion (Oliver & Barnes, 1998; Shakespeare, 2006), where people experience considerable inequalities in all areas of social life. The inequalities that define disability are linked to poverty, barriers to employment, education and health care, inaccessible spaces, stigma and negative societal attitudes, denial of their sexuality, and vulnerability to violence and abuse. Thus, disability is no longer solely a biomedical or a social issue, but a human rights issue.

Interpersonal violence is another human rights issue and is a common feature in the lives of South Africans. In South Africa, violence is profoundly gendered, and many women have been and will be exposed to violence during their lifetime. One in four women in report experiencing sexual, physical, emotional, or financial abuse during their lifetime (Machisa, Jewkes, Morma & Rama, 2011), and the most pervasive perpetrators of violence are their intimate partners (Abrahams, Jewkes, Hoffman, & Laubsher, 2004; Abrahams, Jewkes, Laubscher, & Hoffman, 2006; Jewkes et al., 2001; Jewkes, 2002; Jewkes, Dunkle, Nduna, & Shai, 2010; Jewkes, Sikweyiya, Morrell, & Dunkle, 2011). Research shows that every eight hours a woman is killed by her intimate partner (Abrahams et al., 2012). Moreover, South Africa has extremely high rape statistics—one in four South African men have ever reported rape perpetration (Jewkes et al., 2011). The intersections between violence and gender in South Africa reveal hegemonic cultural values and norms that prescribe men's roles in society and condone gender inequality and women's subordination, sexual entitlement, and violence (Jewkes & Morrell, 2010; Jewkes, Sikweyiya, Morrell, & Dunkle, 2009). The 'emphasised

femininity' of women as weak, passive, and dependent (Connell, 1987) serves to emphasise the unequal power relations between men and women and make women more vulnerable to violence in the country (Jewkes & Morrell, 2010).

Women with disabilities often must confront additional disadvantages and discrimination even in comparison to men with disabilities and the women without disabilities - women without disabilities, and are more likely to be poor, uneducated, unemployed, and socially isolated (Mitra, 2011; WHO/World Bank 2011). They experience barriers to health care and have the added responsibilities of child care. Women with disabilities experience violence because of gender bias, and violence is compounded by their disabilities. Because of their impairments, their gender is reconfigured to exaggerate their passivity, dependence, and weakness, and plays an important role in determining how a woman's disability is perceived and reacted to (Gerschick, 2000). The intersections between gender, violence, and disability reveal how women with disabilities face multiple oppressions and, along with a mix of social and cultural assumptions, illustrate how these oppressions shape the experiences of a person already experiencing discrimination (Crenshaw, 1991). In other words, these intersections highlight "how with the addition of each new category of inequality, the person becomes more vulnerable, more marginalised and more subordinate" (Davis, 2008, p. 71).

Research shows that women with disabilities are at higher risk of violence than those without disabilities, and experience multiple forms of violence during their lifetime, by multiple perpetrators and for longer periods (Hughes et al., 2012; Nosek, Foley, Hughes, & Howland, 2001; Young, Nosek, Howland, Chanpong, & Rintala, 1997). Their reduced physical and emotional defences, social isolation, and dependence on care givers means that power and control over disabled women is exaggerated, making them more vulnerable than women without disabilities. Due to poverty, lack of education and employment, or reliance on

assistance for their daily activities, they are more likely to tolerate abuse rather than resist and are less likely to report the abuse (Oktay & Tompkins, 2004; Swedlund & Nosek, 2000). Their risk of experiencing violence is further increased by societal stigma and discrimination, communication barriers, along with not being viewed as credible witnesses (Swedlund & Nosek, 2000). Because they are more likely to be institutionalised, women with disabilities living in residential facilities are more likely to experience multiple types of abuse and neglect, including physical, sexual, and emotional abuse, as well as abusive behavior by service providers and failure to provide basic requirements (French, Dardell, & Price-Kelly, 2009).

Women with disabilities have been found to have a greater chance of experiencing intimate partner violence than women without disabilities (Brownridge, 2006; Rich, 2014), and partners are likely to be the most common perpetrators of violence against women with disabilities (Barrett, O'Day, Roche, & Carlson, 2009; Barranti & Yuen, 2008; Copel, 2006; Hague, Thiara, & Mullender, 2011; Krnjacki, Emerson, Llewellyn, & Kavanagh, 2016; Smith, 2008). Their low sexual and body esteem are factors contributing to their vulnerability to intimate partner abuse (Hassouneh-Phillips & McNeff, 2005). Further vulnerabilities include myths around non-sexuality and ineligibility for marriage (Kvam & Braathen, 2008). Because of these myths, it is rarely assumed that women with disabilities have intimate partners, so intimate partner violence often goes undetected or unreported (Barnett, Miller-Perrin, & Perrin, 2005).

Stigma around the sexuality of disabled women makes them particularly at risk of experiencing sexual violence. Their assumed non-sexuality shapes the belief that they are virgins and therefore suitable candidates for risk-free sex; in Asia and Africa, there myth that having sex with a virgin can cure a person with HIV/AIDS puts them at heightened risk of rape (Groce & Trani, 2004). Their reduced physical defences mean that physical force is a regular

feature in their sexual violence experiences, and those with reduced intellectual capacity are less likely to be aware of the abuse or report it (Nosek et al., 2001).

More than 7.5% of the South African population have a disability, and many of these are women (Statistics South Africa, 2014), yet the state of research on violence among disabled women in South Africa is still extremely limited. Only recently has research focused on the role of poverty and structural violence in disabled women's lives (Neille & Penn, 2015); on intellectually disabled women's access to justice after violence; and on the role of stigmatisation in accessing post-violence services (Meer & Combrinck, 2015). An older small-scale exploratory research project with women with physical, visual, and hearing disabilities highlighted the lack of services and responses for disabled survivors of gender-based violence.

Acknowledging the lack of evidence in South Africa and the heightened risk of violence for women with disabilities highlighted in international literature, this article reports on the forms and experiences of violence against women with physical disabilities (including visual and hearing impairments) in South Africa. In it, we describe the forms of violence women are exposed to and highlight how gender and disability intersect to shape women's vulnerability to both familiar and additional forms of violence in the South African context.

5.2. Methods

Qualitative data for this study came from interviews with 30 women living in Cape Town, South Africa, between 2013 and 2015. Women were recruited from seven protective workshops[9] and four residential care facilities for disabled persons operating in the Cape

[9] Protective workshops are day-programme facilities set up in urban and rural communities by the Department of Social Development. The aim of the workshops is to provide skills building and income-generating opportunities to persons with disabilities whose functionality does not necessitate institutional care but is too severe to qualify for employment.

Town area of the Western Cape. The workshops were run by local and regional non-profit organisations dealing with disabled persons, with some support from government. The care facilities were community-based entities providing residential accommodation to disabled adults. The workshops and care facilities for recruitment were selected from an Internet database on disability services for the Western Cape Province. Permission to access these sites were granted by relevant site managers. The first author and translator visited these sites, explained to potential study participants what the study entailed, and the risks and benefits involved in participating, and asked women whether they would be interested in participating in the study.

All women recruited had to have had a physical disability for at least 10 years at the time of being interviewed, and aged 18 years or older. Women who volunteered to participate were asked to give individual informed consent and could give their written consent or a taped verbal consent if they were unable to write. They were assured of anonymity and confidentiality. All consent information and interviews were conducted in the language of the participant. The first author conducted the interviews in English and Afrikaans, and the research assistant worked as a translator for those participants that spoke isiXhosa. All hearing-impaired women could nominate their own sign language interpreter with whom they had an established rapport. Sign language interpreters were asked to sign informed consent entailing the confidentiality of the interview.

All interviews were conducted in a private room, at either the disability service organisation, the protective workshop, the care facility, or the participant's home. The interviews lasted 60 min to 120 min and were stopped if participants got tired or no longer wished to continue with the interview. The idea was to conduct repeat interviews with women who consented to be interviewed again. Repeat interviews allowed us to saturate all

the themes in the scope of inquiry. The repeat interviews also allowed for building rapport between researcher and participant. Because the study explored different experiences of stigma, gender inequality, and violence, we did not expect the respondents to divulge all their experiences at the first interview. Repeat interviews also allowed the researcher to return to sensitive issues at a follow-up interview depending on the readiness and willingness of the participant. Between one and three interviews were conducted with each woman. Overall, 52 interviews were transcribed and analysed. Participants were given reimbursement for their transport, refreshments, and R150 compensation for their time spent doing the interviews.

The scope of the interview was used as a guide for interviews and covered violence experiences over their lifetime, and themes that were discussed included abuse and punishment during childhood, violence in their home and community, violence in intimate relationships, barriers and challenges in everyday life, self-perceived stigma and stigma in the community, sexuality and reproductive health, risks and consequences of violence, protecting themselves and preventing violence, and pathways to care and access to justice.

Women were warned of the adverse effects of talking about violence in their lives, and were each given service provider information sheets with contact details. The interviewer and translator underwent regular debriefing with their supervisors.

Interviews were audio recorded with the consent of the participants, and notes were taken by the researcher and the translator. All interviews were transcribed verbatim into English and cross-checked against the original recordings. The translated transcripts were coded using the software package ATLAS.ti Version 7.5.6. The data were analysed inductively, with analysis commencing during data collection, and, where there were multiple interviews, the first interviews were analysed before the follow-up ones. This assisted in planning the

follow-up interviews. Interviews were coded by the first author and were initially coded into categories that drew on the main themes of the scope of inquiry, with sub-coding stages driven by ideas emerging from the data. These were interpreted using processes of analytic induction to build up into a substantive theory or argument. Pseudonyms have been used to protect the identities of the participants.

The study was approved by the ethics review boards of the South African Medical Research Council and the Human Research Ethics Committee at the University of Cape Town.

5.3 Demographics and Setting

The 30 participants were aged from 19 to 54 years. Nineteen women were born with impairments and nine acquired disabilities during childhood via illness such as polio, meningitis, a stroke, or physical injury through accident, and two women acquired their impairments from experiencing gun violence. Women's impairments ranged from immobility caused by cerebral palsy, Spina Bifida, para- and quadriplegia, amputation, deformity, muscular dystrophy, and transverse myelitis. Sensory impairments included hearing and visual impairments. Two women had albinism with sight impairments.

Women were mostly isiXhosa-speaking, residing in informal settlements. The informal settlements are mostly characterised by poverty, informal housing or 'shacks', lack of infrastructure and poor access to basic services, high unemployment rates, and high crime, alcoholism, and substance abuse. The physical terrain of the informal settlements is often inaccessible to people with physical disabilities. The houses are very close together, the ground is uneven and unpaved, and one needs to walk long distances to fetch water or use communal toilets which do not reasonably accommodate one's physical impairments. These

restricting environments prevent people with disabilities from participating in their communities.

During their lifetime, half the participants had ever partnered, of which five women were currently in relationships with a boyfriend and seven were currently married. Two women had been divorced. One was a widow. Most of the women spoke of the difficulties of forming long-lasting intimate relationships. Twelve of the women had children. Mostly, participants had not completed their secondary school education. Participants spoke of the lack of schools suited to the needs of disabled youth. Most had been enrolled in mainstream schools where they received little to no rehabilitation and where they struggled to keep up with their non-disabled peers. Generally, parents of disabled youth have difficulties in enrolling youth in special schools that are in districts far away from their communities (Lorenzo, 2013). Lorenzo (2013) writes that poverty and lack of special schools that cater for disabled children in South Africa mean that many disabled youths have lower chances of finishing school than their non-disabled peers. Majority of participants did not finish secondary schooling, and only two women had been enrolled in tertiary education.

Participants' living arrangements varied, with nine participants being residents in a care facility, 14 living with a partner or husband, and seven living with parents or siblings. Participants struggled to gain formal employment due to the already high rates of unemployment in the country, and a lack of education or physical impairment further limited their opportunities. Seventy percent of participants were unemployed or working for a stipend at a protective workshop. Those in residential care facilities were the least likely to be employed or to have an income other than their disability grant. All participants received

a disability grant[10]. Refer to Table 1 for the socio-demographic characteristics of participants in Appendix 3.

5.4 Findings

In this article, we rely on data from the first few themes in the scope of the interview, namely abuse and punishment during childhood, violence in the home and community, violence in intimate relationships, barriers and challenges in everyday life, and self-perceived stigma and stigma in the community, while highlighting the types and nature of the violence women with disabilities experienced. All the participants interviewed had experienced some form of violence. From early on in their lives, women faced neglect and deprivation, emotional and psychological abuse, and financial, physical, and sexual abuse from a wide range of perpetrators, as seen in Table 2 in Appendix 4.

5.4.1 Neglect and deprivation

More than half of the participants claimed they had experienced multiple layers of neglect and deprivation. Women faced neglect at school when younger, where in one instance, a teacher at a special needs school refused to change a participant's diaper. In another instance, a participant with Spina Bifida reported being left alone on a few occasions in her room at boarding school while everyone else went to eat dinner. Such neglect continued into adulthood with women reporting that they were left alone at home with no support while their family members went to work. A woman with muscular dystrophy reported her vulnerability as follows:

[10] The South African governmental disability grant is available to those with certified impairments who are medically unfit to work. At the time of the study participants were receiving US$103 monthly.

> I'm scared at home, I am all alone, with no one to help me if I fall . . . I have nothing to do and no one to talk to. (Rhonda)

A woman with paraplegia living in a shack behind her sister's house reported how when her family would leave for work, it was difficult for her to enter their house to use the toilet:

> They sometimes go out and lock up the house, and then I have no place to go [to the toilet]. (Lindiwe)

Some women said their able-bodied partners deprived them of a real 'public' romantic relationship by hiding them away from their friends because they were ashamed or embarrassed; describing how their partners would only take them out at night when no one could see them together or hold their hands or kiss them when no one was around. Care facility staff were often said to deprive residents of their autonomy and neglect their care needs:

> The carers here neglect you, they don't care. You say you are cold, they ignore you . . . You sleep without supper or wake up with no breakfast or lunch and you must figure it out by yourself what to eat. But the sad thing is to watch those with a mental handicap weeping the whole day because they don't know what's going on because they are cold and hungry, and they can't say what they need. (Nandipa)

However, not all women living in care facility residences were negative about their residential accommodation. Some said they were happier living there because they were often left alone at home and felt unsafe. For them, the neglect at the care facility was more tolerable compared with what they experienced at home.

5.4.2. Psychological violence

Psychological violence during their lifetime was associated with disability-related stigma and had varying dimensions. It mostly took the form of verbal abuse or name-calling, leaving women feeling belittled, humiliated, or worthless. Since they were young, women had been called dehumanising names such as *inkawu* (monkey) or *isidalwa* (creature). Others were labelled *isishwawa* (a "punishment" or "burden") or *isidenge* ("not right in the head") by family members, peers, and strangers. Some reported how their male partners would call them "dumb", "useless," "a fool," or "someone who has no brain"—insinuating they were mentally impaired.

A few partnered women spoke about emotional abuse from their partners' mothers who branded them incapable of being suitable partners or wives for their sons, and thus unsuitable for *lobolo* (dowry). Some experienced psychological abuse from government officials and health service providers. One woman with paraplegia was questioned by someone at the Department of Housing on why she was applying for a house as she "couldn't even walk or help herself, how would she survive in a house all to herself?" (Frozzie). Another young participant with Spina Bifida experienced abuse at the hospital where she went to request an abortion. Health care staff shunned her for being pregnant and interrogated her ability to have sex or become pregnant:

> And even when I went to have my abortion, I went to this one hospital, and this nurse says to me: how did you get pregnant? I didn't know you could 'do it' [have sex] in wheelchairs? (Zandile)

She reported that one of the nurses told her that to have a disability is already "a burden", and that being pregnant would exaggerate the "problem" of living with a disability, so she must have an abortion. A woman with Albinism and sight impairment mentioned the

discriminatory attitudes and neglect by health providers she experienced while in labour at a local hospital:

> They put me in a room and left me . . . I was scared, I didn't know where the nurses were or what was happening, it was all quiet for hours, and then they came in and shouted at me that I must call someone else to take the child, they did not want to give it to me. (Thandi)

A participant with muscular dystrophy said her mother scoffed at her when she discussed having a baby in the future, questioning her ability to care for a child when she herself was like a child that needed looking after.

5.4.3 Financial abuse

Mostly, participants had limited education and skills required to be formally employed and most were reliant on disability grant income. Some said the grant was not compensatory enough for their lack of job opportunities and added disability-related needs, the grant was deemed inadequate to meet their daily living expenses. Most of the women interviewed said receiving the grant puts them at risk of financial abuse as others take control over how it is spent. One participant claimed,

> The first and last time I see my money is at the grant pay point, from there on my mother controls what happens to it. (Nomonde)

Another participant claimed her family members used the grant money for their own benefits, such as purchasing furniture on credit, and a further participant claimed her grant was used to buy groceries for the family, yet in the end they would not share the luxury items with her:

> With my money, they go to the [grocery store] and buy the expensive stuff, like bacon and cheese, they cook it and I can smell it through the window, but they don't share it with me. (Lindiwe)

Some participants reported that neighbours would come over on the grant pay-out days and ask to borrow money, which one participant claimed they never paid back. One participant's husband demanded that he get half the allocated amount for his personal use every month, which the wife claimed he used to purchase alcohol. A married participant said her husband physically beat her if she did not give him part or all her grant money. Two younger participants claimed that men were only likely to date them because they received grant money—and they felt they were taken advantage of financially. One woman with paraplegia said,

> The first thing they [non-disabled men] will ask you is "Do you work?" And you say no. "Ok, do you go to school," and you say no. They ask "But you do get a grant, don't you?" And if you do, then they want to be with you. (Zandile)

However, not all women felt extorted for their grant money. Some were relieved that they could supplement their families' income, despite being unable to work due to the severity of their physical impairment. Others felt they would rather have full employment, which would disqualify them as a grant recipient: "I'd rather have work and earn my own money, than get this grant every month" (Noluthando).

5.4.4 Physical violence

During their childhood, participants reported receiving beatings or threats of physical violence by teachers, parents, or caregivers because they were 'too slow' or had wet themselves. While at school, some participants reported having stones thrown at them by peers or being purposefully tripped up while walking with their assisted devices. A woman with paralysis in her right leg recounted how, as a child, she was carried or forced to limp next to her mother while her mother begged for money in the road. Another woman with a

physical impairment experienced physical beatings and verbal abuse from her grandmother who had been allocated to take care of her when her mother died giving birth to her:

> She would tell me it was my fault that my mother died. She would come in and beat me and tell me I was bringing the family down, that it was too much work to take care of me . . . I cried often and locked myself in the room. (Thabile)

Physical abuse was also reported at a care facility with one resident claiming that staff would hit some residents if they asked for help or had wet the bed. In these cases, physical abuse followed psychological abuse in the form of being berated or blamed for being a "burden". Disabled women were easy targets for crime because of their impairments. One participant was mugged while having an epileptic fit on the pavement when walking home from the shops:

> He took the chance, he could see I was unaware, unable to stop him, I had dropped my bags and was on the floor, he took all that I had bought, he took my cellphone from my pocket, and he didn't even run away, he walked. (Nomthandaza)

5.4.5 Sexual violence

Approximately a third of women described their sexual experiences as coercive. They spoke mostly of a wide range of unwanted sexual behaviour that occurred during their lifetime, including fondling, forced oral and anal sex, and non-consensual sexual intercourse, with some of these events occurring in the early years of their lives. The perpetrators were all male—family members, intimate partners, friends of parents, community members, or residential care facility staff. Sexual violence experiences occurred in many different situations.

