Through a different lens:

Examining commonality and divergence in constructions and depictions of the sexuality of persons with physical disabilities in South Africa

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Declaration

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the authorship owner thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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Abstract

Historically, people with disabilities have been held in contempt or pitied by the non-disabled members of the communities in which they live, and by society as a whole. One area in which people with disabilities have been excluded and discriminated against is that of sexuality. Sexuality has been deemed the purview of the non-disabled. The societal inability, or disinclination, to reconcile sexuality and disability has had damaging consequences for people with disabilities who have variously been infantilised, and treated as asexual. The international literature suggests that this stereotype of asexuality has been more widely applied to individuals with physical disabilities than to those with other disabilities. In low- and middle-income countries there is a gap in the state of knowledge concerning

a. the attitudes of non-disabled people towards the sexuality of people with physical disabilities; and

b. the experiences of sexuality (including sexual and reproductive health, relationships and sexual activity) of people with physical disabilities.

In this dissertation, I survey the attitudes of some South Africans, from different backgrounds, with different levels of education, knowledge about, and exposure to, people with physical disabilities, towards the sexuality of people with physical disabilities. Secondly, I present and discuss accounts of lived experience – as gathered in a photovoice study – of sexuality and of sexual and reproductive health care amongst people with physical disabilities. I propose photovoice and self-representation as means by which the narratives illuminated in answer the second question, may be presented and made “real”. In the survey segment of the study, I found that non-disabled South Africans perceive people with physical disabilities to be less sexual than they are. This appears to be underpinned not only by a belief that people with physical disabilities are less sexual than non-disabled people, but also by non-disabled people’s active desexualisation of people with physical disabilities in interactions, and negation of the gender of people with physical disabilities. In the photovoice segment of the study, I found that a sample of South Africans with physical disabilities were concerned with their sexual fitness – their suitability as sexual subjects. This originated in their ideas about how non-disabled people might view their different-than-average embodiment, or how they viewed their embodiment as measured against internalized non-disabled norms. I reflect on the value of photovoice as methodology, and the value of self-generated images of the sexuality of people with physical disabilities in challenging societal representations. These images go some way to right the wrong of past misrepresentation which parallels and perpetuates the exclusion of people with physical disabilities from sexual life. I discuss future directions for inquiry into physical disability and sexuality, with a special interest in the global south context.

Geskiedkundig is mense met gestremdhede in minagting of verontwaardiging gehou deur die nie-gestremde lede van die gemeenskappe waarin hulle woon, asook deur die samelewing as geheel. Een gebied waar persone met gestremdhede uitgesluit en teen gediskrimineer is, is seksualiteit. Seksualiteit word beskou as die oogmerk van die nie-gestremde. Die samelewingsonvermoë, of ongerymdheid, om seksualiteit en gestremdheid te versoen, het skadelike gevolge vir gestremde persone wat beide kinderloos bevind word, en as aseksueel beskou word. Die internasionale literatuur dui daarop dat hierdie stereotipe aseksualiteit meer toegepas word op individue met fisieke gestremdhede. In lae- en middelinkomste lande is daar 'n leemte tussen so 'n teorie en die stand van kennis aangaande a. die houdings van nie-gestremde persone teenoor die seksualiteit van mense met fisieke gestremdhede; en b. die ervarings van seksualiteit (insluitend seksuele en reproduktiewe gesondheid, verhoudings en seksuele aktiwiteit) van mense met fisieke gestremdhede. In hierdie proefskrif ondersoek ek die houdings van sommige Suid-Afrikaners, van verskillende agtergronde, met verskillende vlakke van opvoeding, kennis oor en blootstelling aan mense met fisieke gestremdhede, teenoor die seksualiteit van mense met fisieke gestremdhede. Tweedens, bied ek aan en bespreek ek die beleefde ondervinding – soos ingesamel in 'n fotovoltaïese studie - van seksualiteit en seksuele en reproduktiewe gesondheidsorg onder mense met fisieke gestremdhede. Ek stel fotovolusie en selfverteenwoordiging voor as middel waarmee die vertellings wat verlig word in antwoord op die tweede vraag, voorgestel en gemaak kan word. In die opnamesegment van die studie het ek bevind dat nie-gestremde Suid-Afrikaners mense met fisieke gestremdhede beskou as minder seksueel as wat hulle is. Dit blyk nie net deur die oortuiging dat mense met liggaamlike gestremdhede minder seksueel as nie-gestremde mense is nie, maar ook deur nie-gestremde persone se aktiewe ontseksualisering van mense met fisiese gestremdhede in interaksies en negasie van die geslag van mense met fisiese gestremdhede. In die fotovoltaeksegment van die studie het ek bevind dat 'n steekproef van Suid-Afrikaners met fisieke gestremdhede bemoeid was met hul seksuele fiksheid - hul geskiktheid as seksuele voorwerpe. Dit het ontstaan in hul idees oor hoe nie-gestremde mense hul anders-as-gemiddelde beliggaming sien, of hoe hulle hul beliggaming beskou het soos bepaal word deur geïnternaliseerde nie-gestremde norme. Ek besin oor die waarde van fotovolusie as metodologie en die waarde van selfgegenereerde beelde van die seksualiteit van mense met fisieke gestremdhede in uitdagende samelewingsvoorstellings. Hierdie beelde bied een of ander manier aan om die verkeerde wanvoorstelling van die verlede, wat die uitsluiting van mense met fisiese gestremdhede uit die seksuele lewe voortduur, reg te stel. Ek bespreek toekomstige aanwysings vir ondersoek na fisieke gestremdheid en seksualiteit.

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DEDICATION

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CHAPTER ONE

Introduction to the Present Study

1.1 Introduction

Historically, people with disabilities[1] have been held in contempt or pitied by the non-disabled members of the communities in which they live, and by society as a whole. The history of eugenics is testament to the history of contempt, whilst the history of pity finds evidence in societal discourses which have positioned disability either as a personal tragedy to be borne with bravery, or a scientific anomaly to be fixed or cured (Goodley, 2011a; Goodley, Lawthom, & Runswick-Cole, 2014).

One area in which people with disabilities[2] have been excluded and discriminated against is that of sexuality. Sexuality has been deemed the purview of the non-disabled,[3] the healthy, and the nubile. Recent iterations of such sentiment can be found in the literature positing that sexuality is essential for health and quality of life, in attempts to "cure" sexual dysfunction and lack of interest (Bancroft & Graham, 2011; Basson, 2000; Maass, 2007), and in popular culture's emphasis on sex as a site of achievement and a source of health (Attwood, 2009; Swami, Diwell, & McCreary, 2014; Weeks, 1985).

These two historical ways of thinking about disability and sexuality respectively discursively preclude the possibility of "normal" sexuality amongst people with disabilities. That is, disability and sexuality are positioned as antithetical to one another: if one lacks

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[1] There is debate in the field of disability studies over the terminology by which people with impairments are referred to. In this dissertation, I employ "person first" language, where, conceptually, personhood is given primacy over disability identity, hence, "person with a physical disability" (this derives from an American school of thought). There are scholars, however, who prefer the term "disabled people", in order to recognise and value disability identity (this derives from the Social Model school of thought). The former terminology was selected to make the dissertation coherent, as this language was preferred by the journals to which my articles were submitted.

[2] There are a variety of ways of understanding disability, and this will be discussed further below in Section 1.6.1.

[3] The choice of language here is intended to reflect my general alliance with the terminology of the Social Model's understanding of disablement as largely socially imposed. Thus, in referring to people who do not experience the disabling social barriers encountered by people with impairments, I use the term non-disabled (they do not face disablement), rather than able-bodied.

ability (has an impairment), one cannot be sexual, and – equally – if one is not sexual, one is somehow impaired. As Siebers (2008) writes,

> Disabled people are often not allowed to have agency, sexual or otherwise. Rather they are pictured as abject beings, close to nothing, empty husks. To be disabled in the cultural imaginary is to cease to function. (p. 160)

This societal inability, or disinclination, to reconcile sexuality and disability has had damaging consequences for people with disabilities, who have variously been infantilised, and treated as asexual, or – when they do express their sexuality – viewed as "oversexed perverts" (Brown, 1994, p. 125).

The international literature suggests that to some degree the stereotype of asexuality has been more widely applied to individuals with physical disabilities, and the stereotype of hypersexuality to individuals with cognitive impairments (Kim, 2011). Given the sequelae of having one's sexuality denied (discussed presently), the present project is concerned with the sexuality of people with physical disabilities.

As I shall discuss later, some scholars (including Kim, 2011; Liddiard, 2011, 2017) have proposed that there is a moral imperative that people with different bodies (not just those with intellectual disabilities) *should not* be sexual, and that this underlies the societal view of people with physical disabilities *as* asexual.[4] This policing of sexuality – defining the

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[4] The word asexual in this literature has been used to describe the assumption that people with disabilities experience a "relative absence or insufficiency of sexual interest, biologically and socially described function, and interpersonal sexual engagement" (Kim, 2011). Recently, important research and campaigning has resulted in the recognition of asexuality as a sexual orientation, and this recognition must lead us to qualify our use of the term in the present research. Asexuality is a positive sexual identity (see the recent work of Jones, Hayter, & Vomeen, 2017). People with disabilities are generally seen as not having any sexuality, including sexual agency or choice, drives or desires, rather than having made the choice to identify as asexual of their own volition. This is not to invalidate the identification of people with physical disabilities who do describe themselves as asexual. However, what I am concerned with here, is the automatic ascription of asexuality – as an example of desexualisation and de-gendering – to people whose embodiment differs from the norm.

boundaries around “normal sex” – precludes sexuality on the part of those who transgress societal ideas about normal bodies, and normal ways of having sex. The result is that, when people with physical disabilities do express their sexuality, that sexuality is automatically rendered deviant or undesirable (Liddiard, 2011; Tepper, 2000).

There is, however, particularly in low- and middle-income countries (Carew, Braathen, Swartz, Hunt, & Rohleder 2017), a gap between such theory and the state of knowledge concerning:

a. the attitudes of non-disabled people towards the sexuality of people with physical disabilities; and

b. the experiences of sexuality (including sexual and reproductive health, relationships and sexual activity) of people with physical disabilities.

Concerning the former, much of the literature which will be referred to throughout the course of this dissertation regarding social ideas about the sexuality of people with physical disabilities is theoretical. Although this work is useful, empirical data from low- and middle-income countries is lacking. The state of knowledge concerning the woman or man on the street’s thinking about, and disposition towards, the sexuality of people with physical disabilities is modest. Much of the research on this topic consists of surveys administered to undergraduate students at universities, or health professionals, in high income countries. The conclusions drawn are mixed, with most authors finding evidence for negative attitudes (Hergenrather & Rhodes, 2007; Marini, Chan, Feist, & Flores-Torres, 2011; Miller, Chen, Glover-Graf, & Kranz, 2009; Olkin & Howson, 1994; Trieschmann, 1988; Yoshida, 1994), but some not (Marini et al., 2011).

Thus, despite the growing body of theoretical work on the intersection of sexuality and disability, little remains known about the quality and content of public attitudes towards the sexuality of people with physical disabilities, particularly in the Global South. This despite the vast amounts of theoretical work, and some empirical work from the Global North, which suggests that these attitudes are likely problematic, and are also likely to influence the enactment of the sexual and reproductive health rights of people with physical disabilities. In contexts marked by a relative dearth of resources with which to conduct research and inform practice, it is imperative to engage in rights-based, exploratory research where such inquiry is required.

The present project comprises two complimentary lines of research, underlain by two motivations.

1. Firstly, while theoretical work hailing largely from the Global North is interesting and useful, it is the goal of the first (survey) arm of the present project to "take a step back" from these complexities, and simply sketch the lay of the land, as it were, concerning attitudes towards, and constructions of, sexuality and disability in the South African context. This underlies the first arm of the project: a survey of the thinking and feeling about, and constructions of, the sexuality of people with physical disabilities, conducted amongst non-disabled South Africans.

2. Secondly, there is an urgent need to explore sexuality from the perspective of people with physical disabilities themselves. In line with the UN Convention on the Rights of Persons with Disabilities Guiding Principles (United Nations, 2006), there is a need to challenge discriminatory attitudes, and in so doing promote non-discrimination with regards to sexual health issues, promote full and effective participation and inclusion in society as a sexual person, and highlight the need for equality of opportunity in matters of sexual health. One manner in which the lived experience of marginalised groups has helpfully been explored is photovoice: a qualitative research method where participants produce photographs as data.

> Adopting a participatory action approach in disability research foregrounds the importance of accessibility and the effective participation and inclusion of people with physical disabilities in research about people with physical disabilities. It also promises to make an important methodological contribution to disability and sexuality research in the Global South. This underlies the second arm of the present project: a photovoice study conducted with people with physical disabilities, which explores their experiences of sexuality and sexual and reproductive health.

There is a pressing need to establish what South Africans without disabilities may think about the sexuality of people with physical disabilities. There is an equally pressing need to explore the lived experience – of sexuality and of sexual and reproductive health care – amongst this latter population, and then, to share this with the world.

Through these two interrelated arms of work, I set out to undertake three broad tasks in this dissertation:

1. First, I explore the attitudes of some South Africans, from different backgrounds, with different levels of education, knowledge about, and exposure to, people with physical disabilities, towards the sexuality of people with physical disabilities. It is an attempt to look at the quality and content of attitudes *towards* people with physical disabilities, against the backdrop of an argument which positions these attitudes as having implications – real and often negative – *for* people with physical disabilities.
2. Second, I present and discuss accounts of lived experience – as represented in photograph and narrative – of sexuality and of sexual and reproductive health care – amongst people with physical disabilities. It will reflect on how the narrative

data generated by the respondents with disabilities may (or may not) constitute a 'speaking back' to dominant representations and conceptions of the sexuality of people with physical disabilities.

3. Third, I propose photovoice and self-representation as means by which the narratives illuminated in answer to the second question, may be presented and made 'real'.

1.2 A Lot of Theory and Less Research: Disability and (A)sexuality

Since the 1970s, in the United Kingdom and the United States, and subsequently more globally, the disability rights movement has fought for equality, access, and recognition for people with physical disabilities (Hurst, 2003). As authors such as Addlakha (2007) note, there is a recognition of the need to enhance educational and employment opportunities for people with disabilities, to address their exclusion from society, services, and institutions, and – amongst disability right's activists – to speak back to the dominant discourses of the able-bodied which have too long portrayed people with disabilities unfavourably.

As I suggested earlier, for over thirty years, issues around sexual health have been addressed in disability scholarship (Fine & Asch, 1985; Gibson & Mykitiuk, 2012; McKenzie, 2013; Shuttleworth & Mona, 2002), and more latterly, in the realm of public health (Aggleton, Boyce, Moore, & Parker, 2016; Davidson & Phillips, 2017; Lunsky et al., 2017). In recent years there has been a growing global recognition of the sexual and reproductive rights of people with disabilities, and, since the World Report on Disability (WHO, 2011), increased international attention has been given to these issues. Underlying this growing recognition, however, is the fact that the sexuality of people with physical disabilities has hitherto been nullified, and people with physical disabilities systematically excluded from conceptions of sexuality, from sexual health services, and generally considered to be – and treated as – asexual. As Rembis (2010) writes, “Disabled people have a sexual history characterized largely by oppression and discrimination” (p. 53).

For people with physical disabilities, this oppression has largely taken the form of the pervasive popular myth that they lack sexuality (Kim, 2011; Milligan & Neufeldt, 2001; Nario-Redmond, 2009). That is, that they are asexual, experiencing a “relative absence or insufficiency of sexual interest, biologically and socially described function, and interpersonal sexual engagement” (Kim, 2011, p. 480).

Kim (2011) notes that the term “asexuality” began to be stereotypically ascribed to people with physical disabilities in the 1960s, and has endured since then. As will be discussed in the following section, cultural ideologies surrounding disability (Anderson & Kitchin, 2000), as well as the hegemony of heteronormative sexuality (Esmail, Darry, Walter, & Knupp, 2010; Siebers, 2012), play a role in the tenacity with which this fallacy endures. Empirical research into disability and sexuality, though, has largely addressed the physical, and, latterly, the psychological, aspects of sexuality amongst people with physical disabilities (Sakellariou & Algado, 2006). However, ample theoretical work and some empirical evidence supports the idea that social factors, too, impinge on the sexual development and rights of people with physical disabilities.

In fact, theoretical work (not data-driven research) concerning sexuality and physical disability has almost exclusively focussed on social factors, through social theories, as scholars attempt to understand the desexualisation of people with physical disabilities (Esmail et al., 2010; Milligan & Neufeldt, 2001; Wiegerink, Roebroeck, Donkervoort, Stam, & Cohen-Kettenis, 2006). Scholars (Fiduccia, 2000; Siebers, 2012) have elaborated on the manner in which ability and sex are often constructed in relation to one another: that is, the common perception that sex is to be undertaken only by the young, fit, and vigorous.[5] The ideology of ability (and with ability, reproductive potential), authors such as Siebers (2012) have proposed, distorts current attitudes about sexuality, and devalues the sexual potential of people who do not measure up to "normal" standards of ability or reproductive vigour: when ability is considered a cornerstone of sexuality, and one is deemed unfit for sex, one's personhood is called into question. O'Brien and Kendall (2003) illustrate this idea when they recall the sentiments expressed by a doctor to a recently-disabled man, who said, "You may think you'll never have sex again, but remember – some people do become people again" (O'Brien & Kendall, 2003, p. 80).

Clearly, theory concerning the intersection of sexuality and disability is well-developed. It often highlights the centrality of social forces in shaping the experiences of sexuality of people with physical disabilities. Indeed, drawing attention to the ways in which personhood and sexuality are mutually constructed certainly illuminates the far-reaching consequences of having one's sexual identity denied. However, such work generally does not go as far as to examine the actual views and attitudes of the non-disabled towards people with physical disabilities. This is despite the fact that this theoretical work centralises social issues, and the fact that the attitudes of the individual members of a society, as shall be seen, are important, and have been proposed to underlie numerous problematic barriers faced by people with physical disabilities (de Loach, 1994; Schlesinger, 1996; Tilley, 1996).

In the small but growing empirical literature concerning societal attitudes towards the sexuality of people with physical disabilities, individual members of societies have been found to view people with physical disabilities as asexual, or, at the least, as less sexual than non-disabled people (Lee & Fenge, 2016; Mitra, Long-Bellil, Iezzoni, Smeltzer, & Smith,

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[5] This assumption has been challenged in recent years given an explosion in research into the sexual lives of older adults and people living with chronic illnesses (see, for instance, Gott & Hinchliff, 2003; Loaring, Larkin, Shaw, & Flowers, 2015).

2016; Olkin & Howson, 1994; Peta, 2017; Peta, McKenzie, Kathard, & Africa, 2016; Trieschmann, 1988; Yoshida, 1994). The beliefs and the attitudes of the non-disabled have consequences for the lives and experience of people with physical disabilities (O'Dea, Shuttleworth, & Wedgwood, 2012; Sakellariou, 2006; Sakellariou & Algado, 2006; Siebers, 2012). As Runswick-Cole and Goodley (2015, p. 647) write, "the socio-cultural construction of impairment labels … matter because these constructions have very real effects in people's lives".

People with disabilities are excluded from sexual health education (Cheausuwantavee, 2002; Seidel, Wienholz, Michel, Luppa, & Riedel-Heller, 2014), and sexual and reproductive health care (Peta, 2017; Rohleder & Swartz, 2012), experience challenges to their sexual development (such as assaults on their sexual self-esteem) (Howland & Rintala, 2001; Stohl, 1996), and are at increased risk to be victims of sexual violence (Astbury & Walji, 2014). In sub-Saharan Africa in general, and South Africa in particular, attitudes towards the sexuality of this group of people – largely negating that any such sexuality exists – have been suggested to put people with physical disabilities at increased risk for HIV infection (Groce et al., 2013).

Simultaneously, and in tandem with these societal attitudes, the visual representation of people with physical disabilities has a long, fraught history. Disabled bodies have been painted, photographed, and otherwise portrayed as abnormal or abject, or simply concealed. Images prefigure audiences: the way in which something is presented to us as viewers shapes our perception of, and engagement with, it. Thus, viewers come to interpret disability in the stereotypical, limited ways invited by stereotypical, limited images (Hafsteinsson & Bredin, 2010). These visual representations, and audiences' attitude in relation to them, often mirror social representations concerning the sexuality, bodies, and gender of people with physical disabilities. Indeed, these visual representations often have problematic implications for thinking about the sexuality and bodies of people with physical disabilities.