During her childhood, Frozzie, with paralysis in her legs, was sent away to live with her father's brother. She recounts that both her uncle and cousin would visit her bed at night and

sexually assault her. At the age of 15, she became pregnant as a result of ongoing sexual assault:

> I could not do or say anything, they were the ones feeding me, they gave me a home—what should I have done. I lay there hoping they would not come, and then just acted dumb when they did it. The one didn't know the other was also coming to me.

A participant with Spina Bifida became pregnant at age 21 after her mother's boyfriend raped her. The mother had arranged that he wheel her to her place of work as specialised transport was inaccessible in their community:

> He took me the wrong way . . .He pushed my [wheel] chair into the bushes, I remember thinking "Where is he taking me?" I knew what was going to happen . . . and him saying I wanted it, and I knew I didn't want it, I just let him so I could be safe and because I didn't want to be left alone on the ground [without being able to get back into her wheelchair]—I didn't even scream. (Zandile)

This was not her first experience of sexual assault and she further explained how a neighbour had sought opportunities to exploit her sexually when she was a child:

> I was young then, I didn't have my wheelchair, I had crutches back then, and the man next door told me, "when you are at home alone in the house you must call me, I want to come see you." And I am like, no that doesn't sound good. I am like what does he want to see me for? Then he came the next day when I was home alone and he shouted "I know you are in there, open the door" and I opened the door and he kissed me forcefully and I pushed him away and he left. (Zandile)

The nature of participants' physical impairments meant reliance on assistive devices and on others for daily activities. This dependency provided men with opportunities to manipulate and exploit them:

> [Men] they come in and they play with your mind. They make you feel like— you know—like I am helping you, so play with me the way I want you to. They think you owe them something back if they help you. (Zandile)

Their dependency made some participants feel like they were an inconvenience to others; and some intimated their frustration of having to rely on men for help. Their reliance on men made them feel they were expected to give sexual favours in return for assistance.

A 23-year-old participant living in a care facility at the time of the interview, who contracted meningitis as a child and used a wheelchair recalled how she was often left alone at home in the township and had also experienced unwanted sexual advances from a neighbour when she was young. She had also been raped 2 years ago by a man who lived in her community:

> He came into the house, the door was not secure. He slapped me, and pulled me from my chair. Then he was sleeping on top of me. When he moved I cried, he did it again and then he ran away. (Funeka)

Another young woman of 19 years with cerebral palsy spoke about demands for repeated unwanted anal sex from her boyfriend when he claimed that this way they would "protect her virginity":

> I did not like it, I could not see him, just feel him behind me, and it hurt. (Faith)

She further described that it continued for two months, after which the boyfriend ended the relationship:

> He said he was protecting my virginity that he did not want to "spoil" me . . . But he already spoiled me, because that is how I felt. (Faith)

An amputee in a wheelchair reported having experienced forced oral sex from a residential care facility staff member:

> He abused me, he abused me here by the mouth, he put the penis here into my mouth . . . and then I decided to leave [the care facility]. (Liz)

Another woman who had partial paralysis in her legs and used crutches reported having experienced unwanted oral sex from a hairdresser she visited in the community. She explained that she had never experienced such a thing before and was traumatised by the event:

> He came with his thing [penis] up here [shows her mouth] and then I closed my mouth and then he said I must open my mouth and then he put his thing into my mouth and his penis is going in and out in my mouth until this white thing comes, I don't know if it was pee [urine] or what and then this white thing was here in my mouth and then he said to me I must spit it out . . . I was so confused . . . after that I was, I was very shocked because I never knew he can do that to me. (Cindi)

The threat of sexual violence in their physical environments was discussed. Some participants spoke of their difficulties accessing communal portable toilets in informal settlements. Some mentioned they feared being confronted by men at the outdoor toilets, and not being able to escape a sexual attack while in the toilet. A participant described that the remoteness of outdoor toilets meant their risk was elevated as it was unlikely that they would be heard if they cried for help.

In all sexual violence episodes, the perpetrator was an able-bodied man. Thus, dating an able-bodied man was considered a risk for victimisation. Men without disabilities were deemed more likely to understand and have similar experiences to disabled women. Men with disabilities also had access to a disability grant, and therefore participants were less likely to be extorted for their money. Men with disabilities, particularly with physical impairments

that restricted their mobility were considered less threatening with regards to sexual and physical violence. Participants reported feeling generally threatened by able-bodied men:

> I can't date normal guys. Let me say I am not normal because I am in a wheelchair because it's a chance for them to take advantage of you, they are stronger than you. (Zandile)
>
> You are safer in a relationship with a disabled man . . . he cannot get out of his wheelchair and beat you. (Fran)

Not all participants experienced sexual violence, and not all relationships were instrumental or exploitative. A few women who had been partnered described their intimate partnerships as loving and protective. A woman with a sight impairment told of how she met her partner who is also visually impaired at the protective workshop:

> It was love straight away, I can't say at first sight, because we could not see each other . . . Our son now is grown up and we are still together. We do everything together, even though we both can't see the world, we can know what each other wants. (Lizette)

A woman with paralysis who used a wheelchair met her able-bodied husband at church. She said the following:

> He knows I can't do everything, he does the chores when he comes home. He understands me and loves me. (Paulina)

Another woman with transverse myelitis felt that an able-bodied man would more readily help her with chores and parenting, and could "help her up" if she fell. She said able-bodied men were better protectors and providers, and that "you can depend on them."

5.5 Discussion

This article shows that, although the forms of violence experienced by women with disabilities in the sample mimic what women in the general population experience in the country; their disability exposed them to additional layers of sexual and psychological violence, financial abuse, neglect, and deprivation. Also, participants described their experiences of violence in ways that were unique to having a disability. Stereotypes around ability and sexuality, dependence on perpetrators for personal assistance, exposure to violence at care and health facilities, inaccessible home and community environments, and lack of employment options or dependency on a disability grant shaped participants' unique experiences of violence. And while the documented global risk factors for intimate partner violence that include marked inequalities between men and women, lack of employment and education, and lack of self-esteem (Heise, 2011; World Health Organization, 2002) are intensified for disabled women, women in this study experienced more violence outside of their intimate partnerships than within them, and from a wide range of perpetrators. Only half of the women interviewed had ever been, or were currently partnered, so this finding does not necessarily reflect the true nature and extent of violence by intimate partners—that existing research has shown are the most common perpetrators of violence against women with disabilities.

Disability stigma shapes constructions of women with physical disabilities as 'unable', and as particularly passive, non-sexual or unable to reproduce, shaping their experiences of intimate partnerships and/or partner/non-partner violence. The psychological abuse women experienced from their partners' mothers, particularly, links to this undermining of their abilities to be 'proper' women and relates to the patriarchal and cultural expectations of women's roles in the home, and as a wife, in South Africa. Significantly, internalising disability-related stigma leads to depression and lack of self-esteem, and had compound effects on

participants' psychological abilities to cope and be resilient, meaning participants were less likely to seek help, remaining at risk of all forms of violence.

While their impairments did not allow them to fulfil expectations of being a 'proper' wife to non-disabled partners, women expressed ambiguity between dating and marrying disabled versus able-bodied partners. Their constructions of disabled men as unable to help them or protect them, and able-bodied men as predatory, shaped who they chose or wanted as partners.

In this article, we see how dependency and reliance on perpetrators shape disabled women's exposure to violence (Copel, 2006; Plummer & Findley, 2012; Smith, 2008). Physical and economic dependency made women feel like they were a "burden" to others, made them feel even more at risk to being exploited, and made them feel frustrated, depressed, and lacking agency. The expectation or men demanding sexual favours who assisted participants with their daily needs alludes to a dangerous power differential and highlights the vulnerability of women and girls with physical disabilities in their reliance on others for help. Economic empowerment interventions are needed to accord economic agency, and accessible and safe public transport and independent living options would help minimise reliance on perpetrators.

Disabled women's exposure to abuse by care facility staff emphasises how their positions within this particular disability context are risky. Abuse by personal care providers is an expanded form of abuse that is particular to women with disabilities. (Saxton et al., 2001, p.403). This article has shown how neglect and deprivation, being yelled at, or simply left alone, being ignored or dismissed make up a large portion of what women in residential care and health settings experience, showing how there needs to be better training and supervision for staff and awareness of disability rights in these settings. Saxton et al.'s (2001)

study of women with physical disabilities found that the power dynamics and difficulty of recognising social and personal boundaries and abuse shaped most women's experiences of abuse by personal care providers. The intimate nature and physical proximity of care assistants mean they have little to no privacy or autonomy, and the line between appropriate and inappropriate touching becomes blurred, leading to unwanted or ambiguous sexual contact, and reveals how reliance on a spouse for personal care can reinforce a classic cycle of domestic abuse (Saxton et al., 2001).

Overall, psychological violence left women feeling depressed and devalued, and precipitated their vulnerability to other and additional forms of violence and restricted their help seeking. This study also supports Neille and Penn's (2015) findings that highlight how structural violence and poverty underpin disabled women's vulnerability to additional layers of violence – how living in informal settlements with poor infrastructure and poor access to safe and accessible housing put women with physical disabilities at additional risk, and how receiving a disability grant also makes them more likely to experience financial abuse. While there are findings from other research that shows how HIV positive men use their disability grants to attract women and lure them for sex (Jewkes, 2006), the instrumentality of grants for women with disabilities is restrained, as women in this study generally had limited decision-making power of how their grant money would be used. Further research is needed to understand whether and how women with physical disabilities negotiate the value and use of their grants to benefit themselves.

5.6 Conclusion

The paucity of evidence about violence against women with disabilities in South Africa suggests a continued unwillingness of our society to acknowledge that violence toward this

population may be occurring. Although this study highlights some of the forms and additional layers of violence women with physical disabilities are exposed to, population-based evidence is needed to quantify prevalence and the types of violence women with disabilities experience. Population-based surveys should use scales to pick up disability-related violence, such as extorting welfare grants, neglect, isolation and deprivation, and the disability stigma they specifically experience. The health consequences of violence against women are well-known; however, the mental and physical health consequences of violence on already impaired women need attention and mitigation.

This article highlights women's vulnerability to, and experiences of, violence, but further research is needed to examine women's agency in violence situations; their resilience and the protective strategies they use before, during, or after they experience violence. Prevention of violence against women with physical disabilities in South Africa should address the role of disability stigma that shapes the types of violence they experience, change gender norms, and create accessible and safe environments and economic empowerment. Provision, gaps, and examples of good practice of disability organisations, health providers, and justice services should be investigated and reported to inform policies. Furthermore, existing gender-based violence prevention strategies and interventions should be adapted for or include women with disabilities and recognise disability-targeted violence among disabled women to protect them from violence, abuse, and neglect in the future.

5.7 References

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CHAPTER 6. IN PURSUIT OF INTIMACY: DISABILITY STIGMA, WOMANHOOD AND INTIMATE PARTNERSHIPS IN SOUTH AFRICA

Citation:

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Conceptualisation:

The PHD candidate conceptualised and conducted the data analysis for this paper and wrote the full draft and all revisions of the paper. Both supervisors approved the final draft of the paper before it was submitted for publication.

Authors' contributions:

I. van der Heijden – protocol development, data analysis, writing full draft and all revisions of the paper

J. Harries – review of protocol, mentoring of data analysis, critical review of all drafts of paper

N. Abrahams – review of protocol, mentoring of data analysis, critical review of all drafts of paper

Motivation for inclusion:

This chapter addresses the second objective of the study: to describe participants' experiences of intimate partnerships in lieu of identifying how they may be at risk of intimate partner violence and is presented in the format of a journal article.

Abstract

Notions of womanhood inculcate naturalised ideologies of femininity, sexuality, motherhood and caregiving. The paper asks how disability stigma intersects with womanhood to characterise intimate partnerships in South Africa. In-depth interviews with 30 women with a range of disabilities were conducted in informal settlements in Cape Town. Findings suggest that disability stigma may hamper attainment of normative womanhood and sexual relationships for women with disabilities in South Africa. Limited opportunities to meet potential partners, hegemonic gender expectations and restricted sexual and physical contact shape their intimate partnerships. However, women with disabilities also challenge ableist constructs of normalcy and discredit negative images of disabled womanhood. Because of this, theoretical models of intimate partner violence should consider the influence of disability on constructions of sexuality and norms in intimate partnerships. Building on women with disabilities' stigma avoidance strategies will help facilitate better relationship outcomes. Social norms interventions with broader society, communities, women with disabilities and their partners, family and carers can help destabilise assumptions that women with disabilities are unable to have long-lasting and fulfilling sexual and intimate partnerships. Moreover, accessible and relevant sexuality education and information on relationships, intimate partner violence, maternal and sexual and reproductive health care can ensure healthy and safe intimate partnerships for women with disabilities.

6.1 Introduction

The body of people with disabilities has historically been medicalised and viewed as non-functional and 'other'. Societal attitudes towards disability and sexuality mean people with disabilities are often perceived as eternal children, unsuitable romantic partners and devoid of sexuality – including sexual agency, choice, desires or drives (Hunt et al. 2017, Hunt et al. 2018; McKenzie 2012). Conversely, people with disabilities may be perceived as hyper-sexual and unable to control their sexual urges (Milligan and Neufeldt 2001).

Hegemonic gender norms in South Africa further complicate these polarised perceptions, particularly for women with disabilities. While womanhood inculcates naturalised ideologies of femininity, sexuality, motherhood, and caregiving, women's "disabled" (sic) bodies are perceived as incapable of sexual relations, preventing women with disabilities from achieving ideals of womanhood that are typically achieved through dating, sexual seduction and intercourse, reproduction and fertility, and marriage and motherhood (Esmail et al. 2010; Shakespeare 2000). That is, women with disabilities diverge from the heterosexual and able-bodied norms of society (Chappell 2015; McRuer 2011; McRuer and Wilkerson 2003).

Additionally, women with disabilities aspiring to a heterosexual relationship may fall victim to dominating masculinities because their passivity, subordination, physical weakness, and dependence are exaggerated by impairments. These intersecting predicaments undermine their human and sexual rights by heightening risk of gender-based violence, particularly intimate partner violence (Mall and Swartz 2012; Plummer and Findley 2012; Rich 2014; Schröttle and Glammeier 2013; Van der Heijden, Abrahams, and Harries 2016), and may prevent women with disabilities from engaging in or having healthy, safe and lasting intimate partnerships.

Contemporary studies of disability reveal how intersections of gender, disability status, race, sexual orientation and geographical location shape women with disabilities' marginalisation and vulnerability (Winker and Degele 2011). As a result, disability is best conceptualised not solely in terms of impairment (Haegele and Hodge 2016). Disability is socially manifested through stigma, social (including gender) norms and societal, economic and environmental barriers that restrict women with disabilities' participation in daily life (Shakespeare and Watson 2002).

Varying types and severities of impairments mean women with disabilities face different barriers and encounter differing degrees of stigma and exclusion (Darling 2014). Some impairments are readily visible, whereas others remain hidden. Particularly for women with physical impairments, the visibility of the impairment typecasts them as undesirable or nonsexual, thereby limiting their access to intimate partnerships and sexual and reproductive health care services (Bremer, Cockburn and Ruth 2010; Goffman 1963; Hunt, Swartz, Carew et al. 2017; Nguyen, Liamputtong, and Monfries 2016; Wazakili, Mpofu & Devlieger 2009). The onset of impairments also affect sexual relationship experiences. Empirical evidence reveals how long-term disability influences a sense of sexuality, sexual function and fertility, which become internalised as part of one's self-image (Basson 1998; Goffman 1963). Acquiring a disability later in life is more likely to disrupt self-esteem and notions of sexual normalcy because experiences of stigma are new (Bogart 2014). Nevertheless, over time women with disabilities may adopt strategies to counter stereotypes, destabilise ableist norms and challenge hegemonic constructs of womanhood to regain a positive sexual identity, claim reproductive and health rights, and bolster self-worth (Dotson, Stinson, and Christian 2003).

In Southern Africa, studies of how disability stigma and hegemonic gender norms affect sexuality and shape intimate partnerships have emerged. One study has explored how negative cultural constructs of disabled sexuality among black African youth in rural South Africa put young women with disabilities who engage in sexual relations at risk of HIV and gender-based violence (Chappell 2017). Another study examined the populations' perceptions of dating people with physical disabilities in South Africa and how social stigma and anxieties over the burden of care limit disabled people's prospects of romantic relationships (Hunt, Swartz, Carew et al. 2018). Other research examined how women with disabilities in Zimbabwe challenge disability and sexuality stereotypes by demonstrating sexual prowess, including themselves in sexual initiation rites and by attaining reproduction and motherhood ideals (Peta, McKenzie, and Kathard 2015; Peta et al. 2017). A study in South Africa also showed how participants with spinal cord injuries had opposing perceptions of sexuality than dominant ableist discourses of sexual immaturity and passivity (Potgieter and Khan 2005). In a study on women with disabilities' experiences of violence in South Africa, emotional violence by partners and partners' parents was shaped around disability stigma and expectations of a woman's role within intimate partnerships (Van der Heijden, Abrahams, and Harries 2016).

Building on these previous studies, this paper highlights women with disabilities' relationship experiences with men in Cape Town, South Africa. It reveals how disability is socially constructed through self- and societal perceptions of impairments and womanhood, and how women's internalisation of disability stigma and rejection shapes their romantic pursuits.

6.2 Methods

The findings derive from a broader qualitative study on women with disabilities' experiences of gender-based violence and interpersonal relationships. The study, which was conducted between 2013 and 2015, included 30 adult women living with physical, visual and hearing impairments in Cape Town, South Africa. The study was approved by the South African Medical Research Council and University of Cape Town Ethics Committees.

Inclusion of participants depended on type of disability (visual, hearing and physical), being a recipient of a government endorsed disability grant[11] and having lived with a disability for more than 10 years. Participants requiring substantial or significant personal assistance and those with severe cognitive difficulties were excluded. Participants whose onset of impairment occurred within ten years prior to the study were excluded given how onset of disability interacts with self-perceptions and relationship experiences.

Recruitment occurred in protective workshops[12] and residential care facilities for persons with disabilities. Managers and carers at these sites helped identify female participants who met the inclusion criteria. Using purposive sampling, the first author and a research assistant visited these sites and explained to participants what the study entailed and risks and benefits to participating. Participants were assured confidentiality and informed that their names would not be used in published data to protect their anonymity. Information about the study was provided in both written and oral format in participants' preferred language thereby accommodating visual and hearing impairments. Participants who

[11] The South African governmental disability grant is available to those with certified impairments who are medically unfit to work. At the time of the study participants were receiving US$103 monthly.

[12] Protective workshops are day-programme facilities set up in urban and rural communities by the Department of Social Development. The aim of the workshops is to provide skills building and income-generating opportunities to persons with disabilities whose functionality does not necessitate institutional care but is too severe to qualify for employment.

volunteered gave written consent or taped verbal consent if illiterate or unable to sign due to impairments.

The scope of inquiry included women's experiences of living with a disability, self-perceived and societal stigma, sexuality and intimate partnerships, childhood, family and intimate partner violence, protecting themselves and preventing violence, and pathways to care and access to justice.

Participants were invited to partake in initial and follow up in-depth interviews until data saturation was achieved. Not all participants had follow-up interviews due to participants' non-consent or not being forthcoming with detail of their experiences. Interviews were audio-recorded with participants' consent and notes were taken by the first author and assistant. Interviews were conducted in accessible private spaces and lasted between one to two hours. The first author conducted interviews in English and Afrikaans and the research assistant translated for participants who spoke isiXhosa. The research assistant was a qualified occupational therapist and had experience working in the disability sector and conducting qualitative interviews. Hearing impaired participants were encouraged to nominate their own sign language interpreter with whom they had an established rapport. All assistants signed a confidentiality agreement. Participants were warned of possible adverse effects of talking about violence in their lives and were referred to social workers or counsellors if needed. Interviews were discontinued if participants grew tired, emotional or no longer wished to continue. Transport reimbursements, refreshments and monetary compensation of US$13 were given to participants for time spent participating in the study.

In total, 52 interviews were transcribed verbatim and translated into English and crosschecked against original recordings. Using ATLAS Ti 7.5.6, the first author initially coded data deductively by drawing on the main themes of the scope of inquiry. Sub-coding stages

were inductively driven by ideas emerging from the data. A descriptive narrative analysis approach was used to interpret the data.

6.3 Terminology

The authors acknowledge the complexity of defining intimate partnerships in the context of disability. It is difficult to reconcile the nuanced implications of the derivatives of intimacy with women with disabilities' relationship experiences. Substituting the term directly with "sexual relationships" implies sexual consent and is dangerous given the evidence of high sexual violence against women with disabilities. Similarly, using derivatives of "romance" is complicated as romance is not always inclusive of sexual relations. Additionally, intimacy is often enforced by the level of care a person with a disability may require from a personal assistant or carer who may not be a partner. Notwithstanding these difficulties, the paper engages with intimate partnerships in the context of GBV terminology in an effort to reduce the gap of studies exploring women with disabilities' relationship experiences and experiences of intimate partner violence. Intimate partnerships, sexual relationships and romantic relationships are used interchangeably. An intimate partner, sexual partner or romantic partner were terms defined by participants as someone they were married to, dating, attracted to and/or had (potential) consensual sexual contact with. Furthermore, the use of words, language, experiences, and behaviours must be broad enough to represent what women living with disabilities in South Africa have experienced.

6.4 Participant characteristics

Participants' were aged between 19 and 54 years. Physical impairments were congenital (for example participants' born with Cerebral Palsy or Spina Bifida) or conditions acquired in childhood or later in life such as poliomyelitis, transverse myelitis, meningitis, diabetes, stroke, or injury as a result of a motor vehicle accident, fire, or gun-related violence that resulted in mobility or dexterity restrictions, paralysis, limb amputation or disfigurement. Some participants were wheelchair-users and others used alternative assistive mobility devices or moved independently. Hearing and visual impairments were either genetic, congenital or resulting from trauma, autoimmune conditions, cataracts, glaucoma, or chronic condition associated with Albinism or diabetes. Assistive devices included hearing aids or a white cane. However, participants generally had limited access to assistive devices or prostheses[13].

Participants were majority black African (21) and Coloured women (9) residing in urban-based informal settlements on the outskirts of Cape Town City characterised by poverty, informal housing, poor infrastructure and poor access to basic services. In these communities, high unemployment and crime rates as well as pervasive alcohol and other substance abuse create austere social conditions that increase participants' risk of exclusion and vulnerability to violence. The physical terrain of these settlements is often uneven and mostly unpaved ground. Living accommodations are close together and access to communal water or toilets are challenges for all residents. These environmental barriers especially affect those with mobility and sensory impairments.

[13] To avoid medicalising disability, the specificities of participants' impairments are not included in the findings. In this way, participants' anonymity and confidentiality are protected.

Half the participants reported they had ever partnered – all of which were heterosexual relationships. Five participants were currently in relationships and seven were married, while two participants' husbands had left them, and one was a widow. Approximately half the participants had children. Not unlike their non-disabled counterparts, many participants had not completed secondary school education. While low-educational attainment is common among residents in South Africa's informal settlements, participants spoke of lack of schools suiting the specialised needs of youth with disabilities (Saloojee et al. 2007). The majority of participants had been enrolled in mainstream schools where they received little to no rehabilitation and struggled to keep up with non-disabled peers. Only two participants had enrolled in tertiary education. Participants described how formal employment was a challenge due to already high unemployment rates, with a lack of education and impairments further restricting livelihood opportunities. Those attending protective workshops received a daily stipend, whereas those in care facilities were the least likely to be employed or to have an income other than a government-sponsored disability grant (see Table 1 for sociodemographic characteristics of participants in Appendix 3). The intersections of disability and poverty make daily life especially challenging for participants.

6.5 Findings

Goffman conceptualises stigma as "undesired differentness" and has shown how stigma disqualifies a person from full social acceptance (Goffman 1963; Preface). His work demonstrates how discrediting social labels infiltrate a person's self-perceptions, become internalised, and impact on the ways in which others view them (Goffman 1963, 5). For participants, societal exclusion and feeling or being rejected or anticipating rejection from partners was omnipresent and was fashioned around "unrealised norms" (Goffman 1963,

138) of what is expected in intimate partnerships in South Africa. In presenting how disability stigma influences participants' attainment of womanhood and intimate partnerships, the findings draw on themes of limited opportunities to meet potential partners, restricted sexual contact and expectations of being wives and mothers. The findings further reflect how women with disabilities negotiate ideals of womanhood to avoid rejection from men, resist social norms and affirm their sexuality.

6.5.1 Limited opportunities to meet potential sexual partners

Participants claimed impairments and disability stigma restricted their chances of meeting a male romantic partner. The fact that so few participants reported ever partnering may be attributed to social isolation and lacking access to social situations where relationships may be formed. Lack of transport, dependence on others for mobility and minimal opportunities to leave the house or care facility, limited prospects for interaction with potential partners. Some participants spoke of the lack of eligible men at the residential care facility because "they all have disabilities", emphasising how women with disabilities may subscribe to heteronormative ideals of finding a non-disabled partner who can care for and protect them. Those who had partnered had met their partners at school, church, or at protective workshops or, ironically, at residential care facilities they attended. A few participants had been active on social media platforms and online dating sites where physical mobility or hearing impairment posed less of a barrier to interaction and presented accessible opportunities to meet prospective partners. One participant said, "online dating is now the only way to put myself out there and maybe meet Mr .Right" (32 years old, single, mobility impairment). A despondency crept into her voice later when she admitted it seemed a futile exercise and was unlikely to result in an actual face-to-face interaction:

> Dating online is difficult enough – try doing it with a disability. Even guys that match with me - I know that there is no opportunity for us to go out on a proper date, or even meet face to face.

Facebook, Whatsapp and Tinder were the main online applications participants used to initiate friendships or romantic partnerships. Women who used them had both positive and negative experiences. Those able to interact online with potential partners spoke about false pretences, disguising their impairments and thwarting men's expectations: "when they meet you [in person], it is not what they expected" (21 years old, single, mobility and speech impairment). Another participant who uses sign language explained: "I can text them and we can chat, but if I had to see him in real life, we would not be able to understand each other" (25 years old, single, hearing impairment).

6.5.2 Restricted sexual contact: "Dating in the dark"

Participants also experienced restricted sexual contact or what one participant termed "dating in the dark". Participants were asked to share experiences of intimacy and sex during interviews and reported both their personal and partners' anxieties of initiating physical or sexual contact: "Men are scared when you have a disability, they are scared to see how and if sex works" (23 years old, single, physical impairment). Other participants described how partners were scared to be associated with them in public:

> They don't hold hands with you in public, when they date you they only walk together with you in the dark. They want to keep you hidden, because it's a sin to be in love with a disabled woman (43 years old, divorced, physical impairment).

This metaphor of 'sin' depicts how impairments needed to be concealed and how some community members consider dating a disabled woman as immoral. Another participant shared her personal perceptions of revealing her impairments: "When we finally had sex, I

closed my eyes, I looked away, I didn't want to see my body, and I didn't want to see him seeing my body" (28 years old, married, physical impairment). Fearing rejection, she spoke of her hesitancy to disclose her impairments to her partner:

> … he wanted to kiss, and the kissing started to have hands that were going different directions and then I had to always push the hands away … up to a point where he asked me what's wrong and I thought oh my goodness I have to explain now and he's going to run away. When I told him... he didn't understand what his friends would say about him dating a disabled girl.

Social norms about beauty, desirability and able-bodiness shape beliefs about romantic reciprocity or rejection: "If you are beautiful and have a disability then it's okay, but I felt I was ugly too" (43 years old, divorced, physical impairment). Some men expected gratitude for sexual encounters, making participants feel used and worthless: "He said you're not my type, but I'm doing you a favour" (21 years old, single, physical and speech impairment). Another participant in a residential care facility spoke nostalgically about her marriage and how after her spinal cord injury her relationship ended:

> When he left me, I felt nothing. I knew it was coming. If I would have thought he would stay and accept me I would have been lying to myself. I'm in the bottom of what he would expect, the lower shelf. There are plenty of women that are better gifts for men than I can be. I guess I'm not a gift, but a heavy object to carry and then throw away and leave here at this place (the care facility). (32 years old, divorced, physical impairment)

This experience of rejection and humiliation lowered her self-esteem and inhibited future quests for sexual intimacy: "Maybe I shouldn't even try to date or even try to look attractive… I assume it [a relationship] won't happen to me again".

6.5.3 "Not a proper wife"

Participants often felt vilified and perceived as unsuitable romantic companions by partners, community members and (potential) in-laws. A participant in a newly formed relationship described how commuters jeered with surprise when her partner met her at a bus stop: "They say things like you can't have a boyfriend because you can't walk and stuff like that" (23 years old, physical impairment). Relating a story from a previous relationship, another participant claimed her boyfriend had wanted to marry her, but his parents had prevented it:

> He said he wouldn't be able to marry me. His parents would not agree with it. How could I argue when I can't say anything back to change the way it is, the way I am? I can't make them accept me, I just wished that he would accept me, but still I am not enough (34 years old, single, visual impairment).

In South Africa, Xhosa cultural practices of bridal negotiation (*lobolo*) are complex and essentially determine the worth of the incumbent wife. A woman with a disability's prospects as a wife may be reduced because of assumptions that she may be unable to bear or raise children – the cultural hallmark of Xhosa marriage. The onus therefore is placed on the prospective husband to insist that he marry the woman, regardless of family responses, as this participant added: "if he loves me and has the money he will pay *lobolo* and accept me as a wife". Instead of challenging his family and marrying her, he left her. Consequently, she expressed feeling rejected and disillusioned about her future marriage prospects. After acquiring a disability six years into marriage, one participant claimed she could no longer live up to her husband's expectations. She claimed he had stopped initiating sex and had threatened to get another wife. She felt she could no longer sexually satisfy him even though she still felt sexual desire:

> I learned to wash clothes and cook, but I cannot fetch water, and I cannot hang up clothes…. It's something I lost, like sex, it never happened to me again. I kind of switched my brain and told myself that it [sex] would not happen to me again…he said I was no longer good in bed…I was not a proper wife (35 years old, married, physical impairment).

A sense of loss featured dramatically among participants who acquired impairments as young adults – it included both loss of potential romantic partnerships and loss of previous capacity to fulfil expectations of sexual intimacy and garner love and respect from existing partners. The burden of care after acquiring disability also affected the longevity of intimate partnerships. A participant explained how black African culture in South Africa prescribed gendered roles within intimate partnerships, and how disability disrupts living up to these roles:

> The abuse of a disabled woman in black culture is different. Because a man is seen as a superior figure and a woman knows she is obligated to care for him. You know Coloured or white people care about their partners, but us black people - if it's a woman, and a man would care for her, people would look at him like he is a weak man and say, '"how can you wash for a woman?"' So, the husband would rather neglect the wife or leave her (38-year-old, married, physical and visual impairment).

6.5.4 Unattainable motherhood

As in many societies, women in South Africa are deemed responsible for caring for children, spouses and elderly parents. As discussed above, not being considered a good enough wife fortified assumptions that participants were unable to bear and bring up children in a suitable way. A participant lamented:

> Do you think anyone asks me when are you going to have a baby? They think it will never happen. When they believe it, you believe it. And if they do ask me one day

> I will think they are having a joke with me (23-year-old, single, physical impairment).

While a few participants bemoaned their diagnosed infertility or inability to carry a child to term due to medical risks posed by their impairments, others spoke of being abandoned by partners after becoming pregnant: “He left because he was afraid for the child, that I would not bring it up right” (39-year-old, single, visual impairment). Participants sometimes echoed anxieties about how impairments may pose risk to their child’s safety, especially if their partner left them:

> What happens if I fall down and I hurt the baby inside me, or when the child is here, and the seizures happen? Who will be here? (30 years old, single, physical impairment).

Sometimes distress at being abandoned was negated by success in motherhood: “Now I am alone, with the child that was his… he cannot even come to see that I am raising this child; that I am able” (23 years old, single, physical impairment). Another participant shared a similar anecdote about attaining motherhood:

> I was not treated well, even with this child, people were talking about my pregnancy…they would gossip. I just raised my child, I raised him well…there was nothing that was keeping me back, not even my disability (38-year-old, married, physical and visual impairment).

Successful motherhood allowed participants to counter the stigma of infertility and ableist assumptions around child rearing, whether partners remained with them or not, as one participant said: “People say ‘but you can’t have children’ – but I tell them I have a place [womb] and one arm to carry the child - that is enough” (43 years old, divorced, physical impairment). Their capacity to rear children indicated how participants negated assumptions of passivity or physically weakness:

> I proved to him and his family and everyone that I am a good mother. My son is a good boy. He knows he needs to help me, and he does a lot for me… more than my husband does (39 years old, visual impairment).

Some participants were under the impression that their partners feared their offspring may be born impaired. To dispel this myth, one participant intimated that only if her partner carried the gene were they likely to have a differently pigmented child: “My disability is not something that will infect others” (34 years old, single, visual impairment). When participants were able give birth to a non-impaired child, they sensed their relationships would be less volatile and they could garner respect from partners and community members.

6.5.5 “If he could like me, then anybody could like me”

While many of these accounts of intimacy and womanhood seem despondent and pessimistic, some examples of agency, positive identity formation and resisting social norms around disability and sexuality emerged. One participant described adolescent boys as inquisitive and solicitous and how she used her identity as a woman and not someone with a disability to refute taunts, undermine potential rejection and assert her womanhood:

> When guys see me, they are curious. They tease and laugh and ask me if I have a boyfriend. They say they want to try it [sexual intercourse] with me to see if it can be done… I ask them if they even know how sex happens, because they can see I am a woman (23 years old, single, physical impairment).

Occasions of positive affirmation and acceptance meant opportunities for participants to re-examine their self-esteem, avoid stigma and unmet expectations, and inspire confidence for relationship longevity. One participant shared her experience of her wedding night as follows:

> My partner wanted to see, he wanted to feel my leg, even though I was scared. He took my leg [prosthesis] off and said it was better that I be natural and be myself (28 years old, married, physical impairment).

Reflecting on her five years of marriage, she went on to describe how her partner focused less on her impairment and more on her as a woman, allowing her to feel loved and respected:

> He's one of the people that made me feel comfortable about myself, he motivated me that I was beautiful, there was nothing wrong with me even if I had a disability, he liked me the way I was… I knew that if he could like me, then anybody could like me.

While this participant got affirmation from her partner, another participant related how life's experiences had taught her to accept herself, her limitations, and her capabilities. She claimed she learned sexual seduction despite her physical challenges and sought and gave sexual gratification: "I don't just lie there, I show him what I want, and I move, and I take control. I make sure he knows I feel good" (56 years old, dating, physical impairment). She claimed her sexual competence "proved men wrong" and she actively pursued sexual relations to showcase her body and "what it can do and not what it cannot do".

Wearing jewellery and makeup helped some participants to feel feminine and attractive. While one participant lamented how her impairments denied her access to such beauty-enhancing strategies, another explained how she wore makeup, jewellery and a long skirt (to hide her legs) and went into the community on her motorised wheelchair to flirt with men. Despite seeking men's attention, she remained cynical about typical male behaviour in South Africa: "… all men treat all [her emphasis to depict women with and without disabilities] women the same, they use you and leave you" (23 years old, single, physical impairment). She intimated that to protect oneself and avoid rejection one should consider not dating at all. Despite her cautionary advice, she was still willing to risk potential rejection: "I let all my

worries go – because I don't know exactly what they may think or do. I need to at least put myself out there".

A few participants actively sought acknowledgement from men by creating online dating profiles. While online flirtation rarely progressed to real-life partnerships, a few participants felt the 'web' (internet) protected them from real-life rejection. By not disclosing impairments, participants could develop online relationships without feeling self-conscious and simultaneously explore an identity other than impaired. The 'likes' or 'matches' received while dating online invigorated their self-esteem and confidence in attracting potential romantic partners.

6.6 Discussion

Manifestations of disability in arenas of intimate partnerships, sexuality and reproduction remain neglected in social and public health research. However, the Convention on the Rights of People with Disabilities asserts the right of disabled persons to "develop intimate relationships; their right to pursue sexual expression, relationships, family life, marriage and parenthood; and their right to accessible and age-appropriate information and reproductive and family planning education on an equal basis with others" (UN 2006, Article 23). Notwithstanding, in this study we see how social norms of being a wife or mother or being beautiful and sexually desirable intersect with disability stigma to make the pursuit of intimate relationships and realisation of these rights complicated endeavours for women living with disabilities in South Africa.

Limited opportunities to meet partners, restricted sexual contact and expectations of wifely duties or motherhood shaped pursuits of intimacy. Women living with disabilities in South Africa expressed anxiety about engaging in sexual relations because of what they hear

and experience. Participants seemed sceptical about the sincerity of men's advances or whether feelings of attraction would be reciprocated. Similar to research in Malawi, partners' expectations of gratitude for sex or abandonment left participants feeling taken advantage of and exaggerated their feelings of ostracisation (Kvam and Braathen 2008).

Goffman (1963) was one of the first scholars to theorise the interface between societal views and interactions and the self-views of people with disabilities. Participants mainly described romantic experiences in terms of rejection, abandonment and loss which were triggered by negative self-views that were reinforced by how others treat them, and barriers faced in appealing to heteronormative and ableist messages about womanhood. Because of these barriers, efforts to pursue sexual intimacy and acceptance were stifled.

Under the impact of hegemonic masculinity, passive womanhood personifies the ideal woman (Connell and Messerschmidt 2005). In this respect some participants could be seen as performing this ideal. However, this paper reveals how participants are able to subvert stereotypes of passivity and dependency by identifying as sexual, confident, proud and capable women. By hiding or revealing impairments participants could escape ridicule or garner love and acceptance.

Not all participants were successful in challenging ableist and heteronormative assumptions of disability and sexuality, but some embraced their differences and portrayed positive self-views in their sexual conquests – using stigma-avoidance strategies that Goffman (1963) neglects to highlight and interpret. By focusing on personal agency and how women with disabilities resist social norms and develop positive identity schemas of being women, sexual partners, wives and mothers or an online 'match', this paper advocates a move towards resistance theories of disability and sexuality (Chappell 2017; Gabel and Peters 2005; Loja et al. 2013).