Yet, most people with physical disabilities do identify as sexual beings (Bahner, 2012), with a sexual orientation which is not asexual (Ostrander, 2009), with sexual needs (Bahner, 2012; Siebers, 2012), and with the desire for intimacy, intimate relationships (Chubon, 1981; Conine, 1984; Li & Yau, 2006), and children (Nosek, Howland, Rintala, Young, & Chanpong, 2001). The self-described sexuality of people with physical disabilities, then, is at odds with what we know about popular conceptions, and social and visual representations of it.

The myth of asexuality and sexual exclusion has negative consequences for people with physical disabilities which – in South Africa – may include increased risk of infection with HIV. Yet, we know little about the quality (positive or negative or neutral) and content of societal attitudes towards the sexuality of people with physical disabilities globally, and in particular in South Africa. The first part of this project, then, will concern itself with eliciting and examining the prevailing attitudes of a general population sample in South Africa, towards the sexuality of people with physical disabilities. The societal attitudinal climate regarding the sexuality of people with physical disabilities in South Africa must be explored, as these attitudes will likely shape the experiences of sexuality and sexual and reproductive health of people with physical disabilities in this context. The second part of this project is concerned with eliciting the experiences of sexuality, relationships, and sexual and reproductive health of people with physical disabilities. Given the burdensome representational and ideological baggage encumbering people with physical disabilities (as illustrated in the first review), I propose that self-representation, in the form of photovoice work, is extremely well-suited to use in application to this second line of inquiry.

1.3 Problem Statement and Research Questions

The present research is guided by three underlying, but interwoven questions, and also by the questions raised at the interplay between them:

1. What and how do South Africans think and feel about the sexuality of people with physical disabilities;
2. How do people with physical disabilities experience, describe, and self-represent their sexuality in South Africa; and
3. How do the representations of sexuality of people with physical disabilities speak to, or elide the attitudinal milieu revealed by the survey?

1.4 A Roadmap to this Dissertation

These questions will be contextualised and answered in this dissertation. For ease of reading, I will briefly orient the reader to the structure of this work. I begin with reviews of the literature which situate the present project within current thinking about (a) attitudes towards the sexuality of people with physical disabilities, and visual representation, disability, and sexuality (Chapter Two, Part I). I then discuss the lived experiences of sexuality in the context of physical disability (and the influence of the attitudes of others in this experience) (Chapter Two, Part II).

In Chapter Two, Literature Review Part I (section 2.2), I illustrate three broad points:

1. that, according to much theory, and some empirical work, there is a pervasive myth that people with physical disabilities are asexual;
2. this is reflected in and perpetuated by social and visual representations of sexuality and physical disability; and
3. belief in this myth influences non-disabled individuals’ attitudes towards sexuality amongst people with physical disabilities.

I show that research into attitudes towards the sexuality of people with physical disabilities is largely lacking in South Africa. What we do know, though, is that this group of people are especially lacking in access to sexual education (De Reus, Hanass-Hancock, Henken, & van Brake, 2015), are at increased risk of HIV (Chappell, 2015), and are acutely vulnerable to sexual violence and abuse (Chirawu, Hanass-Hancock, Aderemi, de Reus, & Henken, 2014) in South Africa. It is not impossible to imagine that these negative consequences could result from negative attitudes; but we do not know whether such attitudes exist in this context.

I review and discuss some prominent ways in which people with physical disabilities have been represented visually (in media, art, and photography). I show that disabled bodies have been variously portrayed – on canvas and by camera – problematically. I argue that this mirrors, in important ways, social representations concerning the sexuality of disabled bodies. I show that negative attitudes towards the sexuality of people with physical disabilities, and negative social and visual representations of people with physical disabilities and their sexuality, fuel and are fuelled by, negative social constructions of and attitudes towards the sexuality of people with physical disabilities.

In Chapter Two, Literature Review Part II (section 2.3), I review the literature regarding the experiences of sexuality and sexual and reproductive health of people with physical disabilities, and make two interrelated arguments:

1. that contrary to the myth of asexuality amongst people with physical disabilities, many people with physical disabilities do experience an active sexuality, although this is impinged upon by the attitudes of non-disabled others; and – finally –
2. that the myth of asexuality amongst people with physical disabilities (and its societal sequelae, including negative attitudes) has negative consequences for the

lives of people with physical disabilities. Where negative attitudes exist, there are negative outcomes for people with physical disabilities.

People with physical disabilities are perceived as asexual, despite the inaccuracy of such a perception. Theoretical work has proposed that this negation of the sexuality of people with physical disabilities to be a force in their broader social exclusion.

Together, the work presented in these literature reviews comprises the background to the present project. These reviews frame the present project's inquiry into:

a. non-disabled people's attitudes towards the sexuality of people with physical disabilities; and

b. the experiences of sexuality, relationships, and sexual and reproductive health of people with physical disabilities.

In Chapter Three, I very briefly outline the methods which were used in this study, and my role in the data collection, analysis and presentation of findings. Built upon this foundation of theory, literature and methodology, I present the publications which lay out the findings of this study. This dissertation is presented 'by publication', that is, with the methods and results of the study being offered in the form of academic journal articles and book chapters. This process and its rationale is outlined in more detail in the section "Introducing the Publications", below.

In the discussion and conclusion sections, I reflect on, and consider, what can be found when the findings of each publication and their implications are put in dialogue with one another.

1.5 Theoretical Framework and Operational Definitions

1.5.1 Theoretical framework

Disability studies is the name given to an interdisciplinary field of theory, research and practice which is dedicated to addressing issues pertinent to people with disabilities, with a view to righting the traditionally unbalanced accounts of disability which equate disability with impairment or personal tragedy (Goodley, 2011a).

One of the most influential theoretical models employed in disability scholarship is the social model of disability (Thomas, 2001). The view espoused by researchers who ascribe to this model is that individuals have impairments, not disabilities. Conceptually, the social model of disability takes issue with the conflation of impairment (such as blindness, paraplegia, or another form of physical impairment) with disability, which refers to the social consequences of impairment (Barnes, Mercer, & Shakespeare, 1999).

Here, the disablement of the individual lies in society (although social model theorists differ regarding how they conceptualise this disablement as occurring) (Taylor, 2005). Though there are differences in approach, the distinction between impairment and disability in the social model is akin to the distinction between having a particular skin colour or set of physical sexual characteristics (analogous to “impairment”) and the experience of living as a person of a particular race or gender in a racist and sexist society (analogous to “disability”).

Disability studies, though, is not only an interdisciplinary field, but also one in which numerous theoretical paradigms are used to try to understand matters relating to disability, and the social model is but one. While a social model approach alerts one to the social aspects of disability, and offers an important critique of ableist assumptions concerning disability, it is imperfect in the understanding it offers of the lived experiences of people with physical disabilities (Campbell, 2009; Goodley & Roets, 2008; Rembis, 2010; Shildrick, 2009; Tremain, 2001). This imperfection stems, in part, from the fact that, by drawing the distinction that it does between disability and impairment, the social model propagates the old body/subject divide of the medical model, and in so doing perpetuates an occlusion of the body. While such an occlusion might have served an important purpose in a specific historical moment (politicising disability, and resisting the stereotype of impairment as a personal, medical tragedy to be borne privately), such dichotomous thinking is not suitable today (Watermeyer, 2012). Further, such thinking leaves the model entirely neglectful of embodiment, thus failing to account for the very visceral, lived experiences of impairment of people with disabilities.

As Oliver (1990) writes, a social theory of disability should "*be located within the experience of disabled people themselves and their attempts not only to redefine disability*" (p. 11, emphasis added). The social model comes up lacking if it does not explore the experience of disability. This experience must necessarily include embodiment.

Indeed, if we attend to the phenomenological psychoanalytic literature on embodiment (see Watermeyer, 2013), we come to realise that the social model's relative lack of attention to embodiment leaves any account of life with an impairment incomplete.

Contemporary successors to theoretical prominence within disability studies which have attempted to re-embody disability include models of disability which draw on posthumanism and phenomenology. In these theorisations, Erevelles (2011) writes, "the disabled subject appears as the irregular and contingent effect of shifting signifiers producing disorganized collections of hybrid associations/assemblages that morph into an unstable and transgressive [body]" (p. 27).

A detailed account of posthumanism is beyond the scope of this dissertation. Briefly, however, posthumanism is a philosophical stance which challenges humanism on the grounds that the latter is premised on the notion of a "normative, rational, independent, autonomous subject", and this has ethical implications for those who do not fit this "bill" of humanity

(Goodley & Runswick-Cole, 2016). Goodley and colleague have proposed a theoretical model of disability, the Dis/human, which explores the contributions of posthumanist thinking to disability, and the disruptive potential which disability has for thinking through humanism. “We seek to develop an understanding of the human being that is driven by a commitment to the politics of disabled people”, write Goodley and Runswick-Cole (2016, p. 2; see also Goodley & Runswick-Cole, 2012; Runswick-Cole & Goodley, 2011). As such, the Dis/human acknowledges many people with disabilities do not have the opportunity to inhabit the ideals espoused by the modernist humanistic subject, but that disability has the potential to “fundamentally destabilise” these ideals, and proffer new ones. Posthumanist disability studies as a theoretical approach is not without its critics (“Toying with the ideas provided by posthumanism may be useful to disability studies, but in our view such ideas should not be adopted without caution”, write Vehmas and Watson (2016, p. 11)). Indeed, Vehmas and Watson’s (2016) contemplation of the place of normativity in disability studies is both instructive and thought-provoking. It calls for the field not to overemphasise the cultural aspects and value of disability at the expense of the material as doing so threatens “misconstruing not just the lives of disabled people but also the crucial ethical issues” (p. 13).

Attempts to “correctly construe” the lives of disabled people come from promising contemporary theorisations by Paterson and Hughes (1999), Shildrick (2009), Titchkosky (2007), and Watermeyer (2013), to name a few, which have engaged with the disabled subject employing phenomenology and psychoanalysis. Goodley (2011b), for instance, offers a contemplation on the value of engaging with the psyche, whilst remaining “accountable to a politicised disability studies” (p. 715). He argues that despite the troublesome history of psychoanalysis in relation to disability (its tendency to pathologise and individualise disability experience), psychoanalytic concepts may offer valuable tools with which to work through disability and disablism (Goodley, 2011b). He contends that such a social psychoanalytic disability studies would

> not [be interested in] disabled people's psyches but with the ways in which: non-disabled people and disablist culture symbolise, characterise, construct, gaze at, project, split off, react, repress and direct images of impairment and disability in ways that subjugate and, at times, terrorise disabled people whilst upholding the precarious autonomy of non-disabled people. (p. 716)

Such a project is entirely compatible with the present work, and the flexibility and curiosity encouraged by Goodley's (2011b) position is one in which I place stock. As such, I draw on some of these ideas in the publications which constitute this dissertation.

Examining the proliferation of theories which characterise contemporary disability studies is well beyond the scope of this dissertation. Still, the contributions made by phenomenological, psychoanalytic, and posthumanist theories of disability are of central importance to inquiry into the lives of people with physical disabilities. This dissertation is not centrally concerned with such inquiry, but, rather, with constructions and representations of different-than-average embodiment.

While social model thinking, and theories of embodiment, are often positioned ideologically in opposition to one another, a likely synthesis between the two is an understanding of the lived experience of physical disability as embodiment which is socially mediated. However, currently, no such theoretical synthesis has been fully realised in relation to one of the most acutely embodied phenomena – sexuality. This project will not seek to reconcile the field of disability studies under one all-encompassing theory, but, rather, proposes that sexuality – as socially mediated and yet intensely embodied as it is – provides an ideal site in which to explore the relative contributions of different ways of thinking about the social and embodied aspects of disabled life.

As the survey component of the present study is focused on external disablism (the external, societal and environmental factors which contribute to the social and sexual disenfranchisement of people with disabilities), the social model is relevant and applicable. The second component of the present study – directly concerned as it is with the lived experiences of people with physical disabilities – will allow a space in which sexuality and representation, and embodiment, can be explored using supplemental theories, contributing to the nuancing of local understandings of impairment, disability, and disablement.

This is a study, however, which is concerned not only with disability, but also with sexuality. Sexuality involves the biological and physical (Master, 1959; Tolman & Diamond, 2001), erotic (Money, 1981), emotional (DeLamater, 1991), and social (Lancaster & Di Leonardo, 1997; Laumann, 1994; Simon, 2017). It is little surprise, then, that numerous fields, disciplines and schools of thought have turned their attention to the study of human sexual sentiment and behaviour. It must be borne in mind, however, that the present work is concerned less with understanding sexuality as a construct, than it is with understanding how individuals make sense of and frame their own sexuality (including gender, sexual activity, and the sexualised body), and the sexuality of others. I am concerned with how sexuality is constructed.

Thus, while theories of sexuality are abundant (I employ and discuss sexual script theory, for instance, in one of my publications below; “Intimacy, intercourse and adjustments: Experiences of sexual life of a group of people with physical disabilities in South Africa”), of most utility in application to this dissertation is general social theory which explains both societal-level attitudes and individual-level ways of seeing (and portraying) social phenomena, including disability and sexuality (social constructionism). This theory goes quite some way in helping to make sense of both facets of the present inquiry (into non-disabled peoples' thinking and feeling about, and constructions of, the sexuality of people with physical disabilities, and of people with physical disabilities' experiences of sexuality). Specific theory concerning human sexuality, then, will be dealt with only as supplementary to broader theories of social life (and disability). Specifically, sexual script theory is used only as supplementary to social constructionism.

1.5.1.1 Social constructionism

The phrase social constructionism has been used to broadly denote any social influence on individual experience (DeLamater & Hyde, 1998). However, as elucidated by Berger and Luckmann (1967), it refers specifically to a theoretical paradigm premised on the idea that reality is a construct. In this form, social constructionism is founded on five ways of thinking about the lived experience of people:

1. human experience of the world is ordered;
2. people perceive the world as an objective reality;
3. language (and arguably other social objects) provide the basis on which we make sense of the world and express our understandings of it;
4. the reality of everyday life is shared; and
5. reality is the product of social interaction; and shared typifications of reality become institutionalised, and circulate via social representations (see section below) (deLamater & Hyde, 1998; Gergen, 1985; Miller, 1997).

Importantly, as flagged by Shakespreare (2014), social constructionist reflections on disability run the risk of "downplay[ing] the reality of impairment" (p. 1), thus they "undermine the lived experience of children and adults who have these conditions" (p. 2). It is not my intention to perpetuate this practice here. Indeed, I fully acknowledge the reality of impairment, and its visceral and lived qualities for people with physical disabilities. However, as employed as a means by which to understand societal constructions of disability, this line of thinking has value.

Indeed, social constructionism contributes a great deal of order to thinking about social phenomena, group behaviour, and culture. However, the reach of the theory extends into the intra-individual, explaining human thinking, feeling and behaviour as the internalisation of culturally-determined meanings and codes for interpreting reality and our own internal world. According to this theory, no internal state can be natural, and is always culturally modified (Armon-Jones, 1986).

In the case of sexuality, which is grounded in biological drives and physiology, the manner and form in which sexual understandings and behaviours emerge is imbued with social meaning, and is socially determined (deLamater & Hyde, 1998). Culture and context define what is, and is not, constitutive of sexuality, defining some behaviours and some relationships as sexual and others as platonic (Foucault, 1979, 1990, 1992; Laws & Schwartz, 1977). In the present work, the benefits of social constructionist analyses are several: the importance placed upon language and social representations illuminates my photovoice and interview data, as well as the linguistic coding of meaning in narrative survey data; equally its capacity to represent and account for shared understandings, and their influence on human attitudes. Finally, given that much of what is at stake in explorations of disability and sexuality has more to do with societal ways of understanding the body, gender, and disability, than purely with sexuality, social constructionism as a general paradigm is sufficiently broad and flexible to account for non-sexuality related findings, and dovetails with much disability theory.

In relation to sexuality, social constructionism has been usefully elaborated by Foucault (1978), Laws and Schwartz (1977), and Simon and Gagnon (1969, 1971). It has also been used as an extremely fruitful paradigm through which to understand gender (Bohan, 1993; de Beauvoir, 1998; Unger, 1989). Social constructionist elaborations of sexuality – and one in particular, sexual script theory – are of particular utility for use in the present work (I discuss this below).

As noted, the second segment of this dissertation, the photovoice project and individual-level inquiry conducted with people with physical disabilities, requires that we look at theory which incorporates not only the social facets of sexuality, gender and embodiment, but also the personal, individual experiences of sexuality. Engagement with the latter in this work is limited, however; my focus on photovoice as methodology, and the role of visuals in claiming and framing identity precluded an in-depth analysis of self-claimed sexuality. Still, I briefly outline one particular theory of sexuality which guided interpretation of the photovoice and interview data in this project.

1.5.1.2 Sexual script theory

I have chosen to use sexual script theory due to its explanatory capacity, but also because it is a progression from social constructionism, and takes into account the role of social forces in shaping individual understandings and experiences of sexuality. Given the focus of the first part of the project (illuminating the social milieu in terms of thinking about disability and sexuality), this seemed more appropriate than taking an individualistic approach to the interview data; given evidence of some of the social forces which may influence disabled people’s framing of their own sexuality, it would not be fitting to ignore these when examining disabled people’s framing of their own sexuality.

Until the early 1970s, psychological thought regarding sexuality was dominated by psychoanalytically-informed work. Such work, whilst yielding important insights, led to a general neglect of the social sources and dimensions of human sexuality (Spanier & Nicholson, 1975). Following the rise of social constructionism in the social sciences, however, social constructionist perspectives on sexuality gained currency. Sexual script theory is perhaps the most prominent social constructionist perspective on sexuality (Simon & Gagnon, 1969, 1971). Simon and Gagnon (1969, p. 71) proposed that sexuality and sexual behaviour amongst humans are social phenomena, determined by an individual's internalisation of prevailing ways of "doing" gendered performances of erotic behaviour (Carpenter, 2010; Gagnon & Simon, 2005; Irvine, 2003; Sakaluk, Todd, Milhausen, Lachowsky, and the Undergraduate Research Group in Sexuality, 2014; Simon & Gagnon, 1986, 2003; Wiederman, 2005).

The basic premise of sexual script theory is that sexual behaviour is socially scripted. Of utility to the present project, is that sexual script theory makes room for scholars of sexuality to think about the contextually and culturally determined ways in which individuals both make sense of, and act out, sexuality. In tandem with contemporary thinking around gendered enactments of sexuality, sexual script theory constitutes an important lens through which to frame any inquiry into human sexuality, albeit an incomplete account of it (Sakaluk, et al., 2014).

Sexual scripts instruct members of a society as to appropriate behaviour and the meanings to attach to certain courting and sexual behaviours. Sexual behaviour and understandings of our own and others' sexuality, according to this theory, derive from internalised scripts – patterned understandings of behaviour which individuals have learned and incorporated during socialisation (Gagnon & Simon, 1987, Simon & Gagnon 1986, 2003). Scripts can be defined as "the mental representations individuals construct and then use to make sense of their experience, including their own and others' behaviour" (Simon & Gagnon, 1984, p. 53). Sexual scripts exist at three distinct levels (Wiederman, 2005):

1. the cultural;

2. the interpersonal; and

3. the intrapsychic.

I discuss each of these, briefly, in turn.

1. Cultural scenarios are contextually and historically determined guidelines which determine expected behaviour and role-taking in the context of courting and sexual interactions (Irvine, 2003; Jones & Hostler, 2001). When internalised, cultural scenarios may also constitute a force through which gendered performances of sexuality are played out (Baumeister & Tice, 2001; Okami & Shackelford, 2002; Oliver & Hyde, 1993). The enactment of private and personal sexual desires is informed by wider patterns of gender relations in a society (Sakaluk et al., 2014).

   Cultural scenarios provide the "backdrop" against which sexual behaviour in a given society at a given time, is played out (Simon & Gagnon, 1986, 1987, 2003; Wiederman, 2015). Cultural scripts do not, however, fully dictate individual behaviour. They influence it to varying degrees (Wiederman, 2015). So, whilst agents of socialisation such as the mass media and cultural and political institutions convey cultural scripts, at the level of the individual, variables (including emotional, biological and psychological factors), filter cultural scripts, and ultimately play a pivotal role in enactments and understandings of sexuality (Gagnon, 1990; Simon, 1996).

2. Between cultural scenarios and individual-level intrapsychic understandings of sexuality, are interpersonal sexual scripts. These outline expected behaviour in interpersonal contact of a romantic or sexual nature, and are rooted in cultural scenarios (Simon & Gagnon, 1986). These constitute the translation of culturally defined boundaries and rules for sexual behaviour, into interpersonal roles and actions (Wiederman, 2015). Interpersonal sexual scripts are codes for behaviour by which sexual behaviour between two or more people is organised (Wiederman, 2015). There is a great deal of fluidity and variation within such organised behaviour, however. This fluidity and variation is due in part to the internal, individual internalisation and experience of scripts by the individual.