6.7 Conclusion

Both womanhood and disability are socially constructed and negotiable concepts. The intersection of disability stigma and sexuality in intimate partnerships involves discourses of able-bodiness and heteronormativity that shape pursuits of intimacy. By acknowledging the difficulties women with disabilities encounter in achieving sexual intimacy and acceptance, and by building on personal ways of coping with or avoiding stigma and rejection, this research can inform wider strategies to facilitate better relationship outcomes for women living with disabilities. Central to such work must be a destabilisation of patriarchal and ableist assumptions that women with disabilities are unable to have long-lasting and fulfilling partnerships. Moreover, accessible and relevant sexuality education and information on relationships and intimate partner violence, maternal and sexual and reproductive health care are necessary to ensure healthy and safe intimate partnerships for women with disabilities.

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CHAPTER 7. BARRIERS TO GENDER-BASED VIOLENCE SERVICES AND SUPPORT FOR WOMEN WITH DISABILITES IN CAPE TOWN, SOUTH AFRICA

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The PhD candidate conceptualised and conducted the data analysis for the paper and wrote the full draft and all revisions of the paper. Both supervisors approved the final draft of the paper before it was submitted for publication.

Authors' contributions:

I. van der Heijden – protocol development, data analysis, writing full draft and all revisions of the paper

J. Harries – review of protocol, mentoring of data analysis, critical review of all drafts of paper

N. Abrahams – review of protocol, mentoring of data analysis, critical review of all drafts of paper

Motivation for inclusion:

This chapter addresses the third objective of the study: “To explore the inclusivity of GBV services, and what an appropriate response should be,” and is presented in the format of a journal article.

Abstract

Worldwide, women with disabilities experience higher levels of gender-based violence (GBV) than women without disabilities. While we know little about GBV among women with disabilities in South Africa, we know even less about the accessibility or inclusivity of post-violence support and services. This paper explores barriers to GBV services experienced by women with disabilities in Cape Town, South Africa. Thirty women with varying disabilities and nineteen disability and GBV service provider representatives were purposively selected and participated in in-depth interviews and focus group discussions. Thematic analysis revealed that women with disabilities experience unique disability-related barriers to GBV care and support. Disability-related stigma, accessibility barriers, inadequate training, limited resources and lack of funding for disability-inclusivity contributed to poor service provision. Disability awareness and training, accessible information, reasonable accommodations, and disability-relevant referrals need to be integrated into existing GBV services to ensure sustainable and accessible pathways to inclusive violence prevention, support and responses in the country.

Keywords: Disability, gender-based violence, violence prevention, accessibility, service provision.

7.1 Background

Globally, women with disabilities experience higher levels of gender-based violence (GBV) than non-disabled women (Rich 2014; Schröttle & Glammeier 2013). Women with disabilities face discrimination and stigma based on both their gender and disability, that increases their risk of victimisation (United Nations, 2017; Mays, 2006; Abu Habib, 1995). Data also show that women with disabilities may fear retribution from perpetrators, lack credibility when reporting, or experience dismissive attitudes from service providers, thwarting their personal help-seeking behaviours (Barrett & Pierre, 2011; Milberger, et al., 2003). Structural barriers and economic and physical dependence on perpetrators further hampering their ability to end violent relationships (Findley, Plummer, & McMahon, 2015; Plummer & Findley, 2012; Hassouneh-Phillips & McNeff, 2005; Hassouneh-Phillips et al., 2005; Potgieter & Khan, 2005). Dependence on others may expose women to disability-specific violence on top of GBV, which often remains undetected and untreated (Curry et al., 2009; Brownridge, 2006; Saxton et al., 2001). Increased vulnerability to violence means the rights and needs of women with disabilities must be integrated into health care and GBV services.

Both the social and psycho-emotional dimensions of disability are important to consider when understanding women's vulnerability to GBV and their access to post-violence care and support (Thomas, 2004; Reeve, 2002). Structural barriers, invalidation and social exclusion as a woman *and* as a person with a disability may contribute to a lack of self-esteem, making tolerance of and exposure to GBV more likely for women with disabilities (Astbury, 2012; Saxton et al., 2001). Research shows how experiences of ongoing and multiple forms of discrimination and violence impact on an individual's psychological well-being, and that women with disabilities experience higher levels of anxiety and depression compared to men

and women without disabilities (Dembo, Mitra, & McKee, 2018). All these factors can undermine the reporting of violence and limit help seeking behaviours.

Among the general female population in South Africa, the prevalence of GBV is staggeringly high. Estimates reveal that up to 40% of South African women have experienced sexual and/or physical intimate partner violence (IPV) during their lifetime, and between 12% and 28% of women ever report being raped (Jewkes & Morrell, 2010; Jewkes et al., 2010; Jewkes et al., 2009; Dunkle et al., 2004; Jewkes, 2002). Yet the data on the prevalence of violence against women in South Africa is undermined by under-reporting. Women are reluctant to report because of lack of confidence in justice outcomes, service provider apathy, stigma and shame, and fear of retributive violence from perpetrators (Mazars et al., 2013). Furthermore, existing GBV programmes and services in South Africa are under-resourced, under-utilised and lack robust evidence-based interventions (Centre for the Study of Violence and Reconciliation [CSVR], 2016).

Globally, women with disabilities face numerous barriers to health service provision and show higher rates of not receiving health services compared to people without disabilities (Stockburger & Omar, 2015; Gibson & Mykitiuk, 2012; Thiara, Hague & Mullender, 2011; World Health Organisation/World Bank, 2011; Barrett, O'Day, Roche, & Carlson, 2009; Coker, Smith & Fadden, 2005; Becker, Stuifbergen, & Tinkle, 1997). In low-middle income countries (LMICs), barriers to health care are exacerbated. Women with disabilities in LMICs have very little knowledge of their rights or how to access sexual, reproductive, and health care services (Lee et al., 2015). Studies in LMICs, including South Africa, reveal that services are largely unavailable because resources for alternative communication, augmentative devices and accessible facilities are inadequate. Furthermore, help-seeking is hampered by myths and

stigmatization of disabled sexuality in Africa, health-provider ignorance and negative attitudes, and the costs of using services (Rugoho & Maphosa, 2017; Mavuso & Maharaj, 2015; Kritzinger et al., 2014; Mall & Swartz, 2012; Swartz et al., 2009; Mgwili & Watermeyer, 2006; Anderson & Kitchin, 2000). Similarly, in the Philippines, service providers have shown little understanding of human rights for women, regardless of disability status; have very little training in relation to disability; and have limited access to resources that would enable disability-inclusive services. Additionally, service providers may be generally unaware of violence and abuse among disabled clients, preventing screening for IPV and access to care (Lee et al., 2015). A study conducted among women with disabilities in Bangladesh showed that, of 84% of women who experienced IPV, less than half (45%) reported seeking support to minimise or avoid violence (Hasan et al., 2014).

Evidence of GBV against women with disabilities in South Africa is emerging (Chappell, 2017; Meer & Combrinck, 2017, 2015; van der Heijden, Abrahams, & Harries, 2016; Neille & Penn, 2015). Research related to the findings presented in this paper has highlighted additional layers of violence against women with physical and sensory disabilities in South Africa, such as neglect, deprivation, sexual assault by institutional staff and stigma-induced psychological abuse by intimate partners. Stereotypes around disability and sexuality, poverty and lack of employment options, social and economic dependence on perpetrators and inaccessible home and community environments shape women with disabilities unique experiences of GBV in South Africa (van der Heijden, Abrahams, & Harries, 2016).

Violence against women with disabilities can be expected to be higher in South Africa where there are greater stigmas associated with having a disability, fewer resources and limited accessibility to infrastructure and health services (Mavuso & Maharaj, 2015; Kritzinger

et al., 2014; Mall & Swartz, 2012; Hanass-Hancock, 2009). While accessing and utilising services is a challenge for GBV survivors overall in South Africa (CSVR, 2016), women with disabilities can expect exacerbated difficulties in accessing GBV services given their impairments, marginalisation and the unique nature of the violence they encounter.

Acknowledging that women with disabilities have equal rights to quality service provision and rights to freedom from GBV (United Nations, 2006), the paper documents some of the experiences and barriers to GBV support and care for women with physical and sensory disabilities in South Africa, and includes recommendations for accessible pathways to inclusive GBV support.

7.2 Study context

The findings presented in this paper are part of a broader qualitative project aimed to understand the violence experiences of women with physical and sensory disabilities living in Cape Town, South Africa. All women in South Africa are subject to high levels of GBV, especially those living in poorer, informal communities, characterised by high levels of crime, low levels of employment, poor infrastructure and limited resources and services. The study was based on the premise that intersecting vulnerabilities of race, gender *and* disability may render black African and Coloured[14] women with disabilities living in such communities more susceptible to experiencing GBV, especially IPV (Neille and Penn, 2015). South Africa's entrenched segregation by race has left an indelible culture of poverty among the majority of the black and Coloured populations living in South Africa, and poverty rates are especially highest among those living with disabilities in informal settlements (Moodley & Graham,

[14] Coloureds are an ethnic group composed primarily of persons of mixed race. They are a minority group within South Africa, but are the predominant population group in the Western Cape. They are generally bilingual, speaking Afrikaans and English, though some speak only one of these languages.

2015; Moodley & Ross, 2015; Ataguba, Akazili & McIntyre, 2011; Loeb et al., 2008; Jelsma, et al., 2008; Emmett & Alant, 2006). A South African disability activist and scholar points out that the lives of people with disabilities in the country are still severely marred by broad failure of service delivery. The situation is made "far worse by a combination of entrenched prejudice, government disregard and the fact of our society being designed and run in ways which exclude [people]" (Watermeyer, 2013). He adds that those with disabilities living in informal settlements have greater restrictions to employment, basic sanitation, transportation and greater exposure to harsh weather, health problems and and verbal, physical and sexual abuse (Ibid).

In recent years, GBV and its negative consequences on society have been prioritized by the South African government and civil society organisations. Various laws on sexual assault and violence against children have been passed, post rape services and access to legal aid have been coordinated, and awareness campaigns around GBV and changing damaging masculine norms have been intensified. In March 2019, the government committed to develop a national strategy to fight GBV and ensure adequate resourcing of post-rape care centres, sexual offences courts and domestic violence shelters "that respond to the needs of all people including people with disabilities and lesbian, gay, bisexual, trans, queer, intersex and asexual persons (LGBTQIA -+)" (South African Government, 2019). It is in this context that this paper serves to identify barriers to GBV service provision for women with disabilities to guide efforts towards improving services for *all* women living in South Africa.

7.3 Methodology

A qualitative study on violence against women with disabilities was conducted in Cape Town, South Africa, between 2013 and 2015. Data was collected from two groups of participants;

service providers in the disability and GBV sectors, and women living with physical and sensory disabilities. It is envisioned that including perspectives from both users and providers allowed for a holistic account of the barriers and constraints to GBV services.

7.3.1 Service providers

Disabled Peoples Organisations (DPOs) working with people living with a range of disabilities in informal communities in Cape Town were approached. DPOs provided disability awareness and advocacy, rehabilitation services, residential care facilities, counselling, individual case management and referrals. Some provided social development services for assistance in accessing disability grants and housing, or provided life skills and job training through internships and protective workshops. DPO's did not specifically cater for GBV support, but referrals to GBV services could be facilitated.

GBV service providers included rape crisis centres, domestic violence shelters and Thuthuzela Care Centres (TCCs)[15]. These services included post-rape medical care and forensics; referrals to criminal justice systems and procedural assistance in reporting violence; 24-hour hotline services for victims; suicide prevention hotline services and counselling for survivors of sexual assault and domestic violence.

Service provider representatives interviewed included senior managers, counsellors and social workers. They were contacted by telephone or email and invited to participate. Nineteen representatives from seven DPOs and three GBV services agreed to participate. With informed consent, seven individual interviews and three focus group discussions with three to five representatives were conducted in private venues and lasted between one and

[15] Thuthuzela Care Centres are one-stop facilities that have been introduced as a critical part of South Africa's anti-rape strategy, aiming to reduce secondary victimisation and improve conviction rates. Fifty-one centres have been established since 2006. The centres are located in close proximity to hospitals and police stations and link up with sexual offences courts, prosecutors, social workers, magistrates, police officers and women and children non-governmental organisations.

two hours. Service providers were offered refreshments after discussions. Questions asked by the interviewer included perceptions of the magnitude of the problem, sources of support, perceptions of services' effectiveness, and recommendations for responding to violence against women with disabilities.

7.3.2 Women with disabilities

Article 1 of the Convention on the Rights of Persons with Disabilities (United Nations, 2006) defines persons with disabilities as those with "long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." Women with sensory and physical impairments were purposively recruited from protective workshops and residential care facilities in the Cape Town metropole. Women with severe cognitive impairments were excluded from the study and their exclusion is recognised as a limitation to the study's representivity. Another limitation is that, because participants were mostly selected through DPOs, they may have been better able to access services than other women with disabilities in the population who were more isolated and likely more vulnerable to GBV.

Participants were aged between 19 and 54 years. Participants were majority black (n=21) and coloured women (n=9) residing in urban-based informal settlements on the outskirts of Cape Town. It is acknowledged that the racial make-up of participants means the data may not be reflective of the GBV experiences of white, upper class women with disabilities in South Africa.

Physical impairments were congenital (for example, participants born with cerebral palsy or spina bifida) or conditions acquired in childhood or later in life through illness (e.g., polio, meningitis, transverse myelitis) or injury (due to, for example, fire, motor vehicle accident, violence). Some participants were wheelchair-users. Others used alternative

assistive mobility devices or moved independently. Sensory (hearing and visual) impairments were either genetic, congenital or resulted from trauma, autoimmune conditions, cataracts, glaucoma, or chronic conditions associated with albinism or diabetes[16].

Women with disabilities were invited to participate in initial and follow up in-depth interviews until data saturation was achieved. Interviews were audio-recorded with participants' consent and notes were taken. Interviews were conducted in accessible private spaces and lasted between one and two hours. Questions posed to women with disabilities were aimed to understand participants' experiences of violence and experiences of support and redress post-violence.

Ethics approval for the study was acquired from the South African Medical Research Council and the University of Cape Town. Ethical and safety recommendations for research on violence against women published by the World Health Organisation (WHO) served as guidelines for the study (Ellsberg & Heise, 2005), as well as other publications on sensitive research strategies with people with disabilities (Northway, Howarth, & Evans, 2015; Nind, 2008; Harris & Roberts, 2003). Informed consent and research methodologies embraced the principle of reasonable accommodation and all participants in the study were accommodated for according to their self-defined needs – the aim was to ensure they were (physically) comfortable, able to communicate effectively, and protected from adverse events precipitated by their inclusion in a study on GBV (van der Heijden, Harries & Abrahams, 2018). Informed consent procedures were made accessible in both written and oral formats, available in the language of the participant, and included an option to give written or verbal consent – taking in to account restrictions in literacy, dexterity, vision or hearing. All

[16] To avoid medicalising disability, the specifics of participants' impairments are not included in the findings. In this way, participants' anonymity and confidentiality are protected.

participants were assured of confidentiality and informed that names would not be used in published data. If a participant expressed any discomfort during the interviews, the interviewer provided a pamphlet of several local resources for support.

The first author conducted interviews in English and Afrikaans and a research assistant translated for participants who spoke isiXhosa (the predominant African language spoken in Cape Town). Hearing-impaired participants were encouraged to nominate their own sign language assistant with whom they had an established rapport. All assistants signed a confidentiality agreement. Interviews were discontinued if participants grew tired, emotional or no longer wished to continue. Transport reimbursements, refreshments and monetary compensation of USD13 were given to participants for time spent participating in the study.

Interviews and focus groups were translated and transcribed verbatim and cross-checked against audio recordings. Using ATLAS.Ti 7.5.6, the first author initially coded data deductively drawing on main themes in the study's scope of inquiry. Subsequent themes were identified through inductive analysis of emerging issues, ideas and patterns. To enhance the trustworthiness of the study, participant quotes are used to reflect their experiences and perspectives. Combined viewpoints from both service providers and women with disabilities further help to validate the data.

7.4 Findings

The findings incorporated viewpoints from women with disabilities and service providers in order to get a holistic view of pathways and barriers to GBV care. The findings demonstrate that women with disabilities do seek out GBV services and support. Nonetheless, various restrictions curb their help-seeking and service utilisation. The identified

barriers include disability-related factors, inadequate information and awareness, lack of training, limited resources and limited funding.

7.4.1 Disability-related factors

The consensus of both groups of participants was that women with disabilities are at higher risk of experiencing violence, particularly because of existing high levels of GBV in the country, compounded by various environmental barriers and added disability-discrimination that increase their vulnerability to GBV and thwart help-seeking. Disability-related factors included functional barriers (physical access and communication barriers), disability-related stigma and dependence on perpetrators, and personal psychological factors.

Functional barriers

Women with mobility impairments were impacted by physical inaccessibility to services. Co-morbid conditions of pain and fatigue associated with their physical impairments further restricted their help-seeking: “I am so tired, and I have pain everywhere. I lack the will to get into the [wheel]chair to go anywhere, let alone to the clinic” (Female, 37 years old, physical impairment). Service providers reported that shelters may not have ground-floor bedrooms, and that constructing entrance ramps or converting bathrooms to make the facilities accessible was constrained by lack of funding. Women with disabilities needing personal-care assistants or assistant dogs were also unlikely to be accommodated at shelters. Service providers described a lack of specialised aids for hearing- or visually-impaired clients. Communication barriers further hindered help-seeking and potentially re-traumatised survivors with disabilities:

> By being a victim of abuse, they face more abuse whether it’s going to the police or to the clinic because […] when somebody’s been through violence and they are

> a hearing person you got a lot of anger inside. You are frustrated and maybe you going to shout and you going to raise your voice. Deaf people communicate with their hands and their face. You don't understand me, so you come across looking at me like something is wrong mentally, so they face more discrimination. People start to think something is wrong and they subject you to more abuse when trying to get the necessary help for the abuse that is already there, so there is just more victimisation (Service provider, DPO manager).

Another service provider commented on how communication barriers were not always anticipated in GBV services:

> A hotline is of little help to a woman that is deaf. When a person with a speech impediment calls in, the person taking the call may not understand her, or think she is drunk, so they do not take her seriously (Service provider, rape crisis hotline operator).

In some cases, communication obstacles compromise credibility and confidentiality. A participant recounted an incident where a woman with a hearing impairment came in to report intimate partner abuse:

> She didn't have a hearing aid and it was extremely difficult. We had to get another family member to come in to assist her. That is a sticky situation as it compromises her privacy. If this family member is complicit in the abuse, there is a very big issue with full and truthful disclosure (Service provider, Thuthuzela social worker).

Functional barriers were compounded by poverty, isolation, costs of specialised transport and minimal family or caregiver support. Additionally, participants with different types and severity of impairments encountered different challenges when accessing services.

Disability-related stigma

Disability-related stigma functioned as a central hindrance when seeking out services or reporting crime. Service providers acknowledged how that, in general, people hold assumptions that women with disabilities are not sexually active or partnered. Non-sexuality was closely linked to the infantilisation of women with disabilities when reporting assault, which may create a hostile environment that re-traumatises survivors with disabilities:

> Even though I was the one who was raped, the police spoke only to my mother. I was there, and she was there, but they did not even look at me, it was as if I was a child that could not speak for myself. (Female, 27 years old, physical impairment)

Both women with disabilities and service providers claimed that due to the particular nature of IPV against women with disabilities – such as psychological and verbal abuse, or financial exploitation, where partners pocketed their disability grant monies – service providers may not consider these violations to be as serious as other forms of IPV that leave visible injuries. A participant explained: “There is no use in discussing these things that happen to us because they are only going to help when you can prove you have been beaten or raped” (Female, 24 years old, physical impairment). A service provider agreed: “They assume the abuse is not real abuse” (Service provider, DPO social worker). Lack of awareness of the unique forms of violence experienced by women with disabilities also meant that women with disabilities were reluctant to disclose disability-related forms of abuse, hampering help-seeking and care:

> How can a counsellor who does not live with a disability know exactly what I am going through? How can she know that he neglects me and calls me names and tells me I am stupid? That is why I do not go to speak to them (Female, 32 years old, physical impairment).

Some participants who sought post-violence support claimed that the attitudes of service providers towards women with disabilities were worse than what women without disabilities may experience:

> The police don't know what the protocol is when they come across a victim with a disability. Regardless of the fact that they treat any woman who has experienced violence disrespectfully, they treat women with disabilities even worse (Service provider, DPO manager)

With regard to negative attitudes and treatment of women with disabilities, a participant claimed: "The system questions a disabled women's credibility more when reporting a violence-related crime" (Service provider, Thuthuzela manager). Another participant affirmed how impairment and lack of credibility undermined help-seeking and support:

> I was abused as a child several times at home and as an adult, and now I get abused by the staff [at the care facility]. I couldn't do anything about it. They think they can do it and nothing will happen […] and because I couldn't get away. I tried to tell people, but nobody believed me that I had been raped (Female, 34, physical impairment).

Dependency

Dependency on partners and caregivers for impairment-related needs did not assure quality care or assistance. Generally, participants with disabilities reported receiving poor assistance at home and residential care facilities that may have limited their ability to leave abusive scenarios:

> I can't even leave the house, so how will I find another place to go? If I leave him where will I go, who else will take care of me? I rely on him to help me get out of bed in the morning (Female, 30 years old, physical impairment).

Furthermore, women with disabilities may not seek services if they blame themselves for violence and for burdening their caregivers: “They believe they are worthless and a problem, so they put up with abuse” (Service provider, residential care facility social worker).

Personal factors

Disability-related factors curbing access to GBV services included the psychological impact of having a disability and experiencing violence. Depression, uncertainty, and lacking options left some women with disabilities without knowing who to talk to or where to go: “The abuse disturbed my mind and I could not think of what to do or how do stop it” (Female, 39 years old, physical disability). Overall, participants with disabilities reported how anxious they felt about disclosing violence because they anticipated apathetic responses and thus were reluctant to seek care.

7.4.2 Inadequate information and awareness

Overall, participants with disabilities received little to no information from DPOs on how to prevent abuse, what to do and where to go afterwards, or whether existing GBV services could accommodate their disability-specific needs. After disclosing multiple acts of IPV to the interviewer, one participant retorted: “I don’t know if the shelter is even accessible to me?” (Female, 32 years old, physical impairment). The absence of information on the inclusivity of amenities for the immediate safety of women with disabilities was an important barrier that one service provider acknowledged:

> We need prevention education and awareness and options for these women within mainstream services. They have no information about their rights, that they have a right to feel safe and a right not to be abused like that (Service provider, protective workshop manager).

Some participants with disabilities felt protective workshops were unstimulating and segregated women with disabilities from mainstream services and resources:

> Women are invisible in this community, they remain voiceless and aren't seen around. They are kept at the [protective] workshops all day and are doing craft work that is suitable for children, not for skills that can help better their lives. We are given no information on how to protect ourselves or empower ourselves. I think they are abusing us by keeping us here with no information or options (Female, 32 years old, visual impairment).

Overall, GBV service providers claimed they do not come across many women with disabilities, so neither structural provisions nor disability-specific training or resources had been allocated: "We don't hear about it, so how can we be ready to deal with it?" (Service provider, domestic-abuse shelter counsellor). Service providers generally felt ill-equipped to deal with disability-related cases. When asking GBV-related services whether they had offered services to a woman with disabilities in recent years, most could only recall a few instances.

7.4.3 Lack of staff training, resources, and funding

Importantly, some disability service-provider participants reported having facilitated GBV-specific assistance to a range of disabled women. This included advocating for court access for a woman with a hearing impairment, counselling services for a rape victim with hearing and mental impairment, and referrals to social workers for ongoing case management. However, service providers admitted that there was negligible follow-up of such cases and referrals and that making provisions for women's disability-specific needs was a challenge:

> We have women from all the communities coming here, with their children. We had a woman here in a wheelchair. We made sure she could feel safe here, but the

> room and bathrooms were inadequate for her needs. And in any case, we do not have funding to upgrade the shelter to make it accessible to women who cannot walk or wash themselves… We need to make shelter services and other first points of care accessible to women with disabilities. Staff need education on disability and to learn sign language (Service provider, domestic abuse shelter social worker).

Seemingly, GBV service providers were also able to coordinate assistance with DPOs: "We organised an interpreter that would be available every time she needed to go to the doctor or to court" (Service provider, rape crisis social worker). However, other GBV providers admitted having to make alternative arrangements for survivors with disabilities due to lack of trained staff:

> We don't like to turn any survivor away, we do what we can for them, but with little capacity staff-wise and not knowing what their needs are, or how to help them feel safe again, its problematic (Service provider, domestic abuse shelter manager).

Disability service providers agreed that GBV services are not always inclusive or disability appropriate: "I am talking from experience that clients who use GBV services are not properly counselled. They are given advice on leaving but get no assistance to leave, or help arranging alternative safer living arrangements" (Service provider, DPO social worker).

Overall, both groups of service providers said lack of funding made it difficult to ensure adequate staffing, disability training or GBV training for staff, and difficult to make structural changes in shelters or other points of care:

> There is no budget provision towards prevention and services for GBV in our organisation, so we are at a loss on how to initiate proper training, responses and violence support programmes (Service provider, DPO manager).

7.4.4 Strengthening pathways to care

When asked to share what provisions were required to facilitate access to care after victimisation, participants' responses recognised that access to service provision was about more than functional accommodations. They recommended giving attention to challenging disability-stigma, decreasing dependency, and providing psychological assistance to women with disabilities. A further recommendation was to network with both sectors to increase inclusivity of services within the existing GBV provision context:

> Because violence against women is prolific in the country, violence responses from the highest level to grassroots should make space for disability. Disability increases risk and restricts support. It is in the interest of GBV services to include and accommodate all women (Service provider, DPO manager).

Service providers mentioned that screening women with disabilities and identifying GBV cases within mainstream health care services could promote help-seeking, and referrals to services that can accommodate women with disabilities' needs.

Other proposals included mobile outreach services to reach women with disabilities who are isolated at home or unable to travel to ensure early identification of neglect or violence. Participants with disabilities and service providers agreed that outreach can facilitate information dissemination and promote help-seeking.

Disability-sensitive training in GBV sectors may facilitate better access and appropriate assistance for women with disabilities. Several service providers commented on the importance of cross-referrals between different services and organisations, and the need for trained GBV advocates to serve on boards of DPOs. Resource and funding allocation and partnering with local GBV and DPO services could facilitate training in both sectors and complement coordinated and accessible service provision:

> What would help is to have a trained person who can understand disability issues and assist in communication and sensitivity relating to disability in police stations, shelters and Thuthuzelas (Service provider, DPO social worker)

Working with legal and justice services to remove perpetrators from disabled women's homes was proposed: "I think department of justice can play a part in that. Because if you look at us, we are removing these victims from places instead of removing perpetrators" (Service provider, DPO Social worker).

Survivors of IPV in South Africa are encouraged to leave abusive situations and relocate to a safe house or domestic violence shelter, or to take out a protection order against the perpetrator to prevent him from accessing the survivor. However, a cited response to prevent further victimisation of women with disabilities was their relocation to residential care facilities or day protective workshops. Domestic abuse shelters were often not considered appropriate for rehabilitative care of women with disabilities and the decisions to move them were most often made by family members and not the women themselves.

A participant with visual impairment who was assaulted by a stranger in her house recounted: "After the incident, the only option to protect me from the people in the community who may take advantage of my situation was to move me [to the residential care facility]" (Female, 32 years old, visual impairment). Another participant described her relocation into residential-care living after she was raped a year ago: "[The family] can't be there all day to help or keep me safe. They must work" (Female, 24 years old, physical impairment). Facilitating safer and independent living is an alternative to residential care to keep women with disabilities safe: "It means that we need to ensure accessible and secure housing that accommodate their needs without them having to rely on others" (Service provider, DPO manager).

While one participant was highly critical of the protective workshop as a place of abuse and disempowerment, another participant claimed that protective workshops provided protection from violence at home and in the community:

> I came [to the workshop] to get away from home...to spend time away from home, where I'm ignored and abused anyway. The thugs can always get to me. At least here I can be safe and do something that will help me earn my pride and my own money, to use as I feel fit [and not have to share it with family members] (Female, 43 years old, physical impairment).

To overcome barriers to inclusive GBV service provision, service providers wanted to be made aware of what safety options were available and accessible to women with a range of disabilities and how independent and safe living could be facilitated. They also asked for the coordination of information, resources and funding for prevention, response and care that specifically catered to disabled populations.

While women with disabilities may attempt to seek help and use GBV services, few participants reported positive or adequate experiences.

7.5 Discussion

This is the first known qualitative study to explore access to GBV services for women with physical and sensory disabilities in South Africa. Service provision for women with disabilities who are survivors of GBV is significant: it can either be a source of support – with information, empathy, support and redress – or where they may feel further victimised by blame, stigma or indifference. The findings show that women with disabilities have needs that may differ from their non-disabled counterparts; that there may be differences in the experiences of

women according to the range of impairments; and that women with disabilities are not a uniform and “vulnerable” group (Dean, Tolhurst, Khann & Jehan, 2017).

The biopsychosocial model of disability places emphasis on impairment, the personal experiences of impairments, as well as the economic, environmental, and social barriers persons with impairments encounter (WHO, 2001). It is not only society’s lack of awareness of people with disabilities or multiple environmental and attitudinal barriers that limit service provision and utilisation. An individual’s behaviours, attitudes, and personal experience of impairment, pain, depression, humiliation, fear, poverty, minimal support and isolation, and other barriers may further restrict their ability to leave violent situations and access GBV services. Thus, attention needs to be given to addressing the effects of disability-stigma and structural barriers for GBV survivors with disabilities. While women with disabilities expressed concerns about whether existing services could accommodate their physical and psychological needs, both disabled participants and service providers acknowledged that the pathways to care may be undermined by various physical barriers, communication difficulties, disability-related stigma, lack of awareness and information, staff attitudes, limited capacity and training, and limited funding that may affect provision of and use of services differently.

The psycho-emotional construction of disability relates to how persons react to their experiences of barriers and stigma (Reeve, 2002). Women’s personal internalisation of stigma and their perceptions of blame and being burdensome played a role in limiting their help-seeking behaviour. Self-blame, inferiority, and depression among women with disabilities can act as both a risk for and consequence of victimisation and can hamper safety and support (Dembo, Mitra & McKee, 2018; Astbury, 2012). Globally, women who endure physical IPV say that the psychological abuse and degradation are even more difficult to endure than the physical abuse (Heise et al., 2002). Knowing this, providers or organisations serving all

survivors should identify the psychological needs of women with disabilities and offer safe, accessible and relevant mental health and counselling that caters to differing experiences of disability and GBV. Responding appropriately to various acts of violence can facilitate pathways to care and well-being and prevent further abuse.

Furthermore, instead of the individual or impairment being perceived as problematic or unable to avoid or leave abusive relationships, a biopsychosocial approach would remove perpetrators, remove barriers within and outside the home, and ensure access to safety, care and psychological support for individuals with disabilities. A biopsychosocial approach and human rights lens would herald the embodied experiences of disability and victimisation, the social processes that increase the vulnerability of women with disabilities, and reinforce the rights of all women to live free of violence and have access to health care, regardless of their disability status.

Like research in South Africa, perceptions of non-sexuality barred participants with disabilities from receiving adequate post-violence care (Meer & Combrinck, 2015, 2017). Service provision can be improved by acknowledging the sexual experiences and sexual health needs of women with physical and sensory disabilities – related to both consensual and non-consensual sex. Guidelines and training for service providers and police on the sexual and reproductive health rights of women with disabilities, and how to communicate and approach survivors with different impairments, may help to alleviate mistreatment and disbelief of women with disabilities and ensure pathways to care and justice.

It is well known that South African women stay in abusive relationships because of the normalisation of IPV. Belief that the abuse will stop; being pregnant or having children by a partner; having an emotional or economic attachment to a partner; or fear of retribution for leaving are often reasons why women remain with abusive partners (Hatcher et al., 2016;

Shamu et al., 2011). While participants with disabilities reported similar reasons for staying in abusive relationships as non-disabled women, disability-related dependency on partners and lack of independence or mobility restricted help and safety-seeking.

Disability-related services like protective workshops should integrate GBV awareness and safety information into their day programmes and facilitate accessible GBV service provision. There is also a need for mainstream health-care providers that serve women with disabilities to include items about victimisation and mental health during screenings and assessments, and to refer them to appropriate and accessible services.

In lieu of these findings, women with physical and sensory disabilities are not receiving the benefits of GBV services in South Africa. Awareness of disability-specific needs and barriers can help tailor inclusive violence response and prevention strategies. Increased disability awareness and training can facilitate disability-relevant accommodations and referrals, help to inform appropriate mental health interventions, and increase access to justice, support services and GBV prevention strategies. Adapting existing GBV services should not only address accessibility barriers but include stigma-alleviation and changes in social norms. That said, integrating services to include disability-friendly strategies may be an extremely complex task given the already over-burdened and under-funded GBV services in the country, and the spectrum and types of impairments that exist. Targeted GBV services may be required to serve women with disabilities and address their disability-specific risks and experiences of violence. Existing or proposed prevention programmes should consult disability experts and women living with disabilities in conceptualising and designing inclusive services. Moreover, further research is required to establish the extent of GBV against women with disabilities, and there are important studies which need to be done on hospital and police data, which may provide further data. Further research to assess whether there is

benefit in mainstreaming GBV services or developing targeted interventions – particularly in LMICs like South Africa where GBV levels may be high, where women with disabilities experience increased isolation, and where resources and services are extremely limited, is also necessary. Robust evidence on what works in service delivery and prevention programmes to alleviate the exclusion of women with disabilities from GBV services is urgently required in order to attract funding for inclusive violence prevention programming and intervention.

7.6 Conclusion

The study contributes to the dearth of literature on the inclusivity and accessibility of GBV services for women with a range of disabilities. Rather: In a country with one of the highest levels of GBV in the world, the lack of accessible and inclusive service-provision for GBV and its after-effects in South Africa presents an ongoing concern. Women with disabilities have rights to equal and quality service provision and rights to freedom from all forms of violence. Understanding the nature of the violence to which women with disabilities are exposed is an essential first step in developing effective and inclusive GBV prevention and support services. Addressing their additional and unique barriers to services requires a collaborative effort by both GBV and disability sectors. Inclusive GBV services that address both the social and psych-emotional dimensions of women with disabilities' vulnerability to violence will ensure better services for all women.

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CHAPTER 8. DISCUSSION, RECOMMENDATIONS, LIMITATIONS AND FUTURE RESEARCH

8.1 Introduction

Knowledge about disabled women's lives and their experiences of gender-based violence (GBV) is largely based on research from the global North. This thesis aimed to describe the GBV experiences of women living with disabilities in South Africa, and to contribute to the evidence base in low-middle income countries (LMICs).

This chapter addresses the fifth objective of the thesis: to link the findings of the study to existing evidence, while suggesting future research questions to help build a better understanding of GBV against women with disabilities, and how to prevent and respond to it.

The thesis may broaden understanding of the intersections between disability and GBV in South Africa by revealing the nature of GBV and additional forms of violence experienced by women with disabilities living in South Africa (Chapter 5). The thesis gives insight into participants' experiences of sexuality and intimate partnerships (Chapter 6) and explores the barriers and enablers to GBV services and care for women with disabilities (Chapter 7). The thesis also highlights the ethical challenges in GBV studies with women with disabilities, and advocates for ethical and inclusive GBV research in LMICs (Chapter 4).

The present chapter sets out how the findings described and discussed in detail in Chapters 4 through 7 contribute to building a composite body of knowledge on violence against women with disabilities in South Africa and other LMICs. The intersectional lens of the study opened an analytic perspective that could expose predetermined assumptions about women with disabilities. Intersectionality also provided an analytical tool for understanding the ways in which types of disabilities and personal factors interact with societal categories

and stigma, thus developing a nuanced understanding of participants' GBV experiences. This chapter also provides recommendations for policy uptake, service provision and intervention development that may help to better prevent and respond to violence against women with disabilities. The chapter also includes the limitations of the project and ends with questions for future research.

Qualitative methodologies were used to meet the study's objectives as they have been shown to be suitable for disability research and for exploring disability-related phenomena or experiences about which little is known (O'Day & Killeen, 2002). The value of the qualitative approach in this study was its flexibility, its ability to address participants' disability-related needs, and to represent women with disabilities as expert knowers of their own experiences (Chappell, Rule, Dlamini, & Nkala, 2014). Qualitative methodological strategies helped to capture narratives and dual perspectives on violence against women with disabilities both from women themselves and from disability and GBV service providers.

8.2 Contributions of the thesis

The methods and analysis used in this thesis helped to reveal the intersections between social and personal factors that shape experiences of disability and GBV (Stone & Priestley, 1996). As discussed in Chapter 2, some disability models may fail to account for participants' own meaning-making around societal marginalisation, as well as their personal risk factors. In the thesis, the premise is that an intersectional lens can incorporate personal experiences of impairments and associated mental-health and physical pain; explore the participants' contexts and social positionings that make them vulnerable to GBV, and elicit their accounts of the barriers to support and GBV prevention. By alternating between social and biopsychosocial models and critical disability theories, the thesis provided an opportunity to

make sense of what is happening to women with sensory and physical disabilities living in Cape Town, South Africa. While it is acknowledged that women with disabilities are diverse in their experiences of exclusion, impairment severity and type of disability, the findings revealed a common social experience of disability entailed by the participants' exclusion from education and employment, and their backgrounds of racial exclusion and poverty, as well as the stigma inherent in their social interactions - all of which may set up barriers, whether to accessing and using GBV services or when fostering intimate partnerships with men.

South Africa has its own unique interfaces of gender inequality, entrenched historical divisions of race and socio-economic status, and culturally embedded disability-stigma that segregate women with disabilities from mainstream GBV research – accounting for their invisibility in existing GBV literature in South Africa. These intersectional forces also impact upon participants' common experiences of GBV. The thesis reveals three interactions of vulnerability for women with disabilities. Women with disabilities are at higher risk of GBV, may experience more adverse consequences due to GBV, and experience additional difficulties accessing GBV services.