3. Intrapsychic sexual scripts are internalised ways of relating to the preceding two levels, and represent the individual's way of enacting romantic and sexual behaviour (Irvine, 2003; Jones & Hostler, 2001). On the individual level, if one is interested in conceptualising human sexual behaviour, intrapsychic scripts may be said to entail specific strategies for carrying out interpersonal scripts, and constitute the culmination of social demands for and individual experiences of, sexuality (Simon & Gagnon, 1986, 1987, 2003; Wiederman, 2015). Broadly, however, sexual script theory holds that these intrapsychic scripts contain filtered versions of cultural scenarios, potentially explaining why so much of individual sexual behaviour and understandings of sexuality conforms to culturally-

determined narrative structures (Puri, 2002; Kirkman, Rosenthal, & Smith, 1998; Seal & Ehrhardt, 2003).

Each of these levels is of utility for thinking through conceptions and performances of sexuality explored in this dissertation, and will be drawn on in supplement to other social constructionist work in the course of this dissertation. Although it could be argued that the idea of “scripts” is very limiting (in that it encourages one to think about sexuality in terms of a number of socialisation-dependent choices for sexual performance), my reading of sexual script theory is quite the opposite. I find that it makes room for thinking about individualised responses to social forces in the performance of sexuality, and encourages a multi-level analysis of sexual behaviour and sexuality.

At each level, there may be room for the inclusion of other theories or perspectives (for instance, in relation to intrapsychic scripts, we may want to think about social interactionism as an explanatory framework in relation to internalised ideas about the self as a sexual object). Certainly, were this dissertation to be concerned with an individual-level exploration of understandings of sexuality, phenomenology (Hughes & Paterson, 1997; Kattari, 2014; Pierre, 2015), or queer theory (Hirschmann, 2013; Kulick & Rydström, 2015; McRuer, 2006; Sherry, 2004), to name but two paradigms, might have been appropriate. However, given the above-discussed foci of the present work, sexual script theory was a logical fit.

1.6 Operational Definitions

1.6.1 Physical disability

In discussing “physical disability”, I adopt, most broadly, the operational definition of the United Kingdom’s National Equality Act (Government of United Kingdom, 2010); “a physical impairment that has a substantial and long term adverse effect on the person's ability to perform normal day to day activities e.g., walking, eating, going shopping" (p. 4). This definition was employed in the survey segment of the present project, to guide respondents' conceptualisation of physical disability, as well as in my recruitment of participants for the photovoice work.

This operational definition is also aligned with what Vehmas and Mäkelä (2008) term a realist ontology of impairment, in which disability is conceived of as part social, and in part not, in origin; "as much as bodies and impairments are biological entities, they are also cultural and social entities" (p. 93). Despite the fact that I take a social constructionist view in much of the present work, my interest in constructionism is in how an object which "exist[s] prior to language" is given different meanings when articulated, defined and represented.

Despite the necessity of such an operational definition, there is also a need to consider, briefly, about two broader ways of thinking about physical disability, both of which underlie this dissertation. Firstly, consistent with the social model of disability, I align myself with the distinction between disability and impairment (Hahn, 1988; Shakespeare, 2006; Thomas, 2004). Impairment is a form of biological or physical difference, defined medically. Disability, on the other hand, are the social sequelae of inhabiting a world "designed" for people without impairments, when one has an impairment (the functional limitations one encounters when navigating a disabling social and physical environment) (Hahn, 1988). As Sherry (2007) notes, "the rationale for this heuristic distinction is to separate the experience of biological difference from the prejudice, discrimination and other negative social consequences that many disabled people experience" (p. 10).

Like Sherry (2007), I also see the need to recognise disability as an identity. To acknowledge that people with physical disabilities may identify as members of a heterogeneous group, who have certain experiences, both social and physical in common, is important in the present work. This draws attention to the social and personal dimensions of physical disability, which may be felt by people with physical disabilities, over and above experiences engendered by the interaction of their impairment with the broader social world.

Both definitions are important, not only given the ascendency of identity politics within disability studies and the disability rights movement (Riddell & Watson, 2014; Shakespeare, 1996), but also because the present inquiry is concerned not only with the social context and experience of disability, but also with the manner in which disability intersects with other facets of identity (for instance gender), and how that intersection is understood and presented. Adopting two definitions of disability may seem cumbersome, and confusing, but it is important given the rise of identity politics associated with the disability movement, and the above-mentioned limitations of employing Social Model-based understanding of disability alone.

1.6.2 Sexuality

Sexuality refers, most broadly, to the quality of being sexual. As noted, it encompasses biological, erotic, emotional, and social feelings, behaviours and the manner in which people make sense of these. Sexuality, like many broad terms, is variously defined, its meaning depending greatly on the context in which it is used. Because it is a broad term, which has varied over time, it lacks a precise definition. In the present enquiry, I define sexuality according to the definition of Trieschmann (1988), as critiqued and supplemented by recent conceptualisations of sexuality informed by a rights perspective.

Trieschmann (1988) defines sexuality as:

> the expression of a sex drive, through sex acts, within the context of the personal identity of the individual: the maleness and femaleness of the individual that is so

> heavily influenced by past cultural learning, one's self-image, and the expectations that others have of the person. (p. 159)

This is of utility, as it makes central the importance of the person-environment interaction in sexuality (which dovetails with the theoretical framework outlined above). Further, it takes into account the role of culture, others, and self-image in determining – both in nature and expression – an individuals' sexuality. This, we shall see, is of particular relevance to the sexuality of people with physical disabilities, whose sexual development and sexual expression is often greatly influenced (and, perhaps, curtailed) by their social environment, and the internalisation of the constraints which it places on their sexuality. This is, of course, in line with the social model of disability.

However, Trieschmann's (1988) definition of sexuality does give primacy to sex acts, and so is usefully buttressed by the World Health Organization's (WHO, 2006) broader, and more inclusive, definition of sexuality. The World Health Organization defines sexuality as:

> a central aspect of being human throughout life and encompasses gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction … influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors. (WHO, 2006, p. 5)

This definition places less emphasis on heteronormative performances of gender and sexuality through sex acts, instead emphasising the numerous intersecting factors which influence an individual's conception of themselves as sexual beings, and their behaviour in relation to sexual thinking and feeling.

In a similar vein, the WHO's (2006) definition of sexual health (rather than sexuality), yields a necessary rights-based nuance to the above definitions. It defines sexual health as:

> … a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. (WHO, 2006, p. 5)

This, importantly, directs some of the attention, when thinking about sex, sexuality, and sexual health and expression, away from sexual acts, and instead takes into account the ways in which an oppressive gendered or sexual climate (in this project, towards people with physical disabilities) might impact sexual health. This positive definition (that is, sexual health is not defined in terms of an absence of illness) also highlights the need for critical reflection on the various subtle ways in which individuals' sexuality, sexual health and sexual development and expression, might be constrained. This is pertinent to the present inquiry, with its focus on how social forces – primarily, the negative attitudes of others – might have a deleterious impact upon the sexuality and sexual health of people with physical disabilities.[6]

1.6.3 Attitudes

At its most broadly-defined in the behavioural literature, led by the work of Ajzen (2001), an attitude represents an evaluation of an object. This "summary evaluation" (Ajzen, 2001, p. 28) falls along a number of possible continua, from, for instance, positive to negative, interesting to boring, nice to not-so-nice (Ajzen, 2001; Ajzen & Fishbein, 2000).

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[6] The WHO definition of sexual health may be problematic in that it conflates sexual expression or behaviour, with health. This makes certain forms of sexual expression and behaviour an aspect of health, as opposed to an aspect of health *and/or* an aspect of identity. By situating sexuality as a facet of health, which is surveilled (Foucault, 1977, 1978), this definition may run the risk of implicitly pathologising asexuality (or a lack of sexual behaviour) as self-claimed identity.

In the present study, however, the prediction of behaviour is not a goal. Neither is it the case that individuals necessarily evaluate the sexuality of people with physical disabilities. Instead, from a social representational perspective (under the umbrella of which much of the literature reviewed in the following section, and a substantial portion of work within disability studies as a whole, falls), attitudes both reflect, and construct, societal thinking and feeling about an attitude object. People may not act in accordance with the attitude, and they may not be evaluating people with physical disabilities per se. Instead, what is at stake in attitudes towards the sexuality of people with physical disabilities, is the maintenance – discursively – of a certain way of thinking about sexuality, bodies, and normativity.

Whether we ascribe to the theoretical work about attitudes towards people with physical disabilities (which posits that they are part of a broader process of sustaining dominant discourses about different bodies), or the work of Ajzen (which posits that they are evaluative beliefs associated with various attributes of people with physical disabilities which guide behaviour towards people with physical disabilities), there is reason to believe that – in their quality (positive or negative or neutral) and content – attitudes towards the sexuality of people with physical disabilities are problematic. This has real-life consequences for people with physical disabilities, including in – but by no means limited to –their social and romantic lives, and access to sexual health care.

However, for purpose of measurement, to conceptualise an attitude as a lasting cognitive and affective predisposition to respond along a positive or negative dimension toward an attitude object, is parsimonious (Arnautovska & Grad, 2010; Kodaka, Poštuvan, Inagaki, & Yamada, 2010). Broadly, this tendency to respond to something along continua, for instance, from approval to disapproval and approach to avoidance, cannot be directly observed, but, rather, can be inferred from an individual’s given responses to an attitude, object, or referent, and is possible to measure by means of scaling questions and continua of response options (Alwin & Krosnick, 1991). However, as noted, in the present study, I am not centrally concerned with the manner in which these attitudes arise, and – due to the cross-sectional nature of the study – am not in a position to address this. Further, unlike the theoretical work about attitudes towards people with physical disabilities (which posits that these attitudes are part of a broader process of sustaining dominant discourses about different bodies), and the work of Ajzen (which posits that they are evaluative beliefs associated with various attributes of people with physical disabilities which guide behaviour towards people with physical disabilities), I am less concerned with the *purpose* of attitudes, than I am with their *quality* and *content*. Thus, a simple, pared-down definition of attitude as a lasting cognitive and affective predisposition to respond along a positive or negative dimension toward the sexuality of people with physical disabilities, and which forms the basis of a person's social construction of the world in which he/she lives, will be subscribed to in the present study.

1.6.4 Social representations

Social representations are societal stocks of shared values, ideas, metaphors, beliefs, and practices through which groups and communities make meaning of the social world. Described as the collective elaboration "of a social object by the community for the purpose of behaving and communicating" (Moscovici, 1963, p. 251), social representations guide behaviour towards, and thinking about, social objects. The given meaning which a social object (for instance, physical disability) is imbued with within a given society, has implications for how that social object is expected to behave, attributes it is expected to have, and which possibilities for engagement with it are appropriate and desired, and which are not.

Social representations guide behaviour towards and thinking about social objects (Moscovici, 1963).

In his defence of diagnosis, Shakespeare (2014) argues against the constructionist assumption that labels necessarily cause stigma. Shakespeare quotes Reinders (2008), who wrote that “Negative connotations do not reside in words but in the mind. Negative connotations are attached to words because of how people think about disability; thus, without changing their habits of thinking, people will use new words just as they used the old ones” (p. 46), and argues that labels in and of themselves do not create negative meanings. Similarly, social representations do not necessarily create negative attitudes towards their signifier; perhaps they reflect them, or sustain them, or underlie them, or a combination of all three. It is not the thesis of this dissertation that social representations are causal (they do not lead to the sentiments of individuals); rather, it is my intention to reflect on them as points in the chain between societal and individual ways of conceiving of and reacting to the sexuality of people with physical difference.

In the present work, social representations constitute the background to the inquiry in the first segment of the project – how do non-disabled people “represent” people with physical disabilities in their mind’s eye and in discourse, and how does this play out in the survey responses. Further, in the second segment of this project, I explore how these social representations perpetuate, and are perpetuated by, visual representations (in the media and art), of physical disability. In the first instance, I am interested in how attitudes towards the sexuality of people with physical disabilities belie the social representations which undergird them – how non-disabled people’s ways of viewing physical disability and sexuality tell us something about how people with physical disabilities are represented in the popular imagining. In the second instance, I consider how the visual representation of physical difference is mirrored in social representations concerning physical disability, and how both act in synchrony to perpetuate myths and stereotypes concerning the sexuality, gender, and bodies of people with physical disabilities, which either pathologise or negate them.

As noted, social representations (and social representation theory – the conceptual framework concerned with making sense of these “images”) overlap usefully with social constructionism. As such, this way of conceiving of societal conceptualisations of others, is of utility in the present work.

1.6.5 Photovoice

Photovoice is a participatory action research method which uses photography as a means by which to gather data about a given topic with a group of research participants (hereafter, co-researchers) (Wang & Burris, 1997). During the course of a given research project, photovoice co-researchers use their cameras to record aspects of their daily lives relevant to the research question. During reflective sessions, led by the principle investigators, the co-researchers may use their photographs as a springboard from which to discuss and reflect on their experiences (Lal, Jarus, & Suto, 2012). This method of research allows not only for co-researchers to create, and share, their own visualised realities, but involves research “subjects” in the process of photography (Lykes, 1997; Wang, 2003).

Photovoice puts co-researchers in charge of the representation of their own circumstances, and prompts them to “act as recorders and potential catalysts for change in their own communities” (Wang & Burris, 1997, p. 369).

Photovoice allows for the generation of knowledge which is closely centred on the experiences of individuals and their interactions with the environment (Letts, 2003). Given the above-outlined importance of thinking about the environment when thinking about disability, this feature of the methodology was particularly appealing. Taking photographs is an activity which allows the creator to look both inward (thinking about what image they want to capture and what it will mean) and outward (being inspired by the environment to think about experience). In a project which is concerned with the interaction between inner and outer forces in determining lived experience, we selected photovoice as an appropriate methodology for exploring the experiences of sexuality of a group of people with physical disabilities.

A distinction must be drawn here between photovoice as defined and outlined by Wang and Burris (1997), and photovoice-type methods, such as those employed in the present project. Wang and Burris (1997) developed photovoice as a replicable, clearly-defined, participatory action research tool. According to these authors, proper photovoice work entails several steps (for a clear summary, see Wang & Burris, 1997). These include:

1. Researchers partner with key stakeholders to identify issues of concern related to a particular community, and research questions are defined.
2. Participants are recruited to participate in two to six group meetings:
    a. During the first meeting(s), participants are engaged in a discussion related to the topic of interest and potential research questions.
    b. Participants are trained in basic photography techniques and ethical issues around photography.
3. Participants are then given cameras and directions to take pictures based on the research topic.
4. Group meetings are held at pre-defined junctures, during which participants select photographs to discuss with the group. Facilitators are present at these meetings, and function to spur dialogue around the photographs.
5. Upon completion of the project, selected photographs with accompanying captions are presented to the wider community, including stakeholder groups of interest (Wang & Burris, 1997).

However, prior to, and since, the work of these researchers, other photovoice-type research methodologies have been developed and employed across a number of contexts (Clark, 1999; Hagedorn, 1994; Moletsane et al., 2007; Zecevic, Magalhaes, Madady, Haylligan, & Reeves, 2010). These projects have in common the use of participant photography as a means of generating data. Yet, they vary greatly in their fidelity to the methodology outlined by Wang and Burris (1997). These deviations are often motivated either by constraints of the practical context (i.e., not having regular contact with the research team when transport costs are prohibitive), or ethical concerns in a given population (i.e., not using group work where there are privacy concerns).

The methods employed in the present project will be outlined in due course (see individual publications). However, it is worth noting that this work employed self-generated photographs, taken by 13 participants with physical disabilities, in the course of the project, as stimuli for discussion around their experiences of sexuality, including gender, access to sexual and reproductive health services, relationships, and sexual activity. Participants were not trained in photographic techniques, other than the basics of using a camera, and met with researchers individually for one, or two, interviews following five months during which they could take photographs. Central to the use of these photographs in the present project was: (a) their utility as a segue into a broader discussion of sexuality, and (b) their value as creative objects, the meaning of which was determined by the creator (who was also often the subject).

CHAPTER TWO

Literature Review

2.1 Preface

Literature relevant to the present work falls into two parts: the first concerns the physical, psychological, and social forces which shape and sustain non-disabled peoples' thinking and feeling about, and representations of, physical disability and sexuality; the second concerns the experiences of sexuality of people with physical disabilities.

Regarding the first, Literature Review Part I (section 2.2), shows that, generally, social and visual representations of people with physical disabilities rely on stereotypes and tropes which position people with different-than-average embodiment as unsuitable sexual subjects. The first goal of the first literature review is to unify past empirical work and representational theory pertinent to thinking about attitudes towards, and representations of, disability and sexuality, to inform my interpretation of the study data. This constitutes the etic aspects of disability and sexuality. Not all of the complex theory will be employed beyond this point. However, such theorising is worth outlining to some extent here as additive, if not fundamental, to the reader's engagement with the rest of this dissertation (including the photovoice project).

The second review, Literature Review Part II (section 2.3), is concerned with work examining people with disabilities' experiences of sexuality. I attempt an integration of theory, with insights afforded by a small but growing body of work (including that conducted in the Global South) concerning the experiences of sexuality of people with physical disabilities. This review, which comprises the second part of this chapter, then, deals with the emic aspects of disability and sexuality.[7]

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[7] The literature included in both reviews was collected iteratively over the course of the period November 2015 – December 2017. I searched for English language peer-reviewed journal articles containing a combination of search terms pertaining to disability (e.g., disab*, physical disab*, handicap*, bifida*, sclerosis*), sexuality (e.g., gender*, sex*), attitudes (e.g., stigma*, social distance*), representations (e.g., social representation*,

2.2 Literature Review Part I

In this first review, I begin by illustrating the pervasiveness of desexualising social and visual representations of, and negative attitudes towards, the sexuality of people with physical disabilities. This is proposed by theoretical work, and evidenced by empirical work, examining popular culture and societal attitudes.

I examine the social forces which might sustain or even shape these attitudes. I argue that, in the case of physical disability, one particular bearer of social meaning, visual representations, mirror in important ways problematic societal conceptions of the sexuality of people with physical disabilities. I argue that social representations of the sexuality, bodies and gender of people with physical disabilities find a corollary in the manner in which disability is portrayed visually.

2.2.1 Asexuality and disability

When sexuality is associated with physical disabilities, an unfavourable light is often cast on people with physical disabilities, their partners, and their capacity to be sexual beings (either cognitively or physically) (de Loach, 1994; Garland-Thomson, 1997, 2017; Gerschick, 2016; Gill, 1996; Juergens & Miller-Smedema, 2009; Juergens, Miller-Smedema, & Berven, 2009; Sakellariou, 2006).

Societal thinking and sentiment about the sexuality of people with physical disabilities, however, is more complicated than mere ignorance on the part of non-disabled people regarding the capacities of people with physical disabilities to engage in sex. Briefly,

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representation*), photovoice (photovoice*, photography*), and low- and middle-income countries (e.g., Global South*, low-resource*, developing countries*) within several scientific databases including GoogleScholar, EBSCOhost and PubMed. I sorted all emerging articles by topic. When the content and focus of the present literature reviews became clear, I supplemented the literature, where necessary, with further searches using specific, emergent foci (e.g., *stereotypes).

this is because, according to societal norms, sex is for "normal" bodies, and the bodies of people with physical disabilities do not conform to a prescriptive definition of "normal" (Campbell, 2009; McRuer, 2011). Therefore, they are assumed to be asexual.

According to Juergens et al. (2009), this assumption is the product of the three following beliefs: (a) that sex is not a priority for persons with disabilities or that they lack sexual functioning (Kaufman, Silverberg, & Odette, 2007); (b) that people with disabilities have limited opportunities for sexual gratification and so will learn not to desire sex (Milligan & Neufeldt, 2001); and (c) that persons without disabilities infantilise people with disabilities and therefore perceive them to be asexual (Kaufman et al., 2007).

Extending the third of these ideas, Kim (2011) argues that the tenacity with which the image of the asexual person with a physical disability endures is a product of the fact that "asexuality [amongst individuals with disabilities] is not only an *assumption* but also a moral *imperative*: disabled people *ought* [sic] be asexual" (p. 482). That is, society takes the disabled body as a "sign" which negates sexuality (Sandahl, 2003). On perceiving this sign, a process of desexualisation is begun, one which renders it impossible to see a body with an impairment as a sexual body. "Desexualisation is a process that separates sexuality from disabled bodies", writes Kim (2011), "making it irrelevant to and incompatible with them because disabled people are supposedly undesirable in society and because disability is believed to lead to sexual incapacity" (p. 483).