More specifically, South Africa's patriarchal norms may reduce women with disabilities' capacity to circumvent GBV, and disability myths and stigma may reinforce participants' marginalisation and risk of GBV. In Chapters 5, 6 and 7, poverty, unemployment, inaccessible environments, limited mobility, limited access to resources, and inaccessible health and violence services are seen to exacerbate women's vulnerability and bar them from seeking help. Such social forces impact on participants, and may facilitate their internalisation of stigma, exacerbate barriers, and introduce additional disability-related acts of violence. Thus, the findings reveal the benefit of applying the social model to understanding the environmental barriers that participants encounter. The findings further highlight how the

biopsychosocial model of disability is warranted for understanding self-stigma and personal experiences of disability, interacting vulnerabilities, and GBV. Applying a critical resistance framework also served to reveal how participants may assert a positive gender or disability identity, thereby resisting stigma.

The study reflects on similarities of violence against women living with disabilities to other evidence in LMICs, which adds to the literature and knowledge that is emerging from settings outside of the global North.

8.2.1 Nature and forms of violence against women with disabilities

The first step to successfully prevent violence against women with disabilities is to understand the nature and forms of violence they may experience. This was the founding objective of the thesis.

Chapter 1 indicated the high levels of violence against women living in South Africa. In the absence of South African evidence on the nature and forms of violence that women with disabilities face in their daily lives, the thesis described different types of violence experienced by participants. All participants with disabilities reported experiencing some form of violence during their lifetime. The most common forms were psychological violence, financial abuse, neglect and deprivation, as well as physical and sexual abuse. Forced sexual initiation was reported by some participants, an experience that is widely experienced by females in Africa (Krug et al., 2002). Psychological violence preceded or accompanied other forms of violence, and was reported by the majority of participants with disabilities, supporting global evidence of psychological violence and degradation as being the most pervasive form of IPV (Heise, Ellsberg, & Gottmoeller, 2002).

Neglect featured predominantly too, whereby participants reported feeling unprotected from likely perpetrators, and receiving little support for their disability care needs. From their youth, they reported being ridiculed and verbally abused, physically and sexually assaulted by teachers, peers, male family members and partners, and community members. Later in life, partners and families may exploit them financially, or deem them unworthy of romantic relationships, marriage or motherhood – findings which align with literature from other LMICs and high-medium income countries (HMICs). Reports of partners' control over welfare grants reveal how male partners can exert power over women with disabilities and may take advantage of their perceived powerlessness. To date, there is no evidence supporting that women without disabilities receiving welfare grants in South Africa experience similar financial extortion by male partners. Moreover, if a woman with a disability enters into a partnership with a non-disabled man, her dependency may increase the power hierarchy of the relationship, which, the participants judge, puts them at higher risk of GBV (Chapter 5). This anecdote requires further population-based data on partners' disability status and GBV-risk in other LMICs. Partner control is not unusual in South Africa and is indicative of the reigning gender norms in the country and women's disempowerment and dependency on male partners. However, the stigma related to women's disability may exacerbate women's powerlessness, increase her dependency on aa likely perpetrator, or expose them to different and additional forms of violence on top of GBV. These additional forms of violence need to be identified, understood and prevented.

Some participants felt they were viewed as "meal tickets" by men who would pursue them for their disability grants, a similar anecdote to Shah and colleagues' findings in the United Kingdom (Shah, Titsou, & Woodin, 2016). The thesis argues that, while the autonomy of women to manage and control the use of their disability grants is often restrained, further

research is needed to understand whether and how women with physical and sensory disabilities negotiate the value of their social assistance grants or encourage others' use of their welfare grants to benefit themselves (Chapter 5).

8.2.2 Disability-stigma and dependency in participants' intimate partnerships and GBV experiences

The thesis revealed various ways in which disability-stigma – including the power imbalances between persons with and without disabilities – is constructed, internalised or resisted, and explored its role in participants' experiences of GBV. The findings confirm the global literature that societal perceptions of women with disabilities as helpless, mentally or intellectually challenged, or non-sexual may impact on women's intimate partnerships and experiences of GBV (Dean, Tolhurst, Khann & Jehan, 2017; Crawford & Ostrove, 2003). Most of these stereotypes were encountered by participants with differing severity and types of physical and sensory disabilities, suggesting that the experience of disability-stigma is fairly common in South African communities.

Social myths, attitudes, and perceptions of disability are played out in everyday life, in interactions with family, community members, government housing officials and health care workers (Chapter 5), within intimate partnerships (Chapter 6), and in accessing GBV services (Chapter 7). Impairments acquired later in life were seen to have different implications for self-identity and sexuality than congenital impairments (Chapter 6). In Chapter 6, as in other literature, the visibility or disclosure of impairments may render participants with disabilities undesirable (Bremer, Cockburn & Ruth, 2010; Hunt et al., 2018, 2017; Nguyen, Liamputtong, & Monfries, 2015; Wazakili, Mpofu & Devlieger, 2009). Moreover, the stigma around physical appearance and sexuality was a central process underlying their experiences of IPV, and made

women with disabilities feel unworthy of pursuing intimate relationships, raising a family, or seeking help to prevent further violence (Retznik et al., 2017; Hassouneh-Phillips et al. 2005).

Another objective of the thesis was to interpret how stigmatised constructions of sexuality for women with physical disabilities shape their intimate partnerships or experiences of IPV. Chapter 5 described how unattainable gendered expectations precipitated emotional violence by partners and partners' parents. Chapter 6 described how hegemonic conceptualisations of intimate relationships and cultural expectations of women's roles within relationships facilitated participants' experiences of rejection and abuse. The metaphor of "sin" surrounding intimate relationships with women with disabilities deterred many of the participants' pursuits of intimacy and may have deepened their experiences of rejection. Disabled participants reported that they were largely discouraged from exploring their sexuality, and complained that their isolation from sexual education and reproductive health care impeded their attainment of healthy and safe intimate partnerships (Chapter 7).

Set within the patriarchal context of southern Africa, this thesis adds to existing evidence of the ways that the intersections of disability stigma with ableist and hegemonic gender norms characterise women with disabilities' experiences of sexuality, intimate partnerships and GBV in South Africa (Chappell, 2017; Peta, McKenzie, Kathard, & Africa, 2017, Peta, McKenzie & Kathard, 2015). In accordance with other literature from South Africa, the thesis findings show that women were expected to be grateful for sexual contact since few men will have sex with disabled women (McKenzie, 2012). It was assumed that participants were "lucky" and should show gratitude for whatever romantic sexual interactions they could get, and thus should not make further demands or complain if they were mistreated. Like Hunt et al.'s (2018) findings, anxieties over the burden of care in South

Africa may further limit romantic prospects for participants; contribute to their low self-esteem; and hinder their attempts to prevent IPV or cope with rejection.

Consistent with others' findings, intimate partners comprised the majority of perpetrators of violence against participants. However, as has been shown by some disability scholars, IPV alone does not capture and represent the complexity of disabled women's experiences of violence (Platt et al., 2017; Astbury & Walji, 2014; Thiara, Hague & Mullender, 2011; Radford, Harne, & Trotter, 2006). Participants who were interviewed for the thesis perceived their experiences of IPV as different to women without disabilities in that they face greater obstacles to achieving the ableist gender norms that are implicit within constructions of intimate relationships in South Africa.

The thesis suggests that many women in South Africa face challenges in their intimate partner relationships; however, women with disabilities may face additional challenges. Acknowledging these differential experiences means acknowledging that existing theoretical models of IPV may not consider how disability status – and the spectrum of disability, and how various forms of stigma and physical barriers, may influence participants' attainment of gendered expectations and may put them risk of IPV.

If we are to gain a holistic and inclusive understanding of GBV and IPV among all women in South Africa, both social perceptions and barriers and the psychological and personal processes of women with disabilities should be incorporated. Overall, psychological violence was widespread among participants, fuelled by disability-related stigma. The psychologically disempowering effects of rejection and deprivation meant that participants may have been far less able to withstand or resist violence than their non-disabled counterparts. Women's individual resistance to stigma and how they embody relationships should also be incorporated into an understanding of experiences of IPV for women with

disabilities in South Africa. That is to say, a newer model is needed that will account for the reality that women with disabilities may simultaneously be structurally disadvantaged or vulnerable *and* have agency. It is also important to acknowledge that some participants reported positive and loving relationships. Some women expressed that a partner's disability status could facilitate empathy, and decrease the risk of physical IPV. The finding that a common disability experience was seen to have a positive influence in maintaining a close and healthy intimate relationship needs to be evaluated more robustly.

The findings hold that, despite his renowned contribution to our understanding of stigma in disability, Goffman (1963) does not explore the differential experiences of disabled stigma based on intersecting forces and identities, nor does he investigate how individuals with disability differently internalise or resist stigma – which is a tenet of critical and resistance theories. The thesis found that participants may have agency in the face of GBV-risk and added layers of disability-specific violence. In Chapter 6, we see how participants' agency can be embedded in certain stigma-avoidance strategies and avoidance of intimate relationships, wherein in a bid to protect themselves from IPV and rejection, participants rejected searching for partners or initiating romantic relationships. This may be similar to women without disabilities who reason that a healthy intimate relationship that is free from violence is largely unattainable in South Africa, given the rampant levels of GBV (Jewkes, 2002). Also, during sexual encounters, some participants openly revealed or concealed their impairments in strategies to avoid or resist disability-stigma (Chapter 6). Evidence that illustrates women with disabilities negotiating their desire for intimate relationships and their avoidance of stigma and rejection is largely absent from the GBV and disability literature. Thus, while the findings reflect participants' vulnerability to GBV, they also show how some

women with disabilities can endure, adapt, and generate new ways of functioning in relation to GBV and disability stigma in order to protect themselves from violence.

8.2.3 GBV service-provision barriers

Several South African researchers argue that violence against women with disabilities in South Africa may be amplified due to the stigma associated with disability, fewer resources, and restricted access to infrastructure and services (Mavuso & Maharaj, 2015; Kritzinger et al., 2014; Mall & Swartz, 2012; Hanass-Hancock, 2009). Yet, little is known about the availability and accessibility of GBV services for women with disabilities in South Africa. The third objective of the thesis was to explore the accessibility and inclusivity of GBV services and consider what responses may be appropriate to help women with disabilities receive appropriate GBV information, support and care. The thesis revealed some of the ways that GBV service providers and disabled people's organisations (DPOs) often fail to include women with disabilities' specific GBV issues (Chapter 7).

The perceptions and experiences of both the service providers and women with disabilities of the barriers and enablers to GBV services revealed a range of barriers that undermine the provision of inclusive GBV care and support, including structural, personal, socio-economic, and stigma-related barriers. These findings support existing literature on the common obstacles encountered by women with disabilities when seeking health and reproductive health care in other LMICs (Baart & Taaka, 2018; Rugoho & Maphosa, 2017; Mavuso & Maharaj, 2015; Lee et al., 2015; Hasan, Muhaddes, Camellia, Selim, & Rashid, 2014; Kritzinger et al., 2014; Mall & Swartz, 2012; Mgwili & Watermeyer, 2006; Anderson & Kitchin, 2000).

Specifically in terms of GBV service provision, Chapter 7 describes similar barriers, echoing previous South African findings on GBV help-seeking and service provision for women with intellectual disabilities (Meer & Combrinck, 2017, 2015). Women with disabilities recounted instances of service-provider apathy and ignorance – pointing to a deeper need to combat stigmatised attitudes within the GBV response sectors in the country. Participants with disabilities also reported that they received little support for the psychological consequences of violence, which may contribute to on-going experiences of GBV (Astbury & Walji, 2014). GBV service providers reportedly lacked disability awareness and training to appropriately support women with a range of disabilities, and services were deemed frequently unable to physically accommodate clients with disabilities, which the service providers attributed to a lack of resources and funding. These findings have similarities to evidence from other LMICs, where barriers to access are compounded by stigmatised attitudes, lack of human and economic resources, and environmental or structural obstacles (Dembo, Mitra, & McKee, 2018).

GBV service providers reported that women with disabilities, like women without disabilities, may be reluctant to report GBV because of a lack of confidence in justice outcomes, service provider apathy, stigma and shame, as well as the fear of retributive violence from perpetrators (Mazars et al., 2013). However, the thesis reveals that, for women with disabilities, these barriers to reporting may be heightened. This may be linked to a general inattention in South African society to the role of disability-related stigma and disability-related abuse that can compound everyday experiences of GBV, and the lack of coordination between the disability and GBV sectors. Disclosing abuse, seeking help in response to their experiences of violence, and revealing the barriers to services may foster women's agency.

8.2.4 Ethical and inclusive GBV research

Acknowledging the lack of literature that specifically addresses the challenges of conducting GBV research with a diverse range of disabled participants, the fourth objective of the thesis was to consider how to promote ethically safe and quality GBV research with women with physical and sensory disabilities. Chapter 4 set up the premises that disability is not a homogenous concept, that methodologies and research processes should be flexible and responsive to a broad spectrum of impairments, and that social factors and environmental barriers shape participant's GBV experiences and may hinder their inclusion in GBV research. The research process revealed several additional ethical considerations that may be required to foster inclusivity when including women participants with physical and sensory disabilities in future GBV projects.

Chapter 4 suggests that the spectrum of disability will shape consent management in GBV research. The accessibility of the consent procedures to the study participants required additional ethical attention, revealing the challenges and benefits of collaborating with disability gatekeepers (such as DPOs) in recruitment, and the potential dilemmas in ensuring confidentiality when using disability-sector intermediaries in research on GBV. Furthermore, while Chapter 3 recognised the potentially positive aspects of the researcher's and assistant's positions as disabled researchers in a GBV research project, Chapter 4 found that, regardless of disability status, researchers may need additional training, skills and resources to reasonably accommodate disabled participants and safely conduct disability-inclusive GBV research. By acknowledging the power hierarchies that are endemic to the research process, and by reflecting on the vulnerability and agency of women with disabilities, Chapter 4 argues that equal participation in GBV research may be achievable.

Overall, the project aimed to be inclusive, to consider barriers and accommodations, and, in doing so, enabled women with disabilities to take part in research about their experiences of violence. Evidence from the study reveals that women with disabilities can be part of GBV research, be active knowers of their unique and common experiences of GBV, and expect benefit and change from participating in the research. These emancipatory factors are significant, especially in a country where GBV is an everyday occurrence - regardless of disability status. Thus, the thesis highlights the need for ethical guidelines to be further debated, implemented, and tested in the field in order to establish best practices for GBV research, and for the inclusion of women with disabilities in such research.

8.3 Recommendations

This study endeavours to contribute to the literature on GBV by highlighting the intersections between disability and vulnerability to violence, while also considering how gender norms in South Africa put women with disabilities at risk of GBV. In addition, the study investigates assumptions about disabled sexuality that may inhibit women's quests for healthy intimate partnerships, and, most importantly, it describes a lack of appropriate and accessible support and care for disabled women who are at risk for GBV. These findings could give rise to further research questions, inform future qualitative and epidemiological research, and may hold implications for policy, service provision and GBV prevention interventions in similar LMICs.

8.3.1 Policy level

The South African government has ratified the Convention on the Rights of Persons with Disabilities (United Nations, 2006) and has the responsibility to ensure that all people with disabilities are protected from all forms of violence. However, limited empirical evidence is

available to inform policymakers' efforts to respond to violence against women with disabilities.

It is possible to say that disabled women are exposed to at least the same, and probably more, GBV than women without disabilities, and require at least the same level of protection and access to redress in the country as all women do. A first step is for government to fund and collaborate in the generation of comparable and inclusive GBV data. Disabled children and adults with a range of impairments should be routinely identified within national crime statistics. A systematic review of GBV policy documents could identify gaps that undermine the inclusion of *all* women in South Africa in GBV prevention efforts and responses.

GBV incidents that are reported are rarely followed up and brought to court. State-sponsored evaluation of the country's legal system should be conducted to ensure that women with disabilities' disclosures of victimisation are taken seriously, and that cases where women survivors report having a disability are actively pursued. Intimate partner and family abuse protection orders should be made more accessible to women with disabilities, and DPOs and GBV organisations should collaborate to empower women with disabilities to report incidents and seek justice. Focus should be given to providing women with disabilities with individual and family assistance to enable them to engage effectively with the police and the judicial process, while simultaneously empowering women with disabilities through economic opportunities that will foster their independence.

Considering that GBV programmes and services are under-resourced, under-utilised and lack robust evidence-based interventions (Centre for the Study of Violence and Reconciliation, 2016), government support is needed to allocate funding for disability-related

research, and to ensure that appropriate resources and training to facilitate inclusivity are integrated into existing programmes and services.

8.3.2 Service provision level

Violence and abuse affect the health of women with disabilities. In South Africa, the lack of accessible health services and support for women with disabilities is likely to compound GBV *and* disability. Thus, higher priority should be given to the development of services that support women with disabilities. Relationships should be strengthened between disability services and women's services that have expertise in responding to GBV. The work of DPOs should strongly align with GBV advocates, GBV programming that works (i.e., has a positive evidence-supported impact), violence screening and research, and GBV assistance and protection services.

Considering the stigma around disabled sexuality, inclusive sexual and reproductive health education is needed, especially for adolescents with disabilities. Accessible and relevant sexuality education and information on relationships, IPV, and maternal, sexual and reproductive health care can be integrated into nationwide sexual and reproductive health education and services, to ensure healthy and safe intimate partnerships. Early detection and screening for risks and experiences of GBV at protective workshops, residential care facilities, and general sexual and reproductive health care centres in the country should be prioritised.

Training modules for GBV service providers should include ways to appropriately support women with disabilities and accommodate their needs. Disability awareness and training on the risk factors for violence among women with disabilities, accessible information, and appropriate accommodation requirements, should be integrated into existing generic GBV services to ensure sustainable and accessible pathways to inclusive GBV

prevention and support. Importantly, both GBV services and DPOs should have knowledge and access to information about accessible and safe places for women with disabilities and disseminate such information in accessible formats.

The findings in the thesis suggest that women with disabilities, especially those living in informal settlements, may access little to no mental health services. Considering that mental health and GBV are interrelated (Mngoma, Fergus & Jolly, 2016), it is crucial that appropriate and accessible mental health provision is integrated into violence prevention and response in the country. A more disability-integrative approach to mental health services would assess impairment-related psychological issues, personal and psychosocial factors, and environmental barriers that may interact to make women with disabilities more likely to experience GBV than women without disabilities.

A programme of community-based mobilisers who identify and reach out to women with disabilities should be implemented and evaluated in terms of its an impact on GBV prevention and mental health in both urban and rural informal communities.

8.3.3 Intervention level

Few interventions exist for inclusive GBV prevention, and many have not been validated (Van der Heijden, 2014). This is an important gap that should be addressed, especially in LMICs. This thesis on GBV against South African women with disabilities could help shape future interventions for GBV prevention in the country and other LMICs. Intervention is needed at different stages: at a primary stage, to prevent violence from happening; at a secondary stage, to ensure that violence is promptly identified, and individuals are referred to appropriate agencies who will intervene to stop it recurring; and at a tertiary stage, to treat individuals who have experienced violence and prevent long-term problems related to physical injury or

mental health. Intervention development in South Africa and other LMICs needs to be informed by integrated, inclusive, innovative, and adaptive approaches to violence prevention and intervention at all three stages.