The logical corollary of this process, equally problematic, is that it implies that there is something wrong (hypersexual or deviant) about people with physical disabilities who have sexual desires (Addlakha, Price, & Heidari, 2017), as any sexual desire on the part of people who are perceived to be normatively sexual may be interpreted as excessive. The process of desexualisation employs tropes of fear of disability "reproduction and contamination" to create distance between sexuality and people with disabilities (Kim, 2011, p. 483). Societal fear regarding the “abnormal” sexuality of persons whose bodies are not typical underlies the imperative to desexualise people with physical disabilities, for fear that their sexuality – if it were to be acknowledged – would be somehow monstrous and uncomfortably different. The sexuality of people with physical disabilities cannot be normal, this logic dictates: they should, therefore, be asexual. As a consequence of this societal assumption (or imperative), any sexual feelings on their part are automatically excessive. As Kafer (2003a) argues, “the sexuality of people with disabilities is understood as always already deviant” (p. 82).

The literature concerning the attitudes of non-disabled persons to the sexuality of people with physical disabilities, however, is most often concerned with the “myth of asexuality” (Cuthbert, 2017; Lund & Johnson, 2015; Lee & Lee-Ann, 2016; Peta, McKenzie, Kathard, & Africa, 2016). Commonly, people with physical disabilities are taken to be asexual, and are denied sexual potential, desire or potency in popular consciousness (Milligan & Neufeldt, 2001; Shakespeare, 1996).

Beginning in the 1980s, however, disability studies scholars began to challenge the pervasive perception that people with physical disabilities are asexual, and that their sexuality and that of those involved with them can only be deviant. Scholars in the field argued that asexuality is not an inevitable by-product of living with a disability, and that individuals with disabilities often lay claim to an active sexuality, and that this claim is a right, and not an act of deviancy (Addlakha et al., 2017; Fine & Asch, 1985; Hahn, 1981; Shuttleworth & Mona, 2002).

But, despite scholarly and activist efforts to reject asexuality amongst people with physical disabilities as a myth, the literature concerning disability and sexuality seems premised on the fact that the perception of the asexual person with a physical disability prevails amongst the non-disabled (Anderson & Kitchin, 2000; Hanass-Hancock, 2009;

Mavuso & Maharaj, 2015; Mckenzie, 2013; Milligan & Neufeldt, 2001; Vilchinsky, Werner, & Findler, 2010).

To this day, much of the literature concerning disability and sexuality states that it is popularly thought that people with physical disabilities are lacking in biological sex drive, are unable to engage in sexual activity, or are lacking the requisite judgement to engage in sexual activity (Lee & Lee-Ann, 2016; Lund & Johnson, 2015; Peta et al., 2016). This conception of the physically disabled person as asexual, pervades the imaginations, and influences the attitudes, of the individual members of societies.

As such, it would be, and is, understandable that people with physical disabilities may find it difficult to lead sexual lives. Kim (2011) notes that, as disabled adults are "desexualized and infantilized, their orientation – sexual or asexual – is rendered irrelevant", so their distance from sexuality and "normal" adult society is increased (p. 483). As noted in the introduction to this project, then, sexuality and disability are positioned biologically, mentally, discursively, and socially opposite to one another.

Kafer (2003a) argues that this rigid process by which society desexualises persons with disabilities actually serves to reveal that disabled people are not always simply taken to be asexual: rather, they are produced as such. *Asexuality* is deemed to be a natural and appropriate consequence of having a disability. The *image of people with physical disabilities as asexual*, though, is also the result of an unremitting process of desexualisation that is applied and maintained by society.

Regardless of whether one sees the process of desexualisation as an assumption or a moral imperative, the resultant myth of asexuality amongst people with physical disabilities has been evidenced by a small but growing body of research which has examined the nature and contents of non-disabled persons' attitudes towards and conceptions of the sexuality of people with physical disabilities (Ahumza, Matovu, Ddamulira, & Muhanguzi, 2014; Esmail et al., 2010; Milligan & Neufeldt, 2001; Valvano et al., 2014).

However, before discussing the attitudinal research, it is worth examining the nature of social representations and stereotypes regarding the sexuality of people with physical disabilities, as it is in part from these social forces that the process of desexualisation stems, and that the attitudes in question are thought to spawn. It is also against these forces that people with physical disabilities' experiences of themselves as sexual beings is chiselled.

It must be borne in mind, though, that these theoretical arguments concerning the societal desexualisation of people with physical disabilities are not my primary foci. Instead, they are a necessary theoretical backdrop – a way of looking at what has been said in nuanced and often complicated ways – about attitudes towards, and experiences of, sexuality and physical disability. They are the backdrop against which questions as simple as the ones posed by this dissertation must be asked: How do some South Africans think and feel about the sexuality of people with physical disabilities, and how do some South African people with physical disabilities think and feel about, and represent, their own sexuality, given or in spite of much complex theoretical thought on the subject?

2.2.1.1 The societal milieu

2.2.1.1.1 Social representations, stereotypes, images, and attitudes

Scholars have long examined and deconstructed the ways in which the marginal position of disabled people in society is sustained and reproduced by non-disabled persons (Anderson & Kitchin, 2000; Deal, 2007; Goodley, 2014; Goodley & Runswick-Cole, 2011; Miller, Parker, & Gillinson, 2004; Watermeyer, 2012). Much psychological research in the field of disability studies has seen attitudes towards persons with disabilities in terms of stigma attached to bodily or functional difference (Goffman, 1963; Hahn, 1981). These intertwined attitudinal and stigma constructs involve an evaluation of the person with a disability by the non-disabled individual, and suggest that prejudice towards persons with disabilities involves an affective or emotional response (Bargh, 1999). Indeed, much of the research reviewed in the section on attitudes below has conceptualised, and found evidence for, prejudice as a reaction to a particular trait (such as wheelchair use).

There is a body of research, however, which strives to examine disability as a group categorisation, the marginalisation of which is sustained through a set of broader societal ideologies, discourses and social representations which position persons with disabilities as other to, and less than, non-disabled persons (Anderson & Kitchin, 2000; Coleman, Brunell, & Haugen, 2015; Kimble, 2015; Thomson, 2017). This work has focused on social representations and stereotypes as the vehicles of this process.

Although an incomplete account of the experiences of people with physical disabilities, the social model of disability does highlight that much responsibility for the denigration of disability belongs on the doorstep of society. A focus on the broader social processes which might contribute to individually held negative attitudes, thinking and feeling about disability and sexuality (by non-disabled people and people with physical disabilities alike), then, is perhaps more instructive than a consideration of the intrinsic determinants of prejudice.

2.2.1.1.2 Social representations

Social representations of physical difference guide behaviour towards, and thinking about, people with physical disabilities. The given meanings which ability, the body, and physical disability are imbued with within a given society, has implications for how people with physical disabilities are expected to behave, attributes they are expected to have, and which possibilities for engagement with people with physical disabilities are appropriate and desired, and which are not.

Stereotypes, visual representations, and other modes of cultural diffusion, all share certain characteristics with social representations, predominantly, that they both reflect and sustain thinking about and behaviour towards social objects. In the present section, I examine work which has traced and theorised social representations concerning disability, particularly physical disability, and argue that these pathologise or negate the sexuality of people with physical disabilities.

Milligan and Neufeldt (2001) found that media representations were a key source of evidence for the myth of asexuality amongst people with physical disabilities. Due to the ubiquity of media in the everyday lives of most people, they have a resounding influence over the perpetuation of social representations (Adams, 2000; Couldry, 2012; Milligan & Neufeldt, 2001). There is, and always has been, a debate over the precise role of the media in relation to dominant ideology – whether it forms, directs, or reflects it (Curran, 2010; O’Shaughnessy & Stadler, 2012). However, Milligan and Neufeldt (2001) contend that when able-bodied people lack personal experience of individuals with disabilities, the former “have little basis from which to discern the representational validity of the media images they consume” (p. 96). As such, the role of the media in perpetuating social representations and stereotypes of people with physical disabilities as lacking sexuality, authors such as Esmail et al. (2010), Norden (1994), and Tepper (2000), have noted, is substantial.

These representations are the product of a process of binary opposition which constructs disabled identity in terms of deviancy from an able-bodied “norm”. Milligan and Neufeldt (2001) write that negative representations of disability “are so durable, pervasive and repetitious that they have come to represent unexamined truisms within our culture, despite their scant resemblance to actual persons with disabilities" (p. 94). These portrayals depict men and women with disabilities as axiomatically prohibited from sexual life.

Equally, social representations of, and stereotypes about, normative sexuality exclude people with physical disabilities. Esmail et al. (2010), for instance, have found that members of the public as well as service providers used concepts of "naturalness" to describe sexuality, and that such narrow descriptions of sexuality (in heteronormative, genital terms) excluded people with physical disabilities. As one of the service providers in this study noted: "People have a really specific perspective of what being sexual means and it would be challenging for a lot of people to expand that to include people with physical disabilities" (Esmail et al, 2010, p. 38). This idea of sexuality based on physical performance and ability is exclusionary (Shakespeare, 2000), constructing the sexuality of people with physical disabilities as the opposite of able-bodied sexuality.

Ideologies about sex and ability, then, legitimate material and discursive discriminatory practices, such as the exclusion of people with physical disabilities from sexual life. These dynamics are perpetuated through the circulation of inaccurate and harmful stereotypes and visual representations of people with physical disabilities which typify them as asexual. These, in turn, sustain unfavourable societal representations of people with physical disabilities which suffuse the imaginings of the individuals within a society, limiting the possibilities for thinking about disability and sexuality about which non-disabled people are aware.

In turn, these societal representations are reflected and contained in, and sustained by, a trove of stereotypes which characterise persons with disabilities as abnormal, child-like, unattractive, dependent and helpless, a danger to themselves, pitiful, and asexual (Anderson & Kitchin, 2000; Coleman et al., 2015; Kimble, 2015; Thomson, 2017).

2.2.1.1.3 Stereotypes

There is a body of research and theory which strives to examine disability as a group categorisation based on coherent and homogenising stereotypical representations applied consistently to people with physical disabilities by the non-disabled majority.

This work – the study of disability as a social construct – began in the 1940s at the Kurt Lewin School of Social Psychology (Asch & McCarthy, 2003). Theorists aimed to move beyond person-based explanations of disability to uncover the broader stereotyping processes which result in an individual being categorised as disabled (Asch & McCarthy, 2003). These processes can be seen to parallel (and either reflect or underlie) the attitudes towards the sexuality of people with physical disabilities with which the present inquiry is concerned.

A stereotype constitutes a set of qualities that a group of people are perceived to share based on their membership of a social category (Ashmore & Del Boca, 1981). One can recall the description of social representations above and easily note the overlap between the concepts (Ashmore & Del Boca, 1981). Stereotypes are *types of representations* used as a social heuristic to define groups in ways that distinguish them from others (even if this distinction is based on a process of binary opposition) (McCauley & Stitt, 1978).

Researchers have attempted to understand stereotyping in relation to persons with disabilities by establishing whether disabled people are viewed in consistent ways (Nario-Redmond, 2010). This research is based on the premise that, while most people hold a unique set of personal beliefs and frame of reference for understanding social groups, these views and beliefs are often influenced by socialisation and so reflect broader cultural stereotypes. Thus, consistency amongst individual views and beliefs reveals the nature of cultural stereotypes (Schneider, 2005). What studies in this area have all revealed, is that some such stereotypes do exist (Braathen & Ingstad, 2006; Coleman et al., 2015; Fiske, Cuddy, Glick, & Xu, 2002; Hanass-Hancock, 2009; Kvam & Braathen, 2008).

In relation to disability and sexuality specifically, Nario-Redmond (2010) elicited students' stereotypes regarding men and women with disabilities, and contrasted them with stereotypes regarding non-disabled men and women. Only non-disabled women and men were stereotyped along traditional gender lines, whereas persons with disabilities were characterised as asexual and unattractive (Nario-Redmond, 2010). Traditional male and female gender stereotypes were found only for non-disabled targets, and the stereotypes of male and female targets with disabilities were characterised as more similar to one another, and, overall, as less gendered. Further, men and women with disabilities were seen as uniformly dependent, incompetent, and asexual (Nario-Redmond, 2010). This buttresses the point, made earlier, that common myths relating to people with physical disabilities are constructed in opposition to the traditional gender characteristics of a group (Schlesinger, 1996; Tilley, 1996).

In a study by Crawford and Ostrove (2008), women with physical disabilities noted a variety of negative stereotypes about their disabilities which they had encountered. These included beliefs that people with physical disabilities are "universally intellectually challenged", asexual, and helpless, and incompetent (Crawford & Ostrove, 2003, p. 186).

Nhuyen, Liamputtong, and Monfries (2016) noted that stereotypes about physical disability resulted in a lack of knowledge about reproductive health of people with physical disabilities, and that people with physical disabilities, especially women, faced stigmatising stereotypes which portrayed them as asexual, degendered, unattractive, and unsuitable for motherhood.

In the KwaZulu-Natal province of South Africa, Hanass-Hancock (2009) found that disability and gender were both associated with stereotypes which made people with disabilities vulnerable to HIV/AIDS, particularly women. People with disabilities were characterised as lacking sexuality, virgins, sexually overactive, cursed, dirty or clean.[8] Each of these stereotypes contributed to their vulnerability to sexual abuse and, subsequently, HIV/AIDS in this context (Hanass-Hancock, 2009).

The above work has important implications for considering how non-disabled people may think and feel about the sexuality of people with physical disabilities. As Sechrist and Stangor (2001) note, identifying the contents of societal stereotypes is important as this content is what influences when and how the stereotypes are used, which in turn has far-reaching consequences for those who are stereotyped. Amongst these consequences is the fact that an able-bodied individual's awareness of societal stereotypes, learned through socialisation, can influence their reactions to people with physical disabilities in stereotype-congruent ways (Bargh, 1999). It is thus important to be cognisant of the presence of such underlying images, as their presence affects individuals' behaviour.

Stereotypical representations of people with physical disabilities as asexual can influence the perceptions, judgements and expectations of non-disabled people even amongst non-disabled participants who discredit the veracity of the stereotypes themselves (Wood & Nario-Redmond, 2009, cited in Nario-Redmond, 2010). For instance, as Nario-Redmond (2009) explains, non-disabled people who do not actively express the assumption that women with physical disabilities are not sexually active, might still be surprised to discover that a woman with a physical disability has a child. Women amongst Crawford and Ostrove's participants (2008) noted that the condescension and pity which they encountered from non-disabled persons felt attributable to negative social constructions of people with physical disabilities.

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[8] As expressed in this research, people with disabilities were seen by others as epitomising one of two equally problematic poles; being seen as either virginal and "clean", or fundamentally flawed and "dirty". In either case, people with disabilities were made vulnerable to sexual abuse and/or being disqualified entirely as sexual beings.

What I hope has become apparent from the discussion thus far is that people with physical disabilities have been very widely argued to be subject to a rigid and relatively unremitting process of desexualisation by society at large. This desexualisation, the literature suggests, is sustained by social representations which position disability as antithetical to sexuality, and stereotypes which characterise people with physical disabilities as infantile, dependent and “de-gendered”. These forces are proposed to constitute the social backdrop against which non-disabled persons’ individual-level thinking and feeling about, and mental representations of, the sexuality of people with physical disabilities develop, are shaped, held, and sustained.

However, although noted in the introduction to this dissertation, it is worth reiterating here that evidence of societal attitudes and misrepresentations of disability and sexuality drawn from research conducted amongst non-disabled people, is lacking, in the Global South in particular (Carew et al., 2017). Thus, it is hard to establish the “real” nature of the social backdrop against which sexual development has occurred, when conducting research with people with physical disabilities. Doing both in tandem – researching the attitudinal milieu as well as individuals with physical disabilities’ experiences, regarding disability and sexuality – in the Global South, is one of the primary contributions of this work.

2.2.1.1.4 Visual representations

The argument which I lay out here provides one way of understanding the perpetuation of both social representations and stereotypes, and the societal conceptions of physical disability and sexuality which they contain. Briefly, I contend that visual representations of different-than-average embodiment parallel the pathologising of the sexuality of those represented. The tropes employed to represent physical disability in the visual arts, media, and film are problematic, and often foreclose on viewers’ seeing of those represented as sexual subjects (or, more rarely, over sexualises them). These tropes reflect and sustain societal thinking about and mental representations of, disability and difference.

Over the years, people with physical disabilities have been portrayed and displayed in different, but almost uniformly problematic, ways. The present discussion will focus on a few of these ways of representing those with different bodies, honing in on how such representations incorporate and signify sexuality. While many of the ways of representing people with physical disability explored here are not directly concerned with the sexuality of the subject (the people with physical disabilities), each has implications for our "thinking it": specifically, many of these modes of representation foreclose on our thinking about people with physical disabilities as agentic sexual beings, and instead invite types of looking and ways of thinking which axiomatically prohibit different bodies from normative sexuality. When these representations do make room for sexuality on the part of people with physical disabilities, more often than not that sexuality is framed as curious, abnormal or even perverse. The following discussion elaborates certain ways of representing people with physical disabilities, and the implications which these have for the ways in which people with physical disabilities can be, and are seen, sexually.

2.2.1.1.4.1 Concealment and looking away

The primary way of representing people with physical disabilities visually is not so much a way of representing people with physical disabilities visually as it is the lack of doing so. In fact, our visual landscape is vastly lacking in difference, except when that difference is presented as novelty or visual fetish. In popular representations – in movies, theatre, magazines and more – people with physical disabilities are often absent.

The absence of disabled people in cultural images conspires to present a narrow perspective of the existence of disability in history, writes Delin (2002), while Dorn (1994) argues that disabled people have historically been set aside from the public sphere. Ironically, the very absence of disability imagery is what determines that we will negate it when we are confronted with it (Garland-Thomson, 2009). People with physical disabilities, or their impairments, are so often concealed that when we encounter disability and bodily difference, our reaction may in fact be to look away (Garland-Thomson, 2009).

Concealment, or absence, then, has implications for reacting to disability – when we (and here I am referring to all people) are denied a certain sight in our usual visual landscape, when we are confronted with it, we are wont to be shocked. When this shock is driven by discomfort, disgust, anxiety or fear, we may be led to look away from that which disrupts the visually quotidian.

Because of our projection of passivity onto people with physical disabilities, looking soon feels intrusive and violent. When we see what we imagine to be the unbearable suffering of disability, we turn away as our imaginations give a frame to the unvoiced and unvoiceable pain which the photograph signifies but does not speak (what Radley (2002) calls the "silent scream" of the viewer).

Garland-Thomson (2009), discussing Radley (2002), suggests that, in looking away from discomforting others, the observer not only removes the unsettling depiction from their view, but, with it, the "difficulty" of its appearance. In an attempt to extinguish the discomfort which we feel when faced with physical difference, and our imaginings about how this would be were it to befall us, we foreclose on connection, mutuality, and understanding.

Our tendency to avert our eyes is caused by discomfort: the visual stimuli disrupts what we want, or expect, to see, and we resist this intrusion (Garland Thomson, 2009). However, not all novel visual stimuli cause us to look away. This only happens when the novelty transgresses some treasured idea/norm. Bodily difference is one instance of visual novelty which transgresses one of our nearest and dearest ideas about ourselves: it reminds us that we are fallible. Further, disability confronts us with our fantasies about what it might be like to be without one of the parts of ourselves which we are accustomed to having – be it sight, mobility, or a normative physical structure. We look away from disability because it evokes uncomfortable emotions. Concealment – be it self- or other-imposed – can be seen as a reaction to the constant onslaught of looking and looking away, to which the disabled subject is subjected. When we look away, we turn away from the anxiety which difference stirs up. In so doing, we disallow ourselves the chance to establish intersubjectivity with the other. "If [such images] are deprived of frameworks that would enable the viewer to fashion a position with respect to them", suggests Radley (2002), "difficult images remain so" (p. 6).

2.2.1.1.4.2 The Freakshow

To begin tracing the history of representations and displays of different bodies necessitates thinking about freakery. Freakshows are exhibitions of "freaks of nature", typically, including people with different-than-average embodiment, such as "bearded ladies" or people of short stature. In her book, *Staring: How we look*, Garland-Thomson (2009) traces the fraught history of undisciplined looking, showing how myth, fairytale and fable have each, in turn, made of staring a moral against unbridled curiosity and human hubris. In each of these storying forms, staring has been met with punishment and condemnation, a prohibition to our eyes to steer clear from fantastic sights or unbridled looking (e.g., Narcissus, Medusa). The freakshow, quite contrary to these mores, invites and celebrates gawking and ogling, and undisciplined, acquisitive delight in visual difference.

I would suggest, however, that the impulse behind freakshow-type aesthetics was, and is, a kind of "safety in numbers" approach to outlaw looking. Staring, Garland-Thomson (2009) reminds us, makes the starer feel uncomfortable and vulnerable (they are revealing the power which the unforeseen sight has over them), and so framing the spectacle as permissible voyeurism – inviting starers to stare, eases some of this discomfort – how could they *not* look?

In the freakshow, difference and impairment were dressed up and delighted in, the object (note, not subject) of curious audiences' stares. In the freakshow, however, the subject does not appear. The disabled body is the focus of attention, and the human behind it and their experience and importance minimised for the sake of centralising the impairment of interest.

Shakespeare (1994) describes the process by which people with disabilities are objectified by cultural representations (of which the freakshow is but one) as "assum[ing] that disabled people are passive, akin to animals, objects rather than subjects" (p. 287). This is exemplified, for Shakespeare (1994), in disability spectacles like the freakshow, in which people with impairments were seen as non-human exhibits. This process, it is worth noting, bears resemblance to the representation of people of colour in colonial displays, medical texts, and art (Gilman, 1985; Strother, 1999).

A comment made by Shakespeare (1994) in relation to the freakshow is incisive: "I would suggest that the term 'fetishism' is useful in capturing the reality of this process", he writes (p. 287). Fetishisation is the process by which an individual becomes excessively or irrationally devoted to an object or activity (note, not a *person*). When something or someone is a fetish, they are rendered an object, and their personhood negated. The type of looking invited by the freakshow cultivates just such a viewer-viewed relationship – the "part of interest" of the different body is played up, similarity and mutuality is played down, and intersubjectivity between the viewer and viewed, suppressed.

Whether the sexuality of the disabled person is perceived as fetish or animal, any recognition of the sexuality of the freak in the freakshow is wrong: recognising the sexuality of the fetish object feels paraphilic, triggering shame and anxiety; recognising the sexuality of the sub-human animal even more so.

The carnivalesque (Bakhtin, 1984) spectacle of the freakshow depended on displaying different bodies as sub-human, grotesque, deviant, and abnormal. Feminist theory has extensively elaborated the manner in which women are necessary for the process of male subject formation, if only as Other. In representing difference, women are the foil to men’s understanding of themselves: women are everything which males are not. Disability representations, particularly as they appear in freakshow-type aesthetics, mirror this dichotomous creation of the self – except here, the role of Other is imposed on people with physical disabilities. The viewer can construct their self in opposition to all of the fantasies which they impose on bodily difference. Reading bodily difference as a metaphor for weakness, monstrosity, and – here – deviant and excessive, or null, sexuality – allows the “normality” and heteronormative sexuality of the non-disabled viewer to be buoyed up. The freakshow is to visual representations of disability what the construction of the differently able as deviant sexual self is to social representations.

Alternative readings of the spectacle of the Freakshow have been offered in recent years, and these must be acknowledged. For instance, in *The Victorian Freak Show*, Craton (2009) draws on the work of Bhakhtin to argue that the metaphorical value of freakery should be reinterpreted. She argues that such a reinterpretation would allow a conception of the freakshow which highlighted alliances and connections between people with physical disabilities, rather than focus on dissonance and exploitation of people with physical disabilities (Stuckey, 2011). She argues that people with different from average embodiment in Victorian literature “often play surprisingly positive roles in such literary imaginings” (Craton, 2009, p. 4). Other writers, such as Church (2006), have made similar observations. In his analysis of films hitherto regarded as perpetuating problematic disability stereotypes, Church (2006) argues that these movies include positive critical readings and empowering depictions of disability.

It is a valuable endeavour to cultivate such readings. However, the project of offering these alternative readings is premised on an understanding that one dominant, and problematic, reading of physical difference, as displayed in the Freakshow, prevails. As such, and given my interest in how the mainstream views the tropes discussed here, my interest is in the dominant reading.

So, while the freakshow as freakshow may no longer exist as it once did, the marks it has left on popular consciousness can still be traced (and will be, in the section which follows). Suffice to say that the themes encountered here – of power asymmetries, fetishism and objectification – recur in subsequent representational modes which conscript people with physical disabilities to the narrative they portray. Not all enactments of visual dominance upon people with physical disabilities are done with the object of entertainment, although many are. The internet, today, is a site of Freakshows, with photographers (such as Roger Ballen, in his series *Platteland*) particularly, often engaging in the curation of disability which may perpetuate the enfreakment of people with physical disabilities (Ballen, 1994).

2.2.1.1.4.3 Metaphor and movies

Drawing on feminist critique and theory from scholars of the dramatic arts, disability scholars have elaborated a facet of disability representation which pervades almost all other forms. This superordinate way of representing people with disabilities makes of impairment a metaphor. Recalling the fairy tales and myths discussed by Garland-Thomson (2009), staring is not the only phenomenon which has been imbued with negative meanings over the ages: disability and bodily difference have been employed as ciphers for metaphorical meanings, moral agendas, and sanctions, for as long as they have been in the public eye.

This is partly responsible for the social representational repertoire of disability stereotypes available and recognisable to us at any given moment, for example:

- the noble cripple (e.g., Kevin in Freak the Mighty by Rodman Philbrick)
- the demonic cripple (e.g., Captain Hook in Disney's Peter Pan)
- the SuperCrip (e.g., Paralympians)
- the simpleton (e.g., Lenny from Of Mice and Men), and
- the clown (e.g., Wee Man from MTV's Jackass) (Barnes & Mercer, 2001; Darke, 2004).

This is perhaps most apparent in movies and theatre (*The Tempest*, *Forrest Gump, There's something about Mary*), but is equally pervasive in popular photography.

Media treatments of people with disabilities, with some exceptions, almost always take an individualised perspective on disability, focusing on disability as personal misfortune. Simultaneously, however, this personal misfortune is given greater metaphorical significance. People with disabilities within popular cultural representations are ciphers. Disabled bodies, then, come to represent specific virtues, values or vices. This meaning is also dependent on the ends of the representer. As Runswick-Cole and Goodley (2015) note in their contemporary analysis of disability and poverty representation in a British television series, "impairment labels are deployed in different ways and carry out different cultural work"; that is, the way in which certain disabilities are portrayed or concealed at different points in time, serves different ends for those representing disability.

Even when they are being themselves, people with disabilities are standing for something beyond themselves – either a message or meaning, or as a representative of their group. Even when standing for themselves, in media products produced by themselves, people with physical disabilities must further their own ends at the cost of further perverting self-representation: The disabled poster man for the veteran's association must act appropriately vulnerable-but-strong in order to commandeer support for his comrades; the woman in a wheelchair must appear strong and stoic and unmoved by her "misfortune". There is little room for nuance, even in this more subtle "narrative prosthesis" – the perpetual circulation of images of disability in print and visual media as a device of characterisation, rather than a developed identity (Mitchell & Snyder, 2000). Such simplified, de-personalising representations, like their more objectifying counterparts, also seem to preclude sexuality on the part of their subject. In the freakshow, the impairment itself is the focus of the representation; likewise in metaphorical renderings of disability. That nuance which is invited by these images, is also difficult to grapple with intellectually: intense debates have been had over the merit or malice of Stokes' (Caso, 2017; Pitchford-Hyde, 2017) photographs of war veterans with disabilities. One line of argument is that the men photographed are portrayed as being sexy and indeed highly sexualised. However, this comes, not from the disability, but from how the disability emphasises the traditionally masculine – muscles, bravery, military, and the strength to fight and endure.

In most metaphorical renderings, however, the recognition of the disabled other's sexuality is not invited in any egalitarian manner – mutuality, an important facet of meaningful romantic relating, is denied. Discussing social research into the representation of people with physical disabilities, Shakespeare (1994) draws on Cumberbatch and Negrine's (1992) content analysis of images of disability in British television. Shakespeare (1994) links these authors' observation that people with disabilities are either absent from television, or appear in limited and limiting roles, to disabling stereotypes, which systematically exclude people with disabilities from mainstream community life. Here, two observations can be made, the first concerning narrative prosthesis, and the second, the absence of disability in popular culture.

If narrative prosthesis functions to employ the disabled figure “as a synecdoche for all forms that culture deems non-normative”, as Garland-Thomson (2002, p. 4) suggests, then disability is constantly fabricated to stand for something different. In accentuating this difference, narrative prosthesis employs one-dimensional portrayals of disabled subjects, flattening subjectivity, and seldom, if ever, incorporating sexual subjectivities. Sexualising such subjects also threatens a disruption of simplified renderings of disability which serve our purposes.

Even when disability is represented in a realist aesthetic, the results are often disastrous. In a recent example from film, *Me Before You* (Wikipedia, 2018) epitomises such problematic representations. In this film, a man acquires a disability. He and his carer start to fall in love, but in the end, the man takes his own life, suggesting disability is an insurmountable hurdle to living a fully sexual life.

In the main, however, disability is absent from popular culture. This absence – a metaphor, in itself, for our impulse to avert our eyes from disability – is equally detrimental to attempts to include disability in popular conceptions of sexuality. We cannot conceive of – in nuanced, personalising ways – that which we do not see. By withholding disabled people from our eyes, we are not challenged to rethink our ideas about disability (including desexualising stereotypes), and think inclusively about sex and sexuality.

The implications of making disability metaphorical will be discussed presently, but an illustrative example of the manifestation of one particularly pervasive “use” of disability as a cipher, is inspiration porn. The exaggeration and romanticisation of disability upon which this phenomenon relies, bears the modern-day marks of era after era of representing disability which has done only that – represented disability, not people with disabilities (Shakespeare, 1994).

2.2.1.1.4.4 Inspiration porn, pity porn

Inspiration porn is the visual representation, in film and picture, of people with disabilities, intended to engender admiration and inspire (non-disabled people, largely) to overcome obstacles (Longmore, 2015; McBryde-Johnson, 2005; Young, 2012, 2014). Inspiration porn is intended to inspire, and feeds into “overcoming narratives” – the enforcement of standards of optimism and “conquering obstacles” to which people with disabilities are often held.

However, much inspiration porn-type imagery is hard to distinguish from pity porn. The latter is intended to inspire sympathy (and pity?) for people with physical disabilities amongst the non-disabled “fortunates” targeted for charitable donation (Shakespeare, 1994). These images are characteristic of charity campaigns. Pity porn is patently meant to inspire sympathy.

Although many of us would consider both types of images uncomfortable, we might be hard-pressed to explain why we find them so. Shakespeare (1994) deftly cuts to the heart of the discomfort, however, by drawing on Lacan (1977). His observations are made in reference to pity porn, but hold for inspiration porn too, which observers (such as Darrow & Hairston, 2016) have noted to engender pity. “Pity”, Shakespeare writes, “is an expression of superiority: it can also be the obverse of hatred and aggression” (p. 287).

“We place no trust in altruistic feeling, we who lay bare the aggressivity that underlies the activity of the philanthropist, the idealist, the pedagogue, and even the reformer,” wrote Lacan, in 1977 (p. 7), “only saints are sufficiently detached from the deepest of the common passions to avoid the aggressive reactions to charity” (p. 13).

These images are uncomfortable, not only due to the pity which they evoke: the parallels between inspiration porn and pity porn, and sexual porn, are also likely to sit uncomfortably with those versed in the ways of looking at bodies germane to the latter. In both pornography and inspiration porn, “the gaze is on the body, which is passive and available. In each case, particular aspects of the body are exaggerated: sexual parts, in pornography, or ‘flawed’ parts in charity advertising”, writes Shakespeare (1994, p. 288).

In terms of pity porn, when images of people with physical disabilities call on us, implore us, coerce us, into taking up yet another position of power in relation to people with physical disabilities – this time as the fortunate “normal” person pitying the unfortunate other, two things are implied. The first is that disability is a personal tragedy, which the non-disabled are fortunate to have escaped, and secondly, that this escape makes it incumbent upon non-disabled people to pity and condescend to people with physical disabilities. Feminist critics, most influentially Simone de Beauvoir (1949), have taught us why pity prohibits mutuality. In representing people with physical disabilities as pitiful, the viewer’s eyes are invited to look down – gently – on the disabled body, fantasise about how it must be to “be like them”, and positioned as custodian of the people with physical disabilities’ fate, there is, once again, no room for sexualised or romantic looking: pity prohibits sexualisation. No one sees the poster boy/girl as sexy.

In terms of inspiration porn, we are encouraged to take a position of power in relation to the person with a disability, too. These images sensationalise disability, whilst simultaneously devaluing it; people with disabilities are seen as inspirational simply due to their capacity to live with disability. This positions disability as a burden which must be overcome. As Darrow and Hairston (2016) write, inspiration porn is “unwittingly victimizing and stereotypical” in its representation of disability (p. 51). The non-disabled viewer is fortunate, the inspirational person who has “managed to live with their devalued attribute” is not.

The type of representation of persons with physical disabilities on which inspiration and pity porn rely, is the very thing which earned it its name: representations which are pornographic. Shakespeare (1994) describes the manner in which “the objectification of disabled people in charity advertising parallels the objectification of women in pornography" (p. 288). However, despite the parallels – both rely on displaying the disabled body which is passive and available, exaggerating certain parts of the body, and depriving the object of the gaze their subjectivity – inspiration porn, through its dependence on the mechanisms of pity, desexualises the object. Again, then, we find a visual correlate of cultural ideologies about disability which rely on typifying people with physical disabilities as people apart. Regardless of whether we are being invited to admire (although I would offer that the images may at times invite condescension more than admiration) people with physical disabilities for overcoming what we imagine to be the atrocity of differently abled life, we are still not being invited to view people with physical disabilities as equals: we are being asked to see them (and think about them) in limited ways, where, as ever, they are standing in for something (be it succeeding in the face of odds, or another grand narrative of triumph). In being placed on a pedestal, people with physical disabilities are nonetheless being removed from us, and situated as "them".

2.2.1.1.4.5 The clinical gaze

Foucault's concept of the clinical gaze has been usefully elaborated by scholars from disability studies (see Condrau, 2007; Garland-Thomson, 2009; Reeve, 2002), and postcolonial criticism (see Browne, 2007), and elsewhere (Clarke, 2003). Contemporary theorisations of medicalisation include biopedagogies, a concept derived from Foucault's notion of "biopower" (Foucault, 1979). Pedagogy is the discipline that deals with the theory and practice of teaching and learning. As employed by theorists such as Rice, Chandler, Liddiard, Rinaldi, and Harrison (2016), however, a pedagogy is a form of pervasive social script which "teaches" individuals how to learn and know about something (MacNeill & Rail, 2010). A biopedagogy, then, is "the loose collection of moralised information, advice, and instruction about bodies, minds, and health that works to control. Negotiations with biopedagogical scripts that create/constrain bodies have bearing on identities like gender and disability insofar as these are understood as constructed, performative artefacts" (Rice et al., 2016). The clinical gaze is one of these scripts' social extensions. As Rice et al. (2016) write, "In our image-oriented culture, visual representations of bodily differences often function as biopedagogies. This is because representations tend to carry (often implicit) instructions for how we should live in our bodies and to establish a set of mind/body norms to which we all must conform".

The clinical gaze exemplifies a type of medicalised looking which aims to categorise and coerce "deviant" or "pathological" aspects of humanity into diagnoses (think of the depersonalised way in which people with impairments or injuries are presented in textbooks for medical students, or prevention posters discouraging maternal alcohol use, for instance) (Snyder & Mitchell, 2001). Difference is deviant and disability is pathology, in this view. As Garland-Thomson (2009) writes, medical-scientific experts have "viewed, measured, and evaluated women, people of color, and the poor" and found them wanting (p. 28).

When the clinical gaze is directed at the bodies of people with physical disabilities, it exerts a cold, indifferent dominance over it, seeking the culprit – the pathology. Medical-scientific looking enacts power: the viewer (the expert professional) probes the physique of the object (note, not subject) of their look, finds them wanting, names the lack or flaw, and then delivers a verdict on whether that lack of flaw is remediable, or not.

The clinical gaze is also objectifying. When persons with different bodies, bodies which the medical-scientific establishment deems wanting, are portrayed, in medical journals, encyclopaedias, and textbooks, they as person are not the *subject* of the image. Their impairment is the *object* of the image.

Scientific and medical knowledge is the purview of elites (Garland-Thomson, 2009). However, if, as Hafsteinsson and Bredin (2010) suggest, images do prefigure audiences, then the subject whose impairment is the object of the clinical gaze, is rendered powerless: the nature of the medicalised image prefigures a powerful, elite, and diagnostic viewer, conferring this power on anyone who takes up the position of viewer to the image. When people with physical disabilities are portrayed in medicalised ways, an asymmetrical power dynamic through the viewing/being-viewed, and the person with physical disabilities comes off second best.

Garland-Thomson (2009), building on the work of Canguilhem (1989), has usefully explicated the manner in which this clinical way of looking has taken root in societal ways of thinking, “extend[ing] its notion of human pathology into the social world in discriminatory ways” (Garland-Thomson, 2009, p. 28). These repercussions include, for instance, social anxiety around reproduction amongst people with “undesirable” physical traits (Kim, 2011). By inviting the conflation of physical impairment with illness and contamination, and physical with moral difference, the clinical gaze examines bodies, finds them lacking, and pronounces pathology. In so doing, the humanity of the examined subject is compromised, and their social desirability tarnished.

The clinical gaze makes of disability a sanitised spectacle. Clinical representations of bodily difference focus on the impairment, neglecting the whole, and in so doing objectifying people with physical disabilities and negating their personhood. Further, the clinical gaze conflates disability with illness, playing on popular fears of Kim’s (2011) “disability reproduction and contamination”.

As Garland-Thomson (2009) noted, the visual representation of different bodies in journals and textbooks, disembodied and de-personalised as they are, then, is the visual corollary of societal thinking about disability which is de-sexualising and objectifying.

Recalling Lamb and Layzell’s (1994) assertion that “the public's attitudes and expectations towards disabled people [involves] seeing them as ‘sick and sexless’” (p. 21), we see how medicalisation of disability further suppresses the possibility of sexuality amongst people with physical disabilities: the objectified, pathologised, sick person with physical disabilities is not a suitable sexual subject.

Considering sexuality, and thinking about sexuality amongst people with physical disabilities, we can see that the societal inability or disinclination to think these two ideas together, is underlain by a similar looking away, only it is the mind’s eye which is averted.

Most of the representations discussed here foreclose on sexuality, rigorously distancing sexuality from disability, to preserve discourses and ideologies of normality, ability, and sexuality. People with physical disabilities are widely desexualised, in visual and social representations. Consider, then, Waxman Fiduccia’s (1999) argument that people who sexualise

> sexual minority members, carry their own stigma due to their association with the sexual other. They become sexual suspects, and are devalued by their association with the sexual other. Their sexuality is also pathologized and criminalized like the paedophile and the incestor. (p. 289)

Could our not thinking about the sexuality of disabled subjects, and our aversion of our eyes when confronted with a sexualised person with physical disabilities, be a result of this conundrum: resexualising a subject so desexualised by society, feels inappropriate. Sexualising children, animals or objects is societally prohibited. Why then are we surprised that sexualising people who are widely portrayed as such feels perverted? As Solvang (2007) argues, the partner with a disability is a deviation from a socially prescribed aesthetic norm for sexuality, so their non-disabled partner’s involvement with them, re-sexualising the "abnormal" body, must be deviant (Solvang, 2007). This makes of all desire for a person with physical disabilities, a perversion (Solvang, 2007). Even when not portrayed in such extreme ways, disabled subjects are inevitably portrayed as passive, again, not a quality society deems desirable or appropriate in sexual subjects: sexualising the rigorously desexualised feels intrusive, wrong, and inappropriate, and so we look away from the sexualised disabled subject if such confronts us, or fail to think it if it does not.

In general, then, both visual and social representations of people with physical disabilities axiomatically prohibit sexuality: sex is for "normal" bodies, and the bodies of people with physical disabilities do not conform to a prescriptive definition of "normal" (Campbell, 2009; McRuer, 2011). Therefore, they are assumed to be deviant or asexual.

2.2.1.1.5 Speaking back

Despite the tenacity with which these types of representational tropes endure, there have been positive developments in disability representation in recent years. In film (Morrison, 2012; Zablocki, 2016) and photography (Enhance UK, 2013; Fermariello, cited in Frank, 2014), people with physical disabilities are coming to inhabit the visual realm in non-stereotypical forms. This comes in two forms: so-called disability production, and mainstream entertainment.

In disability-specific realms, disability film and art are making huge strides, as Zablocki (2016) noted in his Huffington Post reflection on the ReelAbilities: NY Disabilities Film Festival, "The largest minority group in America is stepping into the spotlight with a record number of films made by or about people with disabilities" (p. 1). The author also noted that "the edginess of topics and the forthrightness of their presentation" struck the festival's committee and viewers alike. Amongst these edgy topics, sex and sexuality grew in prominence, bringing this facet of living with a disability to audience's attention (p. 1).