Primary prevention can be supported through appropriate and inclusive sex education. Participants with disabilities in the study reported experiencing violence from a young age, from multiple perpetrators. GBV research and interventions that include children with disabilities will facilitate early prevention and the safety of young girls with disabilities. Addressing neglect and the burden of care at the household level may further prevent violence against children with disabilities. Livelihood strengthening, economic empowerment, and opportunities for independent living should be facilitated via family-based interventions, parental-support interventions and individual empowerment. Later in life, women with disabilities should receive relationship counselling, violence screening and detection, and be offered opportunities to leave violent relationships.

At every stage of intervention, the ableist gender norms embedded in current GBV prevention programming and materials should be challenged and set against the risks they may impose on women with disabilities within and outside of intimate partnerships. IPV interventions should also consider negative constructions of sexuality as well as the influence of positive disability identity and resistance to hegemonic social norms, both within and outside of intimate partnerships.

The prevention of violence against women with physical and sensory disabilities should not focus on functional difficulties, but rather address the role of disability stigma and environmental barriers that shapes the risk and the types of violence they experience. Future epidemiological research should include disability measures like the WHODASII (Madans, Loeb, & Altman, 2011), measure a wider set of perpetrators and measures of the disability-

specific acts of violence (McFarlane et al, 2001) that may compound GBV experiences. Intervention strategies should focus on training GBV service providers in disability awareness, help them to screen for disability-specific violence, and help them to challenge disability stigma and create accessible and safe environments for survivors of GBV.

Strategies to reduce stigma come in many forms but are not always effective. Campbell and Deacon (2006) consider the types of interventions most likely to facilitate resistance to stigma in Ghana, Africa. They argue that the most beneficial are multi-faceted to address the interplay of factors (biophysical, economic, symbolic, social, psychological and structural) that drive stigma. In LMICs, as the authors acknowledge, the most fundamental driver of stigma is poverty and under-resourced health services and, thus, "community psychology has a key role to play in advancing our understandings of the possibilities for collective resistance and for stigma-reducing psychosocial change" (Campbell and Deacon, 2006, p. 415).

Cramer, Brady and McLeod (2013) advocate an empowerment approach to building the capacity needed to address violence against women with disabilities, whereby programmes should increase the agency of women with disabilities by fostering self-efficacy, self-esteem, competence, and perceived control over one's life. The authors argue that programmes need to empower women with disabilities to initiate their own risk avoidance, safeguarding and self-defence strategies by taking into consideration their functional restrictions and building on their abilities (Ibid.). Similarly, Hollomotz (2012) shows that women with learning disabilities are resilient and demonstrate resistance by initiating their own safeguarding techniques. However, further evidence of women with disabilities' stigma-avoidance and safety strategies is required to establish if these will facilitate better relationship outcomes and help to prevent violence.

Programmes should allow women with disabilities to critically engage with their knowledge about relevant relationship issues and practice relationship-building and negotiation skills that are relevant and practical within their relationship contexts and disability-specific challenges. It may be useful to consider multiple models of intimate relationships and a broader focus on carer-dependent relationships, instead of only heterosexual dating relationships.

Effective programmes to address violence against women with disabilities must be multi-faceted and consider IPV and other forms of GBV in the home, but should also include multiple settings, perpetrators, and disability-specific forms of violence. The provision of appropriate communication methods for the dissemination of information and support, as well as programme outcomes, should be done in consultation with disability experts.

Finally, there is some evidence that women with disabilities can play an active role as peer educators in programmes that aim to counter violence and abuse (Frawley & Bigby, 2012). Programmes to prevent IPV and non-partner violence in South Africa should be designed, developed and delivered by women with disabilities. Including women with disabilities as partners in the planning and implementation processes of such programmes may be key to ensure programming that is adaptable to the needs and requirements of the diversity of impairments and disabilities in South Africa. To ensure the inclusivity of GBV prevention in South Africa and other LMICs, research needs to determine the potential utility of existing interventions with women with disabilities, or whether targeted interventions would better suit their needs.

8.4 Study limitations

While evidence on violence against women with disabilities is emerging, study methodologies and definitions of disability vary, and evidence is still lacking in LMICs like South Africa.

While population studies are currently negligent of violence amongst South Africa's most vulnerable and marginalised communities, especially women with disabilities, the content presented in this thesis does not provide representative data in any manner, but rather aims to shed light on certain narratives and to juxtapose them with the existent discourses, or lack thereof, about the lived realities of disabled women. The thesis does not estimate the prevalence of violence against women with disabilities, but rather attempts to make visible the forms and nature of the violence they experience, and the strategies they employ to cope with violence, and how they manage stigma and intimate partnerships.

A limitation is that women included in the thesis sample reported being in heterosexual relationships: thus, the experiences of IPV perpetrated by non-heterosexual intimate partners is missing. Moreover, interviews with the participants' intimate partners may have added additional perspectives and supplementary evidence to GBV perpetration against women with disabilities. Also, online discussions, as opposed to face-to-face qualitative interviews, with women with disabilities may have facilitated better anonymity and disclosure of violence.

By recruiting only women with physical and sensory disabilities, including mobility, visual or hearing disabilities, the most vulnerable women with cognitive or psychosocial impairment were excluded from the study. Thus, the study was not fully inclusive. It was initially felt that while it remains important to include all types of disabilities in a holistic picture of the extent and nature of violence against disabled women in South Africa, the participants in the study needed to have little or no communication or cognitive impairments

in order to convey their stories. Including them would have introduced training, capacity, and resource requirements that were not readily available to the researcher at the initiation of the project. However, it is acknowledged that there are methodologies that are sensitive to research with persons with cognitive or communication impairments, and their exclusion remains a gap in the research project. Future population-based and qualitative studies on GBV and disability require sensitivity to the exclusion of women with cognitive and psychosocial disabilities, and broader sample ranges from other LMIC contexts. It is further acknowledged that the racial make-up of participants means the data may not be reflective of the GBV experiences of white, upper class women with disabilities in South Africa or in other countries.

Current evidence shows that women with disabilities are more vulnerable to violence than their male counterparts, and, for this reason, this study focuses on women. Disabled children and men, however, are not exempt from experiencing stigma and violence, and there is a need for further research on their violence experiences. Disabled children are a group particularly at risk for violence (Jones et al., 2012), but they were not included in the thesis. Research with disabled children and young people should be meaningful and sensitive, and requires significant time and resources, as well as additional ethical and legal requirements. Men with disabilities may also experience violence because of their impairments and inabilities to achieve hegemonic masculine roles (Mitra, Mouradian, Fox, & Pratt, 2016; Shuttleworth, Wedgwood & Wilson, 2012). GBV prevention interventions which focus on hegemonic masculinities may not be suited to their needs and vulnerabilities to violence, and should be informed by GBV research with men with disabilities, and developed in consultation with them.

By using DPOS, social workers, a research assistant, and snowballing via participants for recruitment, the most vulnerable women with disabilities – those who were not accessing services or may be particularly isolated and vulnerable – were not included in the study. Furthermore, the sample size of women from majority informal settlements in Cape Town is a constraint and limits the generalisation of the findings to women living with disabilities in other South African communities.

Replication of exploratory research such as this thesis should consider these limitations and strive to avoid them. Doing so can help to deepen understandings of the nature and forms of GBV against all persons with disabilities in the country; facilitate further reflections on the various enablers and barriers to GBV service provision; and provide useful information for extrapolation to other LMICs.

8.5 Future research questions

Additional research questions arose from reflection on the findings and the limitations of the study.

The thesis acknowledges that women with disabilities have been largely left out of GBV research globally, and that including women with disabilities in GBV research requires additional ethical considerations. Future research endeavours may encounter ethical dilemmas that need to be further problematised in terms of a broader range of disabilities, ages, and living conditions, in order to better inform ethical guidelines and appropriate and inclusive GBV-prevention programming.

Further studies in diverse communities are needed to create a comprehensive picture of how women with a range of disabilities experience violence in their everyday lives. To understand the nature of violence against women with disabilities, it may be helpful to

include disability-specific violence measurements within existing GBV tools. Further exploration of the risks for IPV, of stigma-avoidance strategies and negotiations within intimate partnerships, and of the interaction between women's preconceived gendered ideas about relationships and their ensuing internalisation of disability stigma, may provide important insight for social-norms interventions and for building healthy intimate relationships. Moreover, research and violence interventions with boys and men, including the partners of women with disabilities, may contribute to a better understanding of whether challenging ableist gender norms and addressing disability-related stigma in relationships can help prevent IPV.

Evaluating the impact of environmental barriers to participation and inclusive programming will assist the development and adaptation of existing GBV interventions. Evaluating the accessibility of GBV and health care services and documenting the challenges of their provision, for both users and providers, will hopefully contribute to violence prevention and care for women with disabilities. Further research is needed to highlight women with disabilities' personal experiences of help-seeking and the quality of GBV support and care, as well as their protective strategies they use to avoid or escape violence. Research that focuses on the coping strategies and help-seeking behaviours of women with disabilities may facilitate reporting and help-seeking and the prevention of further violence.

Future research can identify the impact and consequences of violence, focusing on mental health and how GBV can compound existing disability. The bidirectional or causal relationship between violence and disability needs to be further explored if we are to prevent violence against women with disabilities and to prevent disability as a result of GBV.

It is recommended that longitudinal research on women with disabilities be conducted in order to assess the impact of interventions and identify optimal intervention strategies to reduce GBV against women with disabilities.

Most notably, there is a need to translate the recommendations in this thesis into practice and to evaluate their effectiveness. This requires ongoing consultation with the disability sector, policy makers, researchers, and women living with disabilities to ensure the accessibility of findings and inclusive knowledge-sharing of evidence. Consultations will also give insight into other questions about the nature of the violence against women with disabilities that occur in various types of settings, relationships and institutions, which remain largely unanswered.

8.6 Conclusion

Significantly, women with disabilities remain neglected in GBV research in LMICs, and we do not know enough about how similar or different their experiences may be to their non-disabled counterparts.

Gender-based violence against all women in South Africa is a public health crisis. While prior research has explored and described the nature, forms and extent of violence against women in South Africa, this qualitative study is formative to understanding the context and realities faced by a particularly vulnerable sub-group of the country's population – women with disabilities. It addresses the nature of their experiences of violence and abuse, economic vulnerability, gender inequality, neglect and deprivation, and social exclusion. These contexts severely constrain the opportunities and choices available to women with disabilities in terms of preventing and coping with GBV.

This study is not representative of all South African women with disabilities, but it provides an insight into GBV experiences, sexuality, intimate partnerships, and GBV service provision from the participants' own perspectives. The findings should not indicate a commonality of experience, nor common understanding of GBV against women with disabilities in South Africa. Rather, due to intersectional forces, the study reveals that women with physical and sensory disabilities in South Africa may encounter variations of physical, sexual, psychological, and economic violence based on their gendered and racialised positions, *and* additional layers of violence pertaining to their disability.

The empirical findings and opinions set out in this thesis call for extensive and multi-level engagement with policymakers in the disability and GBV sectors if effective violence prevention and appropriate service provision is to be taken forward. The evidence presented here, substantiated by findings from other LMICs, could contribute to the inclusivity of disability in GBV research and GBV prevention strategies in South Africa.

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Appendix 1: Ethics approvals

SOUTH AFRICAN MEDICAL RESEARCH COUNCIL

ETHICS COMMITTEE

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13 December 2012

Ms I van der Heijden
Gender & Health Research Unit
MRC Cape Town

Dear Ms Van der Heijden

Protocol ID: EC034-11/2012
Protocol title: The gendered experiences of interpersonal violence against disabled people in South Africa
Meeting date: 26 November 2012

Thank you for your response to the Committee, dated 10 December 2012. The response was found to be acceptable. I am pleased to inform you that ethics approval is now granted for the study.

Please note that the approval is valid for 1 year, i.e. from 26 November 2012 to 25 November 2013. Any changes to the research protocol must be submitted as an amendment. Any protocol deviations have to be reported.

Wishing you well with your research.

Yours sincerely

PROF. D DU TOIT
CHAIRPERSON: MRC ETHICS COMMITTEE

MRC Ethics Committee: Prof D du Toit (chairperson), Prof A Dhai, Dr N Khaole, Dr NE Khomo, Prof D Labadarios, Ms L Mpahlwa, Prof H Oosthuizen, Dr L Schoeman, Prof AA van Niekerk

UNIVERSITY OF CAPE TOWN

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15 August 2013

HREC REF: 437/2013

Ms I van der Heijden
c/o Dr J Harries
School of Public Health & Family Medicine
Falmouth Building

Dear Ms van der Heijden

PROJECT TITLE: AN EXPLORATION OF DISABLED WOMEN'S EXPERIENCES OF VIOLENCE IN SOUTH AFRICA

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the HREC has **formally approved** the above mentioned study.

Approval is granted for one year till the 28 August 2014.

Please submit a progress form, using the standardised Annual Report Form, if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

Please include the UCT HREC contact details in the participant information sheet, in case participants have any questions or concerns regarding their rights or welfare as research participants.

Please note that the on-going ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

Articles

ETHICS COMMITTEE

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31 March 2015

Ms I van der Heijden
Gender & Health Research Unit
MRC Cape Town

Dear Ms Van der Heijden

Protocol ID: EC034-11/2012
Protocol title: The gendered experiences of interpersonal violence against disabled people in South Africa
Meeting date: 24 March 2015

Thank you for your application to the Committee for a renewal, dated 10 March 2015. I am pleased to inform you that ethics approval was granted for the study for another year.

Please note that the renewal is valid for 1 year, i.e. from 24 March 2015 to 23 March 2016. Any changes to the research protocol must be submitted as an amendment. Any adverse events must be reported within 48 hours. Any protocol deviations have to be reported.

Wishing you well with your research.

Yours sincerely

PROF. D DU TOIT
CHAIRPERSON: MRC ETHICS COMMITTEE

MRC Ethics Committee: Prof D du Toit (chairperson), Prof D Kayongo, Dr NE Khomo, Ms N Morar, Prof N Morojele, Prof H Oosthuizen, Mr D Rebombo, Dr Y Sikweyiya, Prof A van Niekerk, Ms A Labuschagne

ETHICS COMMITTEE

6 April 2016

Ms I van der Heijden
Gender & Health Research Unit
MRC Cape Town

Dear Ms Van der Heijden

Protocol ID:	EC034-11/2012
Protocol title:	The gendered experiences of interpersonal violence against disabled people in South Africa
Meeting date:	29 March 2016

Thank you for your application to the Committee for a renewal, dated 7 March 2016. I am pleased to inform you that ethics renewal was granted for the study for another year.

Please note that the renewal is valid for 1 year, i.e. from 29 March 2016 to 28 March 2017. Any changes to the research protocol must be submitted as an amendment. Any adverse events must be reported within 48 hours. Any protocol deviations have to be reported.

Wishing you well with your research.

Yours sincerely

PROF. D DU TOIT
CHAIRPERSON: MRC ETHICS COMMITTEE

MRC Ethics Committee: Prof D du Toit (chairperson), Prof D Kayongo, Dr NE Khomo, Ms N Morar, Prof N Morojele, Dr SAS Olorunju, Prof H Oosthuizen, Mr D Rebombo, Dr Y Sikweyiya, Prof A van Niekerk, Ms A Labuschagne

ETHICS COMMITTEE

21 January 2018

Ms Ingrid van der Heijden
Gender & Health Research Unit
SAMRC Cape Town

Dear Ms Van der Heijden

Protocol ID:	EC034-11/2012
Protocol title:	The gendered experiences of interpersonal violence against disabled people in South Africa
Meeting date:	27 November 2017

Thank you for your close-out report to the Committee, dated 6 November 2017. The Committee noted the report and that the study is now closed.

Yours sincerely

A. Labuschagne

MS A LABUSCHAGNE
SECRETARIAT: SAMRC ETHICS COMMITTEE

Members present at the meeting: Prof K Moodley (Chairperson), Ms S Behardien, Prof D du Toit, Ms D Gallant, Ms M Ledwaba, Ms N Morar, Prof N Morojele, Dr SAS Olorunju, Dr Y Sikweyiya, Prof J Singh, Dr S Suffla

Appendix 2: Scope of inquiry: Women with disabilities

Introduce and explain the interview

Hello. Thank you for meeting with me. My name is Ingrid and I am a student at the University of Cape Town and I also work at the Medical Research Council. We are doing a study with women with physical and sensory disabilities in South Africa so that we can better understand their situation.

In the interviews I would like to hear about your life; your childhood, adolescence and adulthood. I would also like to hear about your health problems and any other problems you may have had.

I'd like you to share your views, your beliefs and your thoughts about your life and the challenges you face because of your impairments.

I will be interviewing you on three occasions. I will also record the interviews so that I can listen to it again and remember what we spoke about. I will also take notes to write down the important things you say so that next time we meet, we can discuss them more deeply.

Explain confidentiality and informed consent.

I have explained the information sheet and consent form to you. I'd like to talk to you about confidentiality. I hope you feel free to talk to me about your life and your problems and know that everything you say will be kept confidential. By this I mean that everything we discuss between us will not be shared with anyone else. Do you have any questions about confidentiality?

Possible probes:

	Questions
Probes	'How did you feel when…', How did you react when…' 'How did rape affect you / affect your feelings about yourself? About people around you? What did you do after?' I am interested in your story, but can I ask a question? (If goes on too long) What else do you think is important for us to know? What happened next? What did you think about that? Has the problem been solved? What do you think you will do next time?
Follow-up probes	Last time, you told us this story [recap]. Can you tell us more? What has happened since the last time we spoke? [use similar probes to first interview]
Reflective questions	If you could tell social workers, health workers or police how to help you better, what would you say? How has your disability has made a difference in seeking help after violence/abuse? What has it been like to be interviewed/a part of this study?

- So to start, why don't you tell me a bit about yourself? (*Ask about background and family* - Ask sociodemographic information like Age, Race, Residential location, Type of disability, Marital status, Employment Status, Type of housing, No of children)
- Tell me about the place / community that you live in?
- How would you describe a typical day in your life?

Living with a Disability

- When did you first recognise your impairments? How old were you when you when you acquired impairments?
- Do you consider yourself a person with a disability? Why?
- How do you feel/ what do you think about your disability?
- What opportunities or experiences have you missed because of your disability?
- What kinds of opportunities have you had because of your disability?
- Can you tell me a story of how you were treated differently because of your disability?
- If you were a disabled man, how would things be different for you?
- In general, how are women with disabilities treated compared to women without disabilities?
- What are your limitations? What can't your body do?
- Tell me about your health? (probe for body pain, physical health, mental health) How do these health problems affect your life?
- What happens when you go to clinic or hospital for check-ups? How are those experiences? How do the staff treat you?
- Mental health – how do you feel or cope most days? (Probe: Feeling bad about yourself or that you are a failure or have let yourself or your family down. Thoughts that you would be better off dead, or of hurting yourself)
- Do you take any medicine or go for any therapy or counselling– tell me more. How is that for you?
- What services / help do you need?
- What kind of access do you have to services in general?

- How is your living situation? (ask about access and people she lives with) (If in residential care, ask about when got there, why, and what are the differences in living;)
- Tell me about the people you live with / who take care of you. What is your relationship like living with them?
- Tell me about your financial situation? Do you get the disability grant? How does this help you – what do you use it for? Does your family have any say or does anyone else use this money? Have they taken control of your money? How does it make you feel?
- Have you ever experienced a situation in which you felt scared of a family member or abused by a family member, carer or person you live with? (probes: Have they threatened to hurt you Have they ever insulted you / called you names / put you down in front of other people?? Or someone you care about?