However, the audience in question were, naturally, those individuals who had sought out a disability film festival, and so perhaps not the people most in need of exposure to such representations. Which brings us to recent popular, or mainstream, representations of disability which depart from the problematic representational cannon. Morrison (2012), commenting on one film which attempted such a mainstreaming, discussed The Sessions, one of the first Hollywood films to explore disability and sexuality. The film follows the real-life story of the American poet Mark O'Brien, who, at 38 years old, sought the help of a sex surrogate. The film won the Special Jury Prize and Audience Award at the Sundance festival. Director Ben Lewin, himself a man with a physical disability like the film's protagonist, stated that he "was taken by the frankness and explicitness of it – which is rarely associated with discussions of sex. When I was a kid, we didn't talk about sex and disability. I get the impression people are more open-minded now" (quoted in Morrison, 2012, p. 1).

His comment cuts to the heart of an issue which such representations confront: given years and years of problematic representation, and audience's familiarity with problematic ways of reading disability in relation to sexuality, will such films (and photographic campaigns in the same vein, see Enhance UK, 2013) open up a new way of viewing disability and sexuality, or simply be read as freakish or pathetic. I deal with this issue in some depth in one of the publications presented in this dissertation, so will not dwell on it here. However, it is worth flagging this issue, as it speaks to the forthcoming section: how is sexuality in the context of disability "read" and reacted to, and (in Literature Review Part II) what does this mean for people with physical disabilities?

2.2.2 Non-disabled people's attitudes towards, and thinking, and feeling about disability and sexuality

An accurate (albeit clumsy) framing of my focus in the survey part of this study is "non-disabled people's thinking about and mental representations of" the sexuality of people with physical disabilities, rather than "non-disabled people's attitudes towards" the sexuality of people with physical disabilities. The survey is intended to access not "attitudes" per se, but rather, the ways in which non-disabled people think and feel about the sexuality of people with physical disabilities, and represent sexuality and physical disability in their minds eye. However, I will briefly review work on attitudes towards the sexuality of people with physical disabilities, despite the conceptual distance between such work on attitudes, and the more nebulous ideas with which I am concerned. Here I outline the relationship between social forces and individual-level attitudes. I then problematise the notion of attitudes as applied to the present work, and make a case for my examination of the more loosely-defined "thinking about and mental representations of".

It is not possible to generalise directly from the evidence for stereotypes of people with physical disabilities, and theoretical work on social representations, to the attitudes of individuals. Primarily, this is because there is evidence which suggests that certain factors mediate the relationship between an individual's knowledge, what they are exposed to through socialisation, and the attitudes which they actually hold (particularly in relation to sexuality) (Evans & Durant, 1995; Hillman & Strieker, 1994). These factors, which will be attended to presently, mean that attitudes cannot be extrapolated based on findings regarding social representations or stereotypes, and so investigation *into* attitudes is required if one seeks to know *about* attitudes.

At the beginning of this dissertation, I defined attitudes: how mainstream psychological theory conceives of them, how the disability framework used here problematises this notion of attitudes, and how I think of them in the present study. I begin here, then, with a discussion of the work which has sought to examine attitudes towards people with physical disabilities in their own right, and, in so doing, understand how it is that individual members of a society view and react to the sexuality of people with physical disabilities.

A divide has been observed (by authors such as Dale Stone (2005) and Esmail et al. (2010)) in societal attitudes towards persons with visible disabilities and those with invisible disabilities. Traditionally, people with invisible disabilities are not stigmatised as readily as those with visible disabilities (Dale Stone, 2005). The focus of the section which follows, and the study as a whole, is individuals with physical disabilities which are usually, if not always, visible. And, while some have suggested that with visible disabilities, non-disabled people may be more willing to accept that there may be a functional limitation associated with the disability (Dale Stone, 2005; Rashid, Hodgetts, & Nicholas, 2017), individuals with visible disabilities face more social limitations, early stigma and desexualisation than those with less visible disabilities (Esmail et al., 2010; Tuersley-Dixon & Frederickson, 2016). Evidence for these latter claims comes from research into attitudes of non-disabled persons regarding the perceived sexuality of people with physical disabilities.

Milligan and Neufeldt (2001) caution that attitudes measured in studies are often based on vignettes and hypothetical situations, and so are not necessarily predictive of future behaviour towards individuals with disabilities. Equally, studies of attitudes towards persons with disabilities have also been marked by issues of social desirability response bias (Lüke & Grosche, 2017; Rojahn, Komelasky, & Man, 2008). For instance, Rojahn et al. (2008) noted that although the students in their studies' ratings of the romantic attractiveness of an individual was unaffected by the presence of a physical disability, they still showed a clear preference for persons with normative bodies over persons with physical disabilities. This, the authors suggest, is evidence that ratings of attractiveness were biased by social desirability (Rojahn et al., 2008). Attitude research has consistently revealed that there is a hierarchy of disability acceptability, where severe and visible disabilities are ranked as less acceptable than less visible and less disabling conditions (Gordon, Tantillo, Feldman, & Perrone, 2004; Huskin, Reiser-Robbins, & Kwon, 2017; Morin, Rivard, Crocker, Boursier, & Caron, 2013; Strohmer, Grand, & Purcell, 1984; Tuersley-Dixon & Frederickson, 2016; Olkin & Howson, 1994; Westbrook, Legge, & Pennay, 1993). This puts persons with highly-visible physical disabilities at especial risk for negative attitudes.

Some studies have sought to examine attitudes towards the sexuality of people with physical disabilities by asking people with physical disabilities themselves about the ways in which they have perceived others' attitudes towards them (Ahumuza et al., 2014; Burke, Kébé, Flink, van Reeuwijk, & le May, 2017; Crawford & Ostrove, 2003; Kattari, 2014; Powell et al., 2017). However, most research into attitudes towards, and perceptions of, the sexuality of people with physical disabilities has looked to society itself in the shape of qualitative and quantitative inquiry amongst service providers, students, and the general public.

This attitudinal research has revealed that people with physical disabilities are often not seen as dating or marital partners (Hergenrather & Rhodes, 2007; Juergens et al., 2009; Marini et al., 2011; Miller et al., 2009; Olkin & Howson, 1994; Trieschmann, 1988; Yoshida, 1994). For instance, in a recent qualitative study of attitudes towards sexuality and disability in Canada, a sample of the general public revealed a reluctance to initiate relationships with people with physical disabilities because they felt that the latter would be too dependent (Esmail et al., 2010). Vilchinsky, Werner et al. (2010), in Israel, showed that the shyness and embarrassment which individual's typically display when encountering a member of the opposite sex, does not manifest when one of individuals in the encounter has a disability, suggesting that the latter are not taken to be suitable sexual (and thus shyness-inducing) partners. Investigators have also found that the attitudes of non-disabled persons towards sexual behaviours amongst people with physical disabilities are marked by negativity (Haring & Meyerson, 1979; Scotti, Slack, Bowman, & Morris, 1996; Wolfe, 1997). Whereas many people without disability would pursue friendships with people with disabilities, far fewer would consider romantic relationships (Hergenrather & Rhodes, 2007; Marini et al., 2011; Miller et al., 2009). Not only might people with disabilities be regarded as lacking in sexuality, but also people without disability may feel awkward and uncomfortable if in a dating relationship with them, fearing being stigmatised by association based on their closeness with a person with disabilities (Fichten et al., 1991; Gill, 1996; Gordon, Minnes, & Holden, 1990; Olkin & Howson, 1994).

In a study of Jewish Israeli students without disabilities, Vilchinsky, Findler, and Werner (2010) found that when students were asked to read a scenario about an encounter with a person with a disability, they expressed more negative emotions than when they read a similar scenario about an encounter with a person without a disability. However, the authors also found evidence of a dynamic process of self-regulation amongst the students when reacting to the scenario about people with physical disabilities. Initially, the students reacted with a negative emotional response, but quickly moderated it with compensatory positive cognitions and behavioural tendencies (Vilchinsky, Findler et al., 2010). A similar process was noted by Vilchinsky, Werner et al. (2010), in Israel again, who proposed that these findings suggest that people try to hide and overcome their automatic negative feelings towards people with disabilities, a sort of “reaction formation” (an unconscious defence mechanism whereby a socially illegitimate impulse is transformed into an acceptable and exaggerated positive reaction) (Vilchinsky, Werner et al., 2010). Such moderation responses have not been found uniformly across studies, however, with several (Esmail et al., 2010;

Tervo, Palmer, & Redinius, 2004; Vilchinsky, Findler et al., 2010) citing purely negative responses, apparently unaltered by internal modulation.

Given the broadly constructionist orientation of much of the work presented in the project concerning non-disabled people's thinking and feeling about, and representations of, the sexuality of people with physical disabilities, I have focussed here on the role of social forces in shaping attitudes. However, two points bear mention.

The first is that individual-level factors mediate between societal-level representations of people with physical disabilities, and individual-level thinking about and mental representations of members of a society. Findings from studies which have investigated the impact of various characteristics of non-disabled persons which influence their attitudes towards people with physical disabilities suggest this. For instance, a Kenyan study showed that age significantly predicted attitudes towards disability, with older students holding more positive attitudes than younger students (Mamboleo, Diallo, Ocharo, Oire, & Kampfe, 2015). Several other studies have found that females tend to have more positive attitudes towards persons with disabilities, including when it comes to potential relationship-formation than do males (Chen et al., 2002; Findler, Vilchinsky, & Werner 2007; Marini et al., 2011; Stone & Colella, 1996; Vignes et al., 2009; Yuker, 1988).

Additionally, contact has proven to be an important variable effecting non-disabled persons attitudes towards persons with disabilities (Armstrong, Morris, Abraham, Ukoumunne, & Tarrant, 2016; MacMillan, Tarrant, Abraham, & Morris, 2014; Stone & Colella, 1996). In relation to sexuality and dating in particular, for instance, in the United States, Marini et al. (2011) found that non-disabled respondents who had an existing personal relationship with a person with a disability were more willing to engage in a relationship with a wheelchair-user. Factors such as an individual's political views and endorsement of various social norms also impact on attitudes towards disability (Parsons, Reichl, & Pedersen, 2017).

So, while individuals may be exposed to the social representations discussed previously, and may even hold as true, or be aware of, the stereotypes of people with physical disabilities' sexuality, these do not necessarily result in negative thinking and feeling about, and mental representations of, the sexuality of people with physical disabilities.

The second point concerns alternate or competing explanations of individual attitudes towards disability, which draw on internal, psychodynamic explanations, rather than social representational ones. This position has perhaps been best elaborated by Watermeyer (2013). Drawing on psychodynamic theory, he holds that anxiety, fear, ambivalence, pity, and helplessness characterise emotional responses to physical disability. These emotions arise, at least in part, due to non-disabled people's imaginings regarding what disabled embodiment might be like (Watermeyer, 2013). He argues that emotional responses to disability exist and shape non-disabled people's (and disabled people's) relationships to disability whether acknowledged or not (Watermeyer, 2013). These fears and anxieties, in a psychodynamic framing, arise due to fears of bodily frailty and fallibility, and so such theorising places more emphasis on internal psychological processes in determining reactions to disability (and sexuality), than on social processes.

However, if extended into the social world, such theorising explains intergroup behaviour in terms of the ingroup (non-disabled people's) internalisation of images of the other which support the rejection of the latter as different and defective. These internalisations minimise the fear which the disabled other elicits in the non-disabled group member, psychically distancing difference from the self.

Work by Fahs (2017) in the United States examined women's fears and sense of disgust regarding "abnormal" or "dreaded" embodiment. When imagining a dreaded body, one third of Fahs' (2017) sample were concerned about how such embodiment would impair their femininity. Women's responses were characterised by a fear of not being sexy or attractive (Fahs, 2017). In this study, it was glaringly apparent how readily women were able to access ideas and accompanying affective responses, about bodily difference. Fahs (2017) noted that this “rais[es] questions about the ease of accessing such ideas and the production of ‘appropriate’ femininity. The spectre of this dreaded body – appearing in this study in a multitude of ways – provides insight into the visceral qualities of disgust that women have about bodies typically constructed as ‘Other’” (Fahs, 2017, p. 191). Such findings could be taken as evidence of the visceral, internal processes regulating responses to disability and difference. However, they provide equally powerful evidence of the socially-determined and highly gendered nature of these fears.

This project is not overtly concerned with the origins of negative thinking and feeling about, and representations of, physical disability and sexuality, as noted, but rather the form which they take. As such, the psychodynamic work of writers such as Watermeyer (2013), is compatible with my study. However, given the focus of the project as a whole on traditionally social psychological constructs (representations, social constructionism, and stereotypes, for instance), these provide a sufficiently broad landscape in which the work of the present study is situated, and so intrapersonal theories are not foregrounded.

Regardless of their origins, there is much evidence which suggests that individuals’ thinking and feeling about, and mental representations of, the sexuality of people with physical disabilities are unfavourable, and very reminiscent of the ideologies, social representations, and stereotypes discussed. Non-disabled people seem to have difficulty imagining that people with physical disabilities could – or should – have sexual lives. As explicated here, this appears to be the result of societal-level representations, and individual-level stereotypes which perpetuate the idea that sex and disability are somehow at odds, and the image of the people with physical disabilities as not able, and therefore not sexual. These discourses, which conflate ability with sexuality and so disability with asexuality, along with individual-level factors, interact to produce attitudes towards the sexuality of people with physical disabilities on the part of the non-disabled which are negative, and which negate that such a sexuality could exist. Yet, as the following section of this chapter will show, this is vastly at odds with the experiences of people with physical disabilities themselves.

2.3 Literature Review Part II

In this section, I juxtapose the desexualising ways in which societies and individuals represent the sexuality of people with physical disabilities, with the manner in which sexuality is experienced in the context of physical impairment. This includes contrasting how non-disabled people *think and feel about* people with physical disabilities with work concerning how people with physical disabilities *think and feel about* their own sexuality – work which illustrates that the latter group lay claim to sexualities which are active, expressive, and fulfilling. I then outline evidence which suggests that negative societal attitudes towards sexuality and physical disability affect the lives of people with physical disabilities in the realms of sexual self-esteem, sexual identity development, quality of life, education, access to, and quality of, health care, and risk of sexual violence.

I conclude this chapter by drawing attention to the fact that the majority of the scholarship concerning the sexuality of people with physical disabilities – and public attitudes towards it – hails from the Global North (including the United States, Canada, and Israel as per the literature above). I propose that the dearth of research regarding the sexuality of people with physical disabilities in the Global South, and South Africa in particular, is problematic. However, taking the work from Northern contexts as a starting point, I argue for the need to explore public attitudes towards the sexuality of people with physical disabilities in South Africa, as well as some South African's experiences of sexuality in the context of physical disability. In this context, a small body of research suggests, these attitudes are likely to be negative, and these experiences impinged upon by a social milieu which is not affirming of the sexuality of people whose embodiment differs from the average: however, we do not know, and this is the impetus for this project.

2.3.1 Sexuality and disability: Research with persons with physical disabilities

As noted, disability and sexuality have commonly been regarded as incompatible concepts, "the first automatically precluding the second" (O'Toole & Bregante, 1992, p. 273). Yet, since the 1970s, there has been a growth in work examining the lived experience of people with physical disabilities. A portion of this research – although small – is dedicated to understanding these individuals' sexuality. From detailed autoethnographies yielding nuanced first-hand accounts (Tepper, 1999), to large surveys revealing the broad strokes of the phenomenon (Cheausuwantavee, 2002), research now attests to the complexities – vitality and diversity – of sexuality amongst people with physical disabilities.

Before attending to this work, however, I will make some comments regarding gender, as it is often through the filter of gender discourses that sexuality – of persons with and without disabilities – develops and is enacted.

2.3.1.1 Gender

Work on the relationship of disability to gender has historically been limited (Shakespeare, 1999), partly due to the fact that disabled people were taken as being asexual, or a third gender (Shakespeare, 1999). Contemporarily, however, gender is usefully used as a lens through which to explore the sexuality of people with physical disabilities (a logical development given that gender and gender roles have a substantial influence on experiences of sexuality in the context of disability (Lee & Lee-Ann, 2016; Liddiard, 2014; Miller, 2015; Rodarte & Munoz, 2004)).

An important theoretical note which must be made at this point is one concerning symbolic interactionism. Symbolic interaction theory examines the ways in which "societal norms, stereotypes, and judgments affect stigmatized or 'othered' groups" such as people with physical disabilities (Rich, 2014, p. 419). It is particularly concerned with how stigmatised groups may come to internalise negative stereotypes about themselves (Goffman, 1963). Further, symbolic interactionists have posited that marginalised groups employ a variety of strategies to manage others' perceptions of them (Goffman, 1963; Hewitt, 2003; Rich, 2014). Goffman (1963) notes that, according to this perspective, "accounts" are made by individuals in order to hide, minimise, compensate for, or negate the socially stigmatised elements of their identities. Accounts, in this rendering, are the excuses and justifications which individuals use in order to account for socially undesirable traits or behaviours (Orbuch, 1997).

According to symbolic interactionists, disability is a primary hallmark of identity (Rich, 2014). That is, it is an identity which supersedes race and gender. Further, as writers such as Banks (2010; see also Banks & Kaschak, 2003) have noted, gender roles are enacted through the performance of certain activities, activities which disability may make impossible (either in reality, or in the eyes of others). When disability does meet gender, then, the former often works to negate the latter, in interactionist terms. So how then do people with physical disabilities enact or claim gender, or, how does gender influence the ways in which they experience their impairments? I will attend to these considerations in the following sections on disability and masculinity, and disability and femininity, respectively.

2.3.1.1.1 Disability and masculinity

Shakespeare (1999) notes that "the traditional account, such as it is, of disabled masculinity rests on the notion of contradiction" (p. 54). That is, traditional conceptions of masculinity (independence and physical prowess), and disability, conflict with each other (Shakespeare, 1999; Shuttleworth, Wedgwood, & Wilson, 2012). Connell (1995) writes, “The constitution of masculinity through bodily performance means that gender is vulnerable when the performance cannot be sustained—for instance, as a result of physical disability” (p. 54). This, alongside others’ perceptions of men with disabilities as asexual, has been documented to lead men with physical disabilities to employ a variety of strategies to negotiate a masculine identity for themselves in light of disability.

In an article which appeared in 1999, Tepper shares both his personal story and professional perspectives on the impact of acquiring a disability on male sexuality, a story which exemplifies Connell’s (1995) assertion. Integral to Tepper’s (1999) account is the way in which male children are socialised into a certain sexuality. Reading his own experience of becoming physically disabled in the prime of his youth in relation to Zilbergeld’s (1992, cited in Tepper, 1999) work on masculine socialisation, Tepper (1999, p. 40) describes how his experiences of sexuality post-injury were both determined and thwarted by stereotypical conceptions of manhood.

He writes:

> My male energy drove me to deal with my disability. Competitive swimming, diving, and especially the discipline and focus I learned in karate prepared me well for the rehabilitation process. I was stoic, strong, independent, hardworking. I forged ahead, always looking to protect the ones I loved from my misfortunes. But at the same time, masculinity had its detrimental affects. I pushed away my girlfriend whom I started seeing after my ileostomy and was still dating at the time I broke my neck. I also pushed away my mother, or at least rebelled strongly against her when she tried to take care of me.

Tepper’s (1999) account centres on the ways in which a gender identity which centred his manhood firmly around the functioning of his penis (male sexuality is conceived traditionally in a phallocentric and oppressive way), and this dictated his sexual experiences as a newly disabled man. From attempting to woo every woman he met to “compensate” for his own doubts about his legitimacy as a man, to being treated as a “safe” sexually neutral friend by women who assumed him to be sexually inactive, Tepper’s (1999) entire experience of his sexuality was determined by his socialisation into masculinity, and others’ assumptions regarding his sexual prospects (p. 40).

However, given that disability and masculinity are lived and embodied experiences which occur at a personal level, this contradiction has subsequently been critiqued (Shuttleworth et al., 2012). Today, a multiplicity of masculinities are understood to exist, and each of these will intersect differently with physical disability (Wedgwood, 2009). Emergent ways of conceptualising disabled men’s gender attend more now to embodiment (Shuttleworth et al., 2012).

Despite its age and the limitations of the model from which it worked (the contradiction model, as I shall call it), what Tepper’s (1999) autoethnography serves to illustrate is that sexuality does not occur in a gender vacuum. If the sexual experiences, and experiences of sexuality, of non-disabled persons is in no small measure determined by gender scripts, then so too will be those of persons with disabilities. But, as Tepper’s (1999) account illustrates, when the performance of these dominant roles and prescriptions is inhibited by physical limitation or societal ideas, the experience of sexuality is complicated.