Community perceptions/ stigma

- Tell me about your community.
- What is your experience of being a disabled woman in this community? How are disabled women treated?
- How do people react around you? (other's eyes on you) – gossip, support, embarrassed, withdraw, abuse. Can you give me examples?
- What does discrimination mean to you?
- Have you ever felt discriminated against – tell me the story.
- How does discrimination affect your life?
- Why do you think it happens?
- What do you do when it happens? (coping)

Childhood

- Tell me about when you were young.
- How did your parents behave at home?
- Tell me about school? How were you treated at school?
- Were you ever punished (hit) as a child, by who? Where were you when it happened? Did other children get same treatment?
- What is your worst experience you had as a child?
- What is your happiest memory from when you were young?

Sexuality

- What does being a woman mean to you?
- What happens during menstruation?
- Part of being a woman is having children. What are your thoughts on having children/being pregnant?
- How has 'being a woman' changed since you became disabled?
- Where did you learn about sex? Contraception? Did you have sex education at school?
- What services have you accessed for reproductive or sexual health? What happened? What were the challenges you encountered?
- Have you ever used contraception? Any difficulties?
- What have you heard of sterilization? What are your thoughts about it?
- Have you had a breast exam or pap smear? How was your experience?
- Do you know about HIV/STIs? Have you ever been tested? Tell me your experience.

Dating, intimate partner relationships and sexuality

- How are your romantic relationships – before and after acquiring a disability? How did it change?
- Tell me about your dating relationships or previous partners. Where did you meet your partners? What was dating like for you? Were your partners also disabled? What was his disability? Tell me about dating or being married to someone that is also disabled?
- If not disabled, what was it like dating a man without a disability?

Explore personal barriers to dating – perceived societal barriers to dating

- Are you currently in a relationship? How is that?
- What do you expect when you are in a relationship?
- Who makes the decisions in your relationship/marriage? What kind of decisions?
- In your relationships, do you go to bed with a man? (Have sex?) What is having sex like? (in terms of your physical limitations?)
- Do you enjoy having sex? Do you get pleasure?
- Do you usually use condoms or other contraception (why/why not?)
- Do you feel you can refuse to have sex with your partner/husband?
- How would you describe the first time you ever had sex?
- When was the last time you had sex? Did you use a condom? Where you drunk or under the influence when it happened?
- What are your best relationship experiences? What are the good things about being in a relationship?
- What are your worst relationship experiences? What are the bad things about being in a relationship?

- Have you ever felt scared of your partner? Has he ever forced you to do something you don't want to do? Does he speak badly to you or about you? Does he control the money? Does he ever get angry or aggressive? How did it start? How do you feel about the experience? Were you able to share this experience with anyone? Who? What happened after the violence? How did it make you feel?

General violence

- Do you feel safe in this community/home? (Probe.) What kinds of bad things happen here? Where is the most dangerous place in your community, tell me about it? Have you been there?
- Has anyone you know made you feel unsafe? What happened? When did this happen?
- Has anyone you know made you afraid they would hit, kick, slap, shove or otherwise physically hurt you? What happened? When did this happen?
- Has anyone you know hit, kicked, slapped, shoved, or otherwise physically hurt you? What happened? When did this happen?
- Has anyone you know physically handled you in a rough way? What happened? When did this happen?
- Has anyone you know held or tied you down or made you stay someplace when you did not want to? What happened? When did this happen?
- What do you think is the reason you were hurt? (Probe for substance abuse, couldn't escape)

Family / carer violence

- Would you prefer to live at home, with parents/partner, alone/independent, in a home for disabled people? Do you feel safe at home? (Probe.)
- Have you ever felt scared being with the people you live with/who care for you?
- Has anyone you know yelled at you repeatedly or hurt your feelings on purpose? When? And what happened?
- Has anyone you know ignored or refused to help you with an important personal need such as using the bathroom, banking, dressing, eating, communicating, or going out in the community? When? And what happened?
- Has anyone you know purposely broken or kept you from using things such as a wheelchair, breathing machine, communication device, or service animal? When and what happened?

Community violence

- Tell me about your experience of violence/abuse in your community. What makes you feel unsafe/afraid or safe in the place where you live? Where does the violence occur? Have you ever reported a crime to the police – tell me about it.
- What problems do women and girls experience in your community? [probe on violence - How are girls/women involved in violence?]

Sexual violence / Rape

- Has anyone you know made you afraid they were going to touch you in a sexual way that you did not want? What happened? When did it happen? (Probe for reporting of violence – did they tell anyone?)

- Has anyone you know touched you in a sexual way that you did not want? What happened? When did it happen? (Probe for reporting of violence – did they tell anyone?)
- Has anyone you know made you touch them in a sexual way that you did not want? (Probe for reporting of violence – did they tell anyone?)
- Has anybody ever forced you to have sex when you did not want to? What happened? When did it happen? (Probe for reporting of violence – did they tell anyone?)

Reporting of violence

- Have you ever told anyone what about the bad things that have happened to you? Did you ask for help? Report to the police? How did this occur?
- Why did you not disclose / seek help? (Shame, dependence, futile?) What obstacles did you encounter?

Vulnerability to violence

- Do you think disabled women are exposed to more violence and/ or abuse than disabled men? Non-disabled people? Why?
- How can you protect yourself from violence?
- What can be done to help disabled people (especially women and girls) who have been exposed to violence and/ or abuse?

What changes are needed?

- What would make your life better?
- What must change in your community to better your situation / the lives of other disabled women like you?

- What must change in South Africa for disabled women?

Part of getting the change needed to make life better for disabled women is talking to women with disabilities like you and finding out the major problems the face. Thank you for sharing your stories with me.

Experience of participating in research (ask after each interview)

- What did you like or not like about participating in this study?
- What were the difficulties you encountered in participating?
- What were the difficult parts of the interviews?
- What are your concerns or worries now that the interviews have come to an end?
- Can you please share with us how the interview process could have been made better or easier for you?

Appendix 3: Socio-demographics table

N=30	n (%)	N =30	n (%)
Age		**Education**	
19-25	10 (33%)	Special needs	11 (37%)
26-35	12 (40%)	Mainstream	19 (63%)
36-45	5 (17%)	Secondary	8 (27%)
46-54	3 (10%)	Tertiary	2 (7%)
Race		**Employment**	
Coloured	9 (30%)	Formal	5 (17%)
Black	21 (70%)	Informal	4 (13%)
Living arrangements		Protective workshop	21 (70%)
Living with partner	14 (47%)	**Impairments**	
Residential care	9 (30%)	Congenital	19 (63%)
Living with family	7 (23%)	Acquired	11 (37%)
Ever partnered	15 (50%)	**Education**	
Married	7 (23%)	Special needs	11 (37%)
Boyfriend	5 (17%)	Mainstream	19 (63%)
Divorced	2 (7%)	Secondary	8 (27%)
Widower	1 (3%)	Tertiary	2 (7%)
Children	12 (40%)		

Appendix 4: Table of perpetrators

Forms of violence	Perpetrators	No. of women with disabilities (N=30)
Psychological / Emotional	Peers, strangers, partners, in-laws, service providers, care facility staff	26 (87%)
Financial (exploit their grant monies)	Parents, family members, partners, care facility staff	24 (80%)
Neglect / Deprivation	Teachers, parents, family members, partners, care facility staff	15 (50%)
Sexual abuse / rape	Partners, non-partners, family members, care facility staff	11 (37%)
Physical abuse (assault / remove their assistive device)	Parents, peers, partners, non-partners, family members, care facility staff, community members	10 (33%)

Appendix 5: Scope of inquiry: Service providers

1. What type of services does your organisation provide to people/women and girls with disabilities?

2. What range of disabilities do you cater for or come across?

3. What are the biggest challenges or barriers for the disabled community?

4. What is your definition of violence or abuse against PWD?

5. In your experience, do you think that violence and abuse is an issue for people with disabilities especially? Explain.

6. What forms of abuse or violence are they most vulnerable to?

7. Where does it take place / which context? (What contexts put them most at risk?)

8. Who are the common perpetrators of violence and abuse against people with disabilities?

9. Specifically women with a disability. What forms of abuse or violence do women experience? Where does it take place? Who are the common perpetrators?

12. What makes them at risk/vulnerable? Is it about being a woman or being disabled?

(Please provide case stories of abuse or violence that you know of that has happened to women and what came out of that…)

13. What are the pathways to care that are available to them? What services does your organisation provide to people with disabilities who experience violence and abuse? What

happens [via your organisation] to a woman with a disability if she has been raped or sexually abused, or experiencing partner/family abuse?

14. Do you connect/refer to disability-specific services or general?

15. What are the challenges in care/offering support?

16. What are the barriers/facilitators to reporting the abuse to family, care providers, police?

17. What access to justice do they have? What are the barriers to justice?

18. What reasonable accommodation should be made to facilitate access to care and justice?

19. How can your organisation help to facilitate violence awareness, screening, reporting and access to services and justice? (Do social workers screen for abuse?)

20. What training is provided to service providers and staff to respond to or prevent violence and abuse against PWD? [Ask for examples or cases of abuse that was facilitated by organisation].

21. How can we protect women with disabilities?

22. How can they protect themselves?

Appendix 6: Information sheet and consent form (Women with disabilities)

Introduction

Hello. My name is Ingrid and I am a researcher at the Medical Research Council in Cape Town. I am doing a study of disabled women in South Africa. I want to invite you to talk to me about your life, your health problems, and the difficult times you have had. I'd like you to share your views, your beliefs, and your thoughts - good and bad.

You should not agree to participate in this study unless you fully understand what is required of you and you are happy about all the things that are involved in the study. This information leaflet is to help you decide if you want to participate. If you do not understand the information or have any other questions, do not hesitate to ask me.

Purpose of the study

This study is done to understand the health and life experiences of disabled women in South Africa. By talking to women who are disabled, I can gather data that shows the problems and realities of their lives. It is important for government to hear about the lives of disabled women so that the life situations and services for disabled women can be improved.

What will happen in the research?

If you agree to be part of the research, I will meet with you and ask you questions about your childhood, your family, your relationships, your health, and the difficulties that you have had

during your life. We can make plans to meet where it will be most comfortable for you. I hope that I can talk to you three times so that I can hear about things from when you were young up until now. I hope that we can talk for about 1 hour each time. When we talk there will be myself and someone else to help with the language translation so that you will feel comfortable talking in your own language. If there is a need, another person can join us to help you tell me your stories so that I can better understand them (SASL interpreter). With your permission I would like to record what you share with me so that I can remember your story. I also want to take notes so that I can remember the important things you say.

Risk and Discomfort involved.

Some of the things we talk about might be difficult to answer or you might get upset. You don't have to answer questions you are not comfortable with, and you can stop talking at any time. If you get tired of talking, you can tell any of us and we can take a break. If during our discussions, you find that what we talk about makes you sad or distressed please inform me or the research assistant or interpreter. If you feel you need to speak to someone, we will arrange for you to be referred to a relevant community-based organization that provides counselling and support services at no cost to you. In terms of the Children's Amendment Act of 41 2007 that stipulates mandatory reporting of abused or neglected children (Section 110) it is a criminal offence not to report child abuse. If you tell me that a child you know is being subjected to abuse or neglect, it is my duty to report it.

Compensation and possible benefits of this study

Your participation in this study is voluntary; there is no reward to be given to you for participating in this study, but you will be compensated for your transport costs and time with R150 and I will provide a snack and drink for you after the interview.

As a person, you might not get any benefit from participating in this study. But the information I am collecting in this study may be helpful in identifying the problems disabled people face during their lives. Getting this information will help government improve the lives of disabled women and it will also help in finding better ways of keeping disabled women safe from possible harm and violence.

Confidentiality

If you are willing to talk to me about your life, I will promise to keep everything you tell me secret. We will talk together in a safe and private place and this will help to ensure that there is no other person from the community who hears what we are talking about. I will ensure that your real name and any other things that would identify you as a participant in this study is not written down anywhere and in the written reports I will use a different name for you [pseudonym]. I won't tell anyone your name or where you live or what you told me in the interview. I won't show anyone the notes and only I will listen to or watch the recording. I will keep the notes and recordings on my computer which is protected with a password for 5 years. When I have finished using the recordings and notes, I will destroy them.

What are your rights as a participant?

Your participation in this study is entirely voluntary. You also do not have to agree to anything that makes you feel uncomfortable. You can refuse to participate or stop at any time without giving any reason, and nothing will happen to you.

Has the study received ethical approval?

This study has been approved by the Medical Research Council Ethics Committee. The ethics committee will continue to see if this study is being done in a safe way until the study is

completed. I have copies of a letter from the ethics committee that show that the study was approved by them. I can give it you to if you wish to have one.

If you have any questions about the study or something that you are not happy about, please feel free to contact the Chairperson of the South African Medical Research Council Ethics Committee Prof. Danie du Toit at 021 938 0341 or email: adri.labuschagne@mrc.ac.za

Information and contact person

My name is Ingrid van der Heijden. I am the contact person for this research. If you have any questions regarding the research, during and after the interview, feel free to contact me on telephone number 021 938 0448 or my supervisor Prof Naeemah Abrahams at 021 938 0445.

If you want help with your problems, I have a pamphlet with a list of professional people you can call or services where you may get help. You can call these places, or, if you agree, we can call them for you and make an appointment.

Consent

I hereby confirm that the person asking me to participate in this has given me information to my satisfaction. She explained to me the purpose, things that are involved, risk and benefits and my rights as a participant in the study. I have also received the information leaflet for the study and have had enough time to read it on my own, ask questions and I am happy with the answers I have been given regarding participation in the study. I have been told that the information I give to the study will together with other information gathered from other people, be written into a report and scientific publications. This will be done without my name and any other thing that you identify me as a participant in the study. I have also been given contact numbers of professionals who I can speak to about my problems. I am aware that it

is my right to refuse participation in this study without experiencing any harm. I hereby, freely and voluntary give my consent to participate in the study.

I agree to participate in this study

Participant's name……..(Please print)

Participant's signature……Date……

Researcher's name……(Please print)

Researcher's signature……..Date……

If verbal consent was tape recorded, please sign below

Participant's name……..(Please print)

Participant's signature……Date……

Researcher's name……(Please print)

Researcher's signature……..Date……

I agree to the audio/video recording of the interview

Participant's name……..(Please print)

Participant's signature……Date……

Researcher's name……(Please print)

Researcher's signature……..Date……

Appendix 7: Information sheet and consent form (Service providers)

Introduction

Hello. My name is Ingrid and I am a researcher at the Medical Research Council in Cape Town. I am doing a study of women with disabilities in South Africa. I want to invite you to talk to me about your perspectives of the challenges they face, specifically in relationship to their risk for violence and abuse.

You should not agree to participate in this study unless you fully understand what is required of you and you are happy about all the things that are involved in the study. This information leaflet is to help you decide if you want to participate. If you do not understand the information or have any other questions, do not hesitate to ask me.

Purpose of the study

This study is done to understand the violence experiences of disabled women in South Africa. By talking service providers, I can gather data that shows the problems and realities of their lives. It is important for government to hear about the lives of disabled women so that the life situations and services for disabled women can be improved.

What will happen in the research?

If you agree to be part of the research, I will meet with you and other service providers and discuss women with disabilities' risks for violence, violence awareness and prevention, and

pathways to care and justice. We will meet at the disability organisation. The focus group or interview will last for about 1 hour. When we talk there will be myself and someone else to help with the language translation so that you will feel comfortable talking in your own language. If there is a need, another person can join us to help you tell me your stories so that I can better understand them (SASL interpreter). With your permission I would like to record what is shared in the focus group so that I can remember the main points of the discussion. I also want to take notes so that I can remember the important things that are discussed.

Risk and Discomfort involved.

Some of the things we talk about might be difficult to answer or you might get upset. You don't have to answer questions you are not comfortable with, and you can stop talking at any time. If you get tired of talking, you can tell any of us and we can take a break. If during our discussions, you find that what we talk about makes you sad or distressed please inform me or the research assistant or interpreter. If you feel you need to speak to someone, we will arrange for you to be referred to a relevant community-based organization that provides counselling and support services at no cost to you. In terms of the Children's Amendment Act 41 of 2007 that stipulates mandatory reporting of abused or neglected children (Section 110) it is a criminal offence not to report child abuse. If you tell me that a child you know is being subjected to abuse or neglect, it is my duty to report it.

Compensation and possible benefits of this study

Your participation in this study is voluntary; there is no reward to be given to you for participating in this study.

As a person, you might not get any benefit from participating in this study. But the information I am collecting in this study may be helpful in identifying the problems disabled women face during their lives. Getting this information will help government improve the lives of disabled women and it will also help in finding better ways of keeping disabled women safe from possible harm and violence

Confidentiality

If you are willing to participate in the interview or focus group, I will promise to keep everything you tell me confidential. However, I cannot guarantee that others in the focus group will not discuss what you say after the focus group. I will ensure that your real name and any other things that would identify you as a participant in this study is not written down anywhere and in the written reports I will use a different name for you [pseudonym]. I won't tell anyone your name or what organization you work for or what you discussed in the focus group. I won't show anyone the notes and only I will listen to the recording. I will keep the notes and recordings on my computer which is protected with a password for 5 years. When I have finished using the recordings and notes, I will destroy them.

What are your rights as a participant?

Your participation in this study is entirely voluntary. You also do not have to agree to anything that makes you feel uncomfortable. You can refuse to participate or stop at any time without giving any reason, and nothing will happen to you.

Has the study received ethical approval?

This study has been approved by the Medical Research Council Ethics Committee. The ethics committee will continue to see if this study is being done in a safe way until the study is

completed. I have copies of a letter from the ethics committee that show that the study was approved by them. I can give it you to if you wish to have one.

If you have any questions about the study or something that you are not happy about, please feel free to contact the Chairperson of the South African Medical Research Council Ethics Committee Prof. Danie du Toit at 021 938 0341 or email: adri.labuschagne@mrc.ac.za

Information and contact person

My name is Ingrid van der Heijden. I am the contact person for this research. If you have any questions regarding the research, during and after the interview, feel free to contact me on telephone number 021 938 0448 or my supervisor Prof Naeemah Abrahams at 021 938 0445.

If you want help with your problems, I have a pamphlet with a list of professional people you can call or services where you may get help. You can call these places, or, if you agree, we can call them for you and make an appointment.

Consent

I hereby confirm that the person asking me to participate in this has given me information to my satisfaction. She explained to me the purpose, things that are involved, risk and benefits and my rights as a participant in the study. I have also received the information leaflet for the study and have had enough time to read it on my own, ask questions and I am happy with the answers I have been given regarding participation in the study. I have been told that the information I give to the study will together with other information gathered from other people, be written into a report and scientific publications. This will be done without my name and any other thing that you identify me as a participant in the study. I have also been given

contact numbers of professionals who I can speak to about my problems. I am aware that it is my right to refuse participation in this study without experiencing any harm. I hereby, freely and voluntary give my consent to participate in the study.

I agree to participate in this study

Participant's name……..(Please print)

Participant's signature……Date……

Researcher's name……(Please print)

Researcher's signature……..Date……

I agree to the recording of this interview

Participant's name……..(Please print)

Participant's signature……Date……

Researcher's name……(Please print)

Researcher's signature……..Date……