2.3.1.1.2 Disability and femininity

In a similar manner, gender roles and norms affect the embodied sexuality of women with physical disabilities. Recalling the work of Banks (2010) noted earlier, specific activities are required of people in order to claim a gender role. Many women with physical disabilities are excluded, or perceived to be excluded, from such activities (Scott, 2015). This, Dotson, Stinson, and Christian (2003), and Hassouneh-Phillips and McNeff (2005) note, may mean that, for women with physical disabilities, femininity is an achieved status as opposed to being assumed to be "natural".

As discussed earlier, women with disabilities are stereotypically infantilised, viewed as passive, unable to be mothers, and as being a burden to carers and partners (Galvin, 2005; Hassouneh-Phillips & McNeff, 2005). It was argued in the past, Rich (2014) notes, that women with physical disabilities were doubly feminised. That is, women are traditionally taken to be weaker and more passive than men, and weakness and passivity are ascribed to people with physical disabilities. This proposition, however, was based only on the image of women as eternal children; passive, and in need of care. However, there are also powerful demands on women to be sexual beings. As Cheng (2009) and Rich (2014) have shown, women with physical disabilities are perceived to be asexual, rather than excessively feminine. This seems to suggest that the demand for women to fulfil the second image (of sexualisation) takes precedence over the demand for them to fulfil the first (of passivity). That is, women are "disqualified" from femininity based on their "failure" to meet standards of sexualisation, rather than elevated in feminine status due to their being perceived as exceeding standards of passivity.

Women in general are affected by societal expectations regarding their physical size, shape, and gracefulness (Wolf, 1991). As women with physical disabilities have bodies which differ from the prescribed ideal, they are vulnerable to negative appraisal; both their own, and others' (Banks, 2010; Hassouneh-Phillips & McNeff, 2005; Wendell, 2006). Further, due to internalised doubts regarding their physicality and femininity, women with physical disabilities may feel that success in relationships or marriages bolsters their sense of themselves as being women like other women, whilst failed ones reinforce perceptions of themselves as asexual (Galvin, 2005). In fact, research has shown that people with physical disabilities are viewed in a more positive light when they are in romantic relationships, providing further evidence of the pressures which they might face to perform normativity (Hasson-Ohayon, Hertz, Vilchinsky, & Kravetz, 2014).[9]

Interestingly, in an echo on the work of Tepper (1999), Batty, McGrath, and Reavey (2014) found that women with physical disabilities enacted exaggerated gender performances in order to affirm their gender identity. Participants in Batty et al.'s (2014) study gave accounts of performing hyper-feminine roles in order to compensate for the fact that others might see them as asexual, as well as their own sense of having their gender called into question. Thus, compensating for the "loss", or altering, of one's original gender identity following an acquired impairment, or developing an exaggerated gender identity in the presence of a congenital disability, may be common strategies employed by both male and female people with physical disabilities to combat the de-gendering that their disability entails.

However, nearly 20 years ago, Shakespeare (1999) noted that masculinity and femininity were in flux in the western world, and so, he warns, one must be careful not to make assumptions about the experiences of individual men and women:

> The lives of real disabled men, involving negotiation and redefinition and continuity as well as change, offer a more complex and sophisticated reality than assumptions may imply. Neither masculinity, nor disability, should be reduced to the level of physical determination, and it is necessary to be open to the variety of strategies employed by different disabled men. (p. 56)

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[9] These authors refer to heterosexual romantic relationships. It is possible that LGBTQ+ relationships may further pathologise people with physical disabilities.

In a similar vein, Kafer (2003b) calls for gender and disability researchers to “begin to attend to the specific, local sites of the gendering process … to begin to acknowledge the ways in which gender is lived through disability and disability through gender” (p. 114).

Thus, it is necessary to explore the phenomenology of disabled sexuality: the perspectives on sexuality of people with physical disabilities themselves. The section which follows, then, will explore the various ways in which people with physical disabilities experience their sexuality. Drawing on evidence from their accounts of relationships, reproduction, gender identity development, and more, the section which follows will lay out the various ways in which a person with disability’s sexuality is constructed, experienced, at times constrained, and at others enjoyed. When backlit by the preceding theory and research concerning cultural ideologies, myths, stereotypes and popular attitudes, the contradictions between popular thought concerning, and the lived experience of sexuality amongst people with physical disabilities, is illuminated.

2.3.1.2 Sexuality and disability

When physical disability is acquired, and the individual’s sexual identity development has already occurred, pursuing sexual relationships, intimacy, and pleasure remain priorities for many individuals of all ages (Fritz, Dillaway, & Lysack, 2015; Higgins, 2010). In contrast, sexual identity development amongst persons who have been disabled from birth occurs in the context of disability (MacDougall & Morin, 1979), and people with congenital physical disabilities have been found in some studies to be limited or delayed in their expression of their sexuality (Howland & Rintala, 2001; Vaughn, Silver, Murphy, Ashbaugh, & Hoffman, 2015). When sexual identity development occurs in the context of disability (as opposed to before its onset), the result can be inhibitory on sexual development (MacDougall & Morin, 1979; Vaughn et al., 2015; Wiegerink et al., 2011). Still, there is some evidence (Blum, Resnick, Nelson, & St Germaine, 1991; Potgieter & Khan, 2005) that some people with physical disabilities develop, in their sexuality, sexual awareness and sexual expression, at rates similar to those of their non-disabled peers.

Needless to say, there is extensive variation amongst individuals with physical disabilities in terms of satisfaction with their sexual lives (Otero-Villaverde et al., 2015; Shuttleworth et al., 2012; Smith, Molton, McMullen, & Jensen, 2015). However, these circumstances do not result in people with physical disabilities retreating into asexuality (although a number of studies noted that others' assumptions regarding persons with disabilities' inability to engage sexually were harmful and made them question their own sexual agency, see Ostrander, 2009; Westgren & Levi, 1999). Instead, a review of the literature on the sexuality of people with physical disabilities reveals that it can be active, and that their sexual lives can be lively and fulfilling (Guldin, 2000; Ostrander, 2009).

However, an important point to be made here pertains to sexuality itself. Sexuality is not limited to penetrative, nor heterosexual, sex. For some people with physical disabilities, sexual activity as defined as penetrative sex, is not possible. However, these individuals may still have sexual desires, and be willing to engage in alternative forms of sexual activity, including, for instance, oral sex or other forms of non-penetrative sex, or employ sexual aids. This dependence on alternative forms of receiving pleasure, and pleasuring their partner, may have the unfortunate consequence of positioning them as less sexual (Shakespeare, 1999) or, I suggest, even perverted in the eyes of those who conceive of sexuality as being heteronormative, penetrative, sex. In this instance, all of the sexual activities open to some people is, by default, perverted (although, in line with Liddiard (2011, 2017) and Shildrick (2009), I would argue that these modes of expression are positive in the way in which they exceed and explode the sociocultural normativity of sexuality). This further exacerbates the stigma, which, in turn, further complicates the sexual lives of people with physical disabilities.

Still, research has shown that, across cultures and countries, many people with physical disabilities desire to be recognised as sexual beings (Bahner, 2012; Carew et al., 2017; Peta et al., 2016; Shuttleworth et al., 2012), partners, and potential parents (Lee & Oh, 2005; Nosek et al., 2001). Specific evidence in refutation of the myth of asexuality amongst people with physical disabilities include findings that they, like non-disabled persons, may identify across a spectrum of sexual orientations (Drummond & Brotman, 2014; Shuttleworth et al., 2012; Whitney, 2006), partner and get married (Esmail, Esmail, & Munro, 2001; Li & Yau, 2006), and have children (Lappetelainen, Sevon, & Vehkakoski, 2017; Lee & Oh, 2005; Nosek et al., 2001; Wint, Smith, & Iezzoni, 2016).

Partnering is one of the most fundamental and normative aspirations of many adults. As noted by Master, Johnson, and Kolodny (1999), human sexuality is a multidimensional phenomenon: it has biological, psychological, behavioural, as well as moral and cultural aspects. And, as Li and Yau (2006) note, “sexuality begins within oneself and extends to relationships with others” (p. 2). Relationships are complex, constituted of individuals’ feelings about themselves (attractiveness, sexual self-esteem, and the like), as well as their attraction to another (Liddiard, 2014).

When one or both partners in a relationship is/are living with a physical disability, this complexity is magnified in many respects: not only does the individual (or the individuals) affected have to contend with their own sense of themselves as sexual beings, but they have to do so in a context of societal attitudes which consider them lacking the capacity for normal and satisfying sexual relationships. Further, when the disability is acquired, their existing identity and self-concept may be altered, and in the process, so too their negotiation of their relation to an existing, or potential, significant other (Chance, 2002; Fritz et al., 2015).

Additionally, although sexual behaviour and relationships have both psychological and physical aspects, there is an important if not fundamental physical dimension involved in any sexual relationship, and a physical disability can be expected to have a fairly serious effect on the development of this important aspect of human experience (MacDougall & Morin, 1979). For instance, Yim et al. (1998) reported that sex was the most serious problem faced by couples where one of the partners has a disability.

Physical disability has been found to have a significant impact on couples' sexual relationship and on roles taken in the relationship, particularly in the case where one partner assumes a caregiving role towards the partner with the disability (Bach & Bardach, 1997; DeVivo, LaVerne, Hawkins, Richards, & Go, 1995; Kreuter, 2000; McKinney, 2017; Taleporos, 2001). As Esmail et al. (2001) note, "it becomes more difficult for the couple to return to the pre-injury level of intimacy as the duration of a caregiver role lengthens" (p. 14). When professional carers are employed, limitations on intimacy may arise (for a well-crafted autoethnography on the subject, see McKinney, 2017). The presence of a disability can also decrease the frequency of sexual activity, resulting in lower sexual satisfaction for both partners (DeVivo & Richards, 1996).

Thus, it is important to acknowledge that sexual relationships involving one or more persons with a disability may involve challenges distinct from those facing non-disabled couples. However, successful and enduring, affectionate relationships involving individuals with disabilities are normative. Thus, it is worth exploring, briefly, the nature and unique characteristics of these relationships.

Generically, studies examining the relationships of individuals with disabilities have noted problems: perceived constraints on attraction, societal barriers, discord, diminished communication, and difficulties in the physical aspects of sexual activity (Howland & Rintala, 2001; Kreuter, 2000; Rich, 2014). Some people with physical disabilities experience difficulties in forming and maintaining intimate and sexual relationships (Taleporos & McCabe, 2001a, 2001b). Some of this difficulty is due to feelings of inferiority, not being "up to scratch" and feeling less valued than those who live up to the cultural ideal of normality (Edwards & Imrie, 2003). Batty et al. (2014) noted that individuals with disabilities in relationships must draw on a number of "compensatory strategies" in order to effectively maintain their existing intimate relationships in the case of acquired disability (p. 686). This, in some cases, involves drawing on hyper-masculine or hyper-feminine enactments of sexuality in their relationships in order to deal with and "normalise" their disabled body, as noted before (Anderson & Kitchin, 2000).

However, studies have also routinely noted that the willingness of the partners (disabled and non-disabled alike) to engage in intimacy and sexual activity is of vastly more importance to the couple's relationship satisfaction than the physical aspects of sexuality (DeVivo et al., 1995; Esmail et al., 2001). Further, as Anderson (1992) notes, the presence of physical disability and sexual dysfunction is not a barrier to establishing close partner relationships.

In its specifics, however, the literature concerning relationships of persons with disabilities has focused almost exclusively on women who were sexually partnered to men with disabilities, and has focused almost entirely on heterosexual relationships. Men who date women with disabilities have not been explored in great detail (except in the case of devotees, see above). Homosexual relationships where one of the partners has a disability have not been examined to the same extent. Further, the relationship and partnering literature in disability studies has focused largely on (a) couples where only one partner has a disability, and (b) couples where the second partner's disability is acquired. In the section which follows, then, I will begin with a description of the findings amongst populations where only one partner has an acquired disability. I will then examine the work which has been done which deals with couples where both partners have disabilities, and couples where the disability of one partner preceded the initiation of the relationship.

The degree of sexual dysfunction experienced by any individual with a disability is related to their openness to partner. In a fascinating study of men with physical disabilities as well as their partners, Esmail et al. (2001) found that, although sexual dysfunction and reduced self-esteem were germane to the men in their sample, they had derived strength and support from their partners, and were able to cite the strategies which had helped them renegotiate their relationships in the context of an acquired disability. The men noted that communication in the relationship was strengthened due to the disability (Esmail et al., 2001). Further, as their sexual function was affected, the men re-evaluated the importance they had previously placed on sexual activities in the context of their relationships, and that intimacy and closeness became more important to them than intercourse (Esmail et al., 2001). A strong bond with their partners was perceived as more important than sexual activity itself (Esmail et al., 2001). Finally, even as the traditional gender roles changed following their disability, and this took negotiation on the part of both parties in the relationships, the men noted that their partner’s acceptance was a major buffer to the difficulties they faced in negotiating their disability, and moving the relationship forward (Esmail et al., 2001). Their partners echoed all these sentiments (Esmail et al., 2001).

Amongst women with disabilities, Li and Yau (2006) note that, in the context of a newly-acquired disability, “a woman may wonder whether a current partner will still find her desirable, or whether she will ever be able to satisfy her partner in a sexual relationship”, (this, of course, reflects gendered norms of what is required of women as partners) (p. 2). McCabe and McKern (2002) found that women with physical disabilities were more negatively impacted in their sexual and relationship functioning than were men. In their study, Li and Yau (2006) found that women’s post-disability concerns included overcoming the challenges to establishing a new romance, adjusting to their partners' attitudes towards their disability, and dealing with their fear of separation and divorce. Mathias and Harcourt (2014) found that, amongst female amputees, women feared rejection, often founded on a negative body image. However, they chose not to conceal their disabilities, and used it to "screen" potential partners in their search for deep and meaningful relationships.

Contrary to those findings outlined in the preceding discussion, amongst individuals with acquired disabilities, MacDougall and Morin's (1979) findings amongst people with congenital physical disabilities indicated that the majority of young adults interviewed were limited in their expression of their sexuality. Nearly all the individuals studied were unmarried, and very few had had a serious long-term relationship (MacDougall & Morin, 1979). Further, almost half of the participants had never had an intimate sexual experience with another person (MacDougall & Morin, 1979). However, almost half of the participants wanted to get married and expressed the desire to be involved in a romantic relationship.

The findings of this study are consistent with the notion that there are many factors that seriously limit the expression of sexuality amongst individuals with congenital disabilities, and that – when sexual identity development occurs in the context of disability (as opposed to before its onset), the result can be inhibitory of sexual development (MacDougall & Morin, 1979). However, MacDougall and Morin's (1979) study took place before disability rights advocates had begun to acknowledge sex and sexuality as a site of oppression for people with physical disabilities. In light of some of the progress which has been made in this realm, and new awareness of the relevance of sexuality to people with physical disabilities, some of the factors noted by MacDougall and Morin's (1979) participants might be less central to the relationship experiences of people with physical disabilities today.

What remains to be examined is those couples where both individuals have a disability. In a rare study of such cases by Crawford and Ostrove (2003), women recounted both negative and positive experiences with disabled partners. On the positive front, women noted that relationships with men who also had disabilities were marked by greater mutual understanding, empathy and similarity, which fostered closeness (Crawford & Ostrove, 2003). A common disability experience seemed to have an important positive influence on sustaining close intimate relationships amongst some of the women, whereas the lack of this similarity was perceived as an impediment to relationships when their partner was not disabled (Crawford & Ostrove, 2003). Nonetheless, the women did note that, in some instances, relationships with men who also had disabilities were marked by manipulation and abuse, both of which the partner dismissed as due to their impairment (Crawford & Ostrove, 2003).

As can be seen, there may well be some common characteristics of relationships amongst persons with disabilities (Ostrander, 2009). Further, as Crawford and Ostrove (2003) note, people with physical disabilities have vastly different experiences in terms of whether or not they are able to sustain a mutually satisfying and reciprocal relationship with either able-bodied or disabled partners. Regardless of these unique factors at play in such relationships, though, there are large commonalities between the relationships of individuals with disabilities and relationships in general.

Further, when it comes to sexual experience, people with physical disabilities have been found not only to enjoy rich and exciting sexual lives, but also to employ creative strategies to overcome physical obstacles to sexual expression (Bahner, 2012; Siebers, 2012; Smith et al., 2015). In an anthropological study, Guldin (2000) explored the “self-claiming of sexuality” of persons with disabilities (this self-claiming, he defined as “how participants cognitively construct, intentionally express, and sensuously and emotionally experience their sexuality" (p. 234)). They concluded that dominant cultural ideas related to sexuality, including the importance of physique and orgasm for sexual ability, were challenged by individuals with disabilities. Although his participants did not reject these cultural ideals, they placed more importance on other areas of sexuality and sexual activity, including the pleasure of their partner and their increased willingness to explore their own sexuality (Guldin, 2000). People with physical disabilities, then, often express the desire to be recognised as sexual beings, and experience a sustained – if not increased – desire for intimacy, even whilst sometimes acknowledging altered capacities for sexual pleasure (Shakespeare, 2006).

A complication in the above argument, and the evidence which supports it, is that there are, indeed, people with physical disabilities who self-identify as asexual. Indeed, disability activists in sex-positive movements often viciously attack the stereotype of disabled people as asexual, whilst overlooking the fact that such a universalising claim (all people with physical disabilities are sexual) rejects a conception of asexuality which can be positively experienced (Kim, 2011).

As Kim (2011) writes, "although asexuality has been persistently denounced as a damaging myth imposed on disabled people, people with physical disabilities who do not identify as sexual highlight the unavoidable intersection of normality and sexuality" (p. 480). That is, if one is to deny that a person with a disability cannot be asexual, one reinforces the assumption that sexuality equals normality, and – therefore – merely develops yet another category of abnormality into which people can be discarded. Kim (2011) notes that researchers tend to deny any connection out of fear that the stigma associated with one might attach to the other. Yet this tendency further reinforces the idea that in order to be normal, one must perform a sexuality.

The purpose of my argument here, simply, is to sever the implicit connection between disability and asexuality as two inherently abnormal conditions always found together (Kim, 2011). Thus, it is not to discount asexuality as a claimed and claimable identity, but rather to challenge its automatic association with disability, and indeed disabilities' association with it. Asexuality is not a flawed identity, but it is one to be claimed on its own grounds, and not one to be imposed.

Much of the research into the sexuality of people with physical disabilities touches on societal and social issues regarding the attitudes of others to the sexuality of people with physical disabilities, but does not explore them in depth. In the section which follows, the intersection between societal attitudes, and the experience of sexuality of persons with disability in the realms of sexual health, reproduction, identity development, and sexual education will be explored. I will outline the various ways in which social factors, chiefly the attitudes of others, affect the sexuality of individuals with disability. The section which follows, then, constitutes the third pillar of research upon which this review rests. The first established that the social milieu ill-frames, or negates, the sexuality of people with physical disabilities, and the second, that this is at odds with the sexualities enjoyed by people with physical disabilities; the following section will explore the sequelae of this disjuncture between societies' views, and the needs and realities of people with physical disabilities in the realm of sexuality.

2.3.2 Sequelae of societal thought and individual attitudes

It is not difficult to argue that broad societal discourses, and individual attitudes, have consequences for behaviour, although the nature of the relationship varies (Ajzen, 1991). Further, it is not difficult to establish that people with physical disabilities face challenges in life, and prejudice, not encountered by non-disabled persons. One possible explanation for the unique "burden of difficulty" placed upon people with physical disabilities in many spheres of their lives, then, are the negative societal perceptions of, and attitudes of others towards, them. As famed by Erevelles (2011), people with disabilities, like all people, "come to know ourselves and others in the world [through] material engagement" (Erevelles, 2011, p. 25). For people with physical disabilities, this material engagement – often with other human beings who hold problematic views of disability – is a fraught process, in which the body of the disabled subject is inscribed with a host of meanings. Disability, in this perspective, is an identity which is continuously shaped, and becomes, in interaction with others. Indeed, several authors have proposed that sociocultural barriers to people with physical disabilities may be as disabling as physical impairment (Oliver, 1995; Sakellariou & Algado, 2006).

Ballan (2008) writes that, "cloaked as protective practices, the lack of appropriate information afforded to disabled people about their sexuality underscores the failings of existing legislation and policy to stop discriminatory practices" (p. 198). This highlights the ways in which, as Wade (2002) writes, barriers to sexual participation for people with physical disabilities are social, and not somehow intrinsic to the individual or due to their impairment.

People with physical disabilities face sexual exclusion from society due in part to the fact that they may be perceived to deviate from strict cultural demands for aesthetic and behavioural "normality" (Davis, 1995; Garland-Thomson, 2009; Shuttleworth & Mona, 2002), but also because, as McRuer and Mallow (2012) note in their book *Sex and disability*, the idea of disability and sexuality are antithetical in the popular imagination, and therefore deemed deviant in combination.

Broadly stated, the negative societal thinking and feeling about, and representations of, the sexuality of people with physical disabilities outlined at the outset of this discussion have negative consequences. They can result in the lives of people with physical disabilities being complicated by barriers in their sexual and personal relationships, obstacles to maximising their sexual potential, and to accessing information about matters of sexuality (O'Dea et al., 2012). Further, and perhaps most importantly, people with physical disabilities may internalise negative societal assumptions about, and attitudes towards, their sexuality (O'Dea et al., 2012; Shuttleworth et al., 2012). I briefly lay out the evidence in support of each of these claims.

Firstly, it has been found that certain societal beliefs and attitudes can have a direct impact on people with physical disabilities' participation in sexuality-related activities, attitudes, sexual self-esteem, sexual identity development, and quality of life (Bremer, Cockburn, & Ruth, 2010; Dune, 2014; Esmail et al., 2010; Li & Yau, 2006; Parker & Yau, 2011; Phillips & McNeff, 2005; Potgieter & Khan, 2005; Sakellariou, 2006; Sakellariou & Algado, 2006; Shuttleworth et al., 2012). Having to negotiate one's sexual identity in light of cultural assumptions and prejudice is no mean feat (Dune, 2014). The incongruity between societies' desexualisation of people with physical disabilities, and these people's expectations and desires for their own lives, has consequences for the sense of their own desirability that people with physical disabilities may hold (Howland & Rintala, 2001). This incongruity may also affect their view of sexuality (Esmail et al., 2010), and their quality of life (Galvin, 2005). Self-esteem, sexual identity development, and sexual-esteem are interconnected, and the effects of harmful, inaccurate, and pernicious societal beliefs which negate the sexuality of people with physical disabilities damage them in concert, and produce pressure for people with physical disabilities to perform "normativity" in order to "pass" as acceptable sexual subjects (Scott, 2015).

Secondly, as society at large – and many professionals – assume that people with physical disabilities are not sexual or sexually active, it is hardly surprising that access to sexual health services for people with disabilities is largely neglected. Individuals with physical disabilities face barriers to sexual health care access which are structural (such as inaccessible health care provider offices) and social (such as health care providers suggesting that people with physical disabilities should not procreate) (Bremer et al., 2010; Lee & Lee-Ann, 2016; Lee et al., 2015; Pebdani, Johnson, & Amtmann, 2014; Valvano et al., 2014). For instance, researchers and activists have found a wide range of attitudinal barriers experienced by women with physical disabilities in their attempts to access reproductive health care (Ahumuza et al., 2014; Collins, 1995; Fine & Asch, 1985; Lee & Oh, 2005; Thomas, 1997, 1999, 2001; Vaughan et al., 2015), and contraception (Smith, Murray, Yousafzai, & Kasonka, 2004; Weiner, 1997).

But the attitudinal barriers encountered by people with physical disabilities in accessing sexual health care include the negative attitudes of health professionals, which have been found to be unsatisfactory, if not damaging, for the individual with a disability. For instance, in a study by O’Dea et al. (2012), it became apparent that negative attitudes on the part of health care providers played a significant role in inhibiting the sexual expression of persons with disabilities. This, in turn, significantly increased the negative consequences of having a disability on the individuals’ quality of life (O’Dea et al., 2012).

Next, as people with physical disabilities are taken to be asexual, the need for sex education for people with physical disabilities is overlooked (Cheausuwantavee, 2002; East & Orchard, 2014; Seidel et al., 2014). The misconception that people with physical disabilities are asexual and so sexually inactive has resulted in a paucity of sex education for students with disabilities (Pebdani, Johnson, & Amtmann, 2014). This, in turn, has consequences for the students themselves, who are placed at higher risk of unwanted pregnancy, the contraction of sexually-transmitted diseases, and limited in their sexual expression (Becker, Stuifbergen, & Tinkle, 1997; Bremer et al., 2010; Nguyen, Liamputtong, & Monfries, 2016; Seidel et al., 2014).

Finally, there is much evidence of an elevated rate of sexual violence perpetrated against women with impairments when compared to non-disabled women (Stromsness, 1993), and – specifically – against women with physical disabilities (Milberger et al., 2003). One of the reasons put forward for this sorry fact, is that – again, due in no small measure to societal attitudes – women with physical disabilities lack social experience and sexual education (Crawford & Ostrove, 2003). But, aside from the high levels of violence itself, a consequence of negative societal attitudes and cultural ideologies regarding the sexuality of people with physical disabilities, is that women from this population who experience sexual violence, seldom disclose it (Astbury & Walji, 2014). As Astbury and Walji (2014) note, if some of the broader social and cultural attitudes which pathologise disabled sexuality are changed, the responses to women with disabilities who are victims of sexual crimes will change too. One possible explanation for women with disabilities' reluctance to disclose abuse is that these women are aware of societal attitudes towards their sexuality, and would rather avoid the discomfort of inept medical and legal services (Kemp & Mallindrokt, 1996). In fact, it has been noted that, when women with disabilities do disclose incidents of sexual violence, they are treated differently to non-disabled women (Kemp & Mallindrokt, 1996).

Thus far, I hope to have illustrated three broad points:

1. that there is a pervasive myth that people with physical disabilities are asexual, and belief in this myth influences non-disabled individuals' thinking and feeling about, and representations of, the sexuality of people with physical disabilities;
2. that – contrary to the myth – many people with physical disabilities do experience an active sexuality; and
3. that the myth of asexuality amongst people with physical disabilities has negative consequences for the lives of the physically impaired. Where negative attitudes exist, there are negative outcomes for people with physical disabilities.

However, the literature on which the preceding review is based almost entirely includes research conducted in the Global North. Research into attitudes towards the sexuality of people with physical disabilities is scarce, and – in South Africa – largely absent. The cultural norms around which attitudes towards the sexuality of people with physical disabilities develop are largely locally-determined and culturally mediated (Devlieger, 1999; Kisanji, 1993; Sharkawy et al., 2006; Wazakili, Mpofu, & Devlieger, 2006), and so context-specific exploration of these attitudes is necessary. The following section will provide a brief survey of the literature concerning sexuality and disability, first from low- and middle-income countries, and then from sub-Saharan Africa and South Africa, in order to better sketch the landscape within which the present study will locate itself.

2.3.3 Notes on culture and context: Studies from Africa and South Africa

This section briefly highlights work hailing from the continent, as well as South Africa more specifically. I begin outlining work concerning the "attitudes" section of this project, and then move on to a consideration of the "experiences" section.

Numerous researchers have found that culture influences individuals' attitudes towards people with physical disabilities (Kisanji, 1993; Sharkawy et al., 2006; Wazakili et al., 2006). Studies of disability in non-western contexts are relatively few and far between. But what work has been done has revealed that what is perceived to be a disability is culturally specific (Simkhada et al., 2013). Moreover, it is related to the level of development of the society in question (Simkhada et al., 2013). In rural Nepal, for instance, the majority of a 400-women sample only considered physical conditions that limit an individual's functioning (and are visible) to constitute a disability (Simkhada et al., 2013).

And, as well as understanding what constitutes a disability, attitudes towards individuals with disabilities also show cross-cultural variation. In the above-mentioned study in Nepal, attitudes towards people with disability were generally positive, and the women surveyed believed that disabled people should have equal rights (Simkhada et al., 2013). They also believed that persons with disabilities could and would get married and have children (Simkhada et al., 2013).

In Africa, Mamboleo et al. (2015) note that the attitudes of non-disabled individuals towards people with physical disabilities vary considerably across cultures within the continent. Mamboleo et al. (2015) highlight that, while anthropological studies suggest that Africans are reticent about expressing negative attitudes towards people with physical disabilities, other studies have found that people with physical disabilities encounter stigma and discrimination in their everyday life (see Macha, Kieti, & Ngunyi, 2007). A complicating factor in influencing attitudes towards people with physical disabilities in Africa, which may be less present in some Western contexts, are cultural-religious beliefs. For example, disability may be attributed to witchcraft, curses from the Gods or one’s ancestors (Getachew, 2011; Kiima, Njenga, Okonji, & Kigamwa, 2004; Ogechi & Ruto, 2002). These beliefs can lead individuals to view disability as shameful, and result in negative societal attitudes towards people with physical disabilities in Africa.

For instance, in Senegal, young people with disabilities reported very low knowledge about sexual and reproductive health, and were not accessing sexual and reproductive health services (Burke et al., 2017). In this study, barriers to accessing services included financial barriers, provider attitudes and physical accessibility of facilities. The youths in this study also reported multiple cases of sexual assault (Burke et al., 2017).

Mamboleo et al. (2015) and Getachew (2011) have further noted that negative attitudes towards people with physical disabilities in some cultural communities in Africa extend to families and friends of the people with physical disabilities. This might be particular to the sexual development and experience of people with physical disabilities in Africa, as involvement in a sexual relationship with a person with physical disabilities could lead to ostracism.

In South Africa, few studies have examined attitudes of any kind towards people with physical disabilities. This is problematic, as, in the words of Hanass-Hancock (2009), “disability and gender [in parts of this region] are associated with myths and stereotypes that exacerbate the vulnerability of people with physical disabilities to HIV/AIDS” (p. 35). In a study of attitudes towards, and beliefs about, persons with disability in KwaZulu Natal, South Africa, Marini et al. (2011) found that people with disabilities were considered to be either asexual or sexually hyperactive, virgins, cursed, dirty, or, conversely, clean. These beliefs, in turn, increased this population’s risk of exposure to abuse and HIV/AIDS.

Despite this risk, two South African studies have found that educators lacked the knowledge and – particularly – confidence to successfully teach sexuality education to adolescents with disabilities (Chirawu et al., 2014; de Reus et al., 2015). This increased the students’ vulnerability to HIV (de Reus et al., 2015). In a vein similar to that noted in the preceding section on self-esteem, research in South Africa has suggested that adolescents are particularly vulnerable to social pressures to be perceived as “normal”. This pressure, when combined with their own sense of physical difference, rendered young people with physical disabilities in South Africa vulnerable to HIV, as they have reported that the need to feel accepted and loved was more important than the need to practice safe sex (Wazakili et al., 2006).

Exacerbating the negative effects of this lack of education and social pressure, is the fact that almost nothing is known about how, or even if, the HIV and sexual health promotion strategies implemented in South Africa are implemented amongst youth with disabilities

(Chappell, 2015). This is despite the fact that researchers have noted an urgent need to provide sexuality education for youth with disabilities (de Reus et al. 2014; Rohleder & Swartz, 2009). Examining the content of societal attitudes towards the sexuality of people with physical disabilities in South Africa could yield important insights into why these issues continue to go unaddressed.

There is variation, however, and disability did not take precedence in conceptualising experiences of sexuality for the participants in Chappell's (2014) study. Participants in Chappell's (2014) study focussed on notions of romantic love and the tribulations of initiating courtship, although they did discuss disability in relation to dating. Indeed, participants focused on the role of gender and culture in relation to love and dating in conceptualising their sexuality, rather than their disability (Chappell, 2014).

2.4 Research Rationale

What I hope to have illustrated in the foregoing discussion is this: disability studies as a field is constituted to examine the ways in which the lives of persons with disabilities are complicated by the meanings attached to impairment by society at large. Within disability studies, the social model (and, by implication, its derivatives) is ideally positioned to examine the ways in which barriers, in this case attitudinal, operate to systematically exclude persons with disabilities. One realm in which these attitudes operate to the disadvantage of people with physical disabilities in particular, is sexuality. The prevailing myth that people with physical disabilities are asexual influences the attitudes of individual members of societies. These attitudes, and at times their behavioural counterparts, cause pain, difficulty, and exclusion for persons with disabilities. In South Africa, where people with physical disabilities are at increased risk of HIV (Chappell, 2015) and sexual violence (Chirawu et al., 2014), attitudinal barriers to sexual education (De Reus et al., 2015), and sexual health services (Rohleder, Swartz, Schneider, & Eide, 2012), are particularly problematic. Further, in this context, little is known about the prevailing attitudes of the general public to sexuality amongst people with physical disabilities in South Africa.

The present study proposes to examine the nature of South Africans' attitudes towards the sexuality of people with physical disabilities. The project, then, examines a topic for which there is a paucity of research, and which is of immediate relevance to broader health concerns, particularly HIV. Further, if some of the barriers faced by people with physical disabilities outlined in the review above are to be overcome, then the content of societal attitudes needs to be closely examined.

Most of the existing evidence in the field of sexuality and disability, and the barriers faced by people with physical disabilities in the realm of sexuality, have looked at these issues from the perspective of people with physical disabilities themselves. In these studies, disability stigma and discrimination from non-disabled persons are highlighted as crucial factors for a negative construction of sexuality and sexual health among people with physical disabilities, as well as for some of the barriers to sexual and reproductive health faced by this group (Kvam & Braathen, 2008).

The present study will explore two things. Firstly, it examines attitudes towards the sexuality of people with physical disabilities from the perspective of non-disabled people, to explore the realities behind the stigma and discrimination perceived by people with physical disabilities and detailed in theoretical models of disability and sexuality. What this part of the research sets out to do is modest: to explore the thinking and feeling about, and representations of, some South Africans, from different backgrounds, with different levels of education, knowledge and exposure to people with physical disabilities, of the sexuality of people with physical disabilities. It is an attempt to look at the quality and content of thinking and feeling about, and representations of, the sexuality of people with physical disabilities, against the backdrop of an argument which suggests that non-disabled people's attitudes have implications – real and often negative – *for* people with physical disabilities.

Secondly, the present study examines the experiences of sexuality and sexual and reproductive health, of people with physical disabilities in South Africa, using photovoice as method. Against the backdrop of the attitudinal milieu outlined thus far, and specified for the South African context by the findings of the survey part of this study, I intend to explore the experiences of sexuality of people with physical disabilities.

2.5 Aims and Objectives of the Present Study

The aims of the present study were to:

1. Examine the thinking and feeling about, and representations of, members of the general public, of sexuality amongst people with physical disabilities in South Africa; and
2. Explore the experiences of a group of people with physical disabilities' experiences of sexuality and sexual and reproductive health care in South Africa.

This project aimed to investigate the thinking and feeling about, and representations of, the sexuality of people with physical disabilities in South Africa. It was hoped that by so doing, a space could be opened in which these issues can be addressed, erroneous opinions and negative attitudes changed (if they are found to exist), and – ultimately – specific focus areas of misinformation and prejudice be identified and then targeted with campaigns and interventions. This is in line with the UN Convention on the Rights of Persons with Disabilities Guiding Principles (United Nations, 2006).

To achieve the first aim of the project, this study addressed two specific objectives. The first objective was to engage people with physical disabilities in determining their priority areas for inclusion in a survey of societal attitudes towards the former group’s sexuality. In line with this, the project was conducted with the direct collaboration of a prominent Disabled People’s Organisation (DPO) in the southern African region, as well as a group of people with physical disabilities.

Secondly, the project involved the use of a survey – with both qualitative and quantitative elements – to elicit public attitudes towards the sexuality of people with physical disabilities. This allowed me to gain insights into the nature of public thinking and feeling about, and representations of, the sexuality of people with physical disabilities, including textured qualitative responses.

Given the imperative (United Nations, 2006) to challenge discriminatory attitudes, and in so doing promote non-discrimination with regards to sexual health issues and promote equality in sexual and reproductive health, there is a need for work which explores, in nuance, experiences of people who may be marginalised in relation to sexuality and sexual and reproductive health rights. The objective of the second arm of the project, then, was to provide a sensitive and nuanced visual and analytic account of the experiences of different facets of sexuality and sexual and reproductive health, of people with physical disabilities. This entailed the use in South Africa of photovoice as a research method of enquiry with people with physical disabilities.

Given the general scarcity of empirical evidence on sexuality and disability, particularly from low-income contexts and from countries with high prevalence of HIV/AIDS, this project will fill a much-needed gap in knowledge.

CHAPTER THREE

Method Narrative

This section is a hybrid between a conventional methods section, and a somewhat self-reflexive narrative about my role in this project. Each publication in this dissertation deals in detail with the methods used in the subsection of the analyses with which it was concerned. As such, I do not reiterate these minutiae here. Instead, I attempt to provide the reader with an overview of the project, clarify the methods, and explain my role in the study.

3.1 How I Came Into This Project

During the course of my honours year, I approached Professor Swartz, who is now my primary supervisor, on the basis that I wanted to do a Masters, with him, and in the field of disability. Prof Swartz was part of a team, headed by my current co-supervisor, Dr Rohleder, which had recently received a grant, from the funding agency FIRAH (International Foundation of Applied Disability Research) (http://www.firah.org/index.php?lang=en), to conduct a study on the sexuality of people with physical disabilities in South Africa. The proposal had been written, the methods of the project largely decided upon, and ethical approval for the work obtained (University of East London Ethics Number UREC141561; Stellenbosch University Ethics Number HS1163/2015) (Appendix A). My desired supervisor, therefore, had a project. The project needed a Masters student. And I needed a supervisor. I read the proposal, made my application to fill the position, and, in late 2015, was awarded the position.

Since this time, I have moved up in position within the team, from a research assistant, whose task it was to collect data and analyse a small portion of it for the purposes of her Masters, to a Doctoral candidate who project managed much of the work for the study. During the course of my Masters year, the project drew the attention of a faculty member, who recommended that I upgrade the Masters to a PhD; I applied to do so, went through four rounds of vetting, and was successfully registered for a Doctorate in 2016. I have generated the bulk of the publications, presentations, and other outputs (including an exhibition of the photovoice work, a short documentary stemming from the project, and a book proposal which is currently under review with Palgrave).

It remains the case, however, that I worked on a project which was not initially of my design (although I was able to play a substantial role in the details of the study), and with an excellent international team. I am indebted to them – for their guidance in their respective areas of expertise, and for their mentorship in project management.

It also remains the case that I came into the specific study of sexuality and physical disability, somewhat by chance. This brings me to an important point, which must precede a detailed discussion of methods – my position in relation to the topic.

About a year into my PhD, I was lucky enough to attend the Nordic Network for Disability Research's biannual conference in Sweden. One of the keynote addresses was given by Don Kulick. The talk, as a whole, was complex and interesting, and I would do it no justice in the retelling here, so I distil a single point (for a publication which deals with some of the ideas presented in this speech in greater depth, please see Kulick, 2015). Kulick argued that researchers in the field of disability studies state their relationship to disability. This, he argued, broadly, presented itself as a demand for some sort of claim or relation to disablement. It reads or sounds – as it is often written in the preface to books about disability, or stated at the beginning of talks about disability – like a tentative and often tenuous search for legitimacy:

> I bear this relationship to disabled people/I am a disabled person, and so I am not part of the oppressive majority of ableist others about who I likely write or speak in this book or talk (Kulick, 2015).

I liked Kulick's point. I did not like to think, at the time, that I needed to have some relationship to disability to make my work legitimate. I worried that I did not have any relationship to disability, and so my work would bear the stamp of someone writing without knowing. I liked the idea that I could do my work, sensitively and with understanding, without having to "know" disability.

Kulick's talk, however, had the colleague I was travelling with, almost outraged. Brian Watermeyer, who has published extensively in the field of psychoanalytic disability studies (Watermeyer, 2006, 2012; Watermeyer & Swartz, 2008), disagreed wholeheartedly with Kulick's argument. One's unconscious or conscious relationship to disability both within oneself and in the broader world, Brian argued, must be understood if one is to work in the field. Particularly, he said, pointedly, when one is doing qualitative work, and is young. I argued with him for a bit, and then dropped it.[10]

But I have thought about these two arguments for a long time. I do not have an answer regarding which approach is better, but I have decided my path, and I present it here: the impact of my personal history on this project.

I have what some might call (but I do not) a psychosocial disability: anorexia nervosa. It has greatly impacted on my relationship with, and others' relationship to, my body, over the years. I have a disgust reaction which is triggered by the slightest deviation of my body from the narrowest possible definition of how a woman "should" look. Oddly and paradoxically, due to the extreme degree to which anorexia removes one's embodiment from what is, actually, considered desirable by society at large, I am also familiar with the experience of evoking disgust and discomfort in others.

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[10] Incidentally, they were talking at cross purposes – Kulick was not negating the importance of self-reflection, simply drawing attention to the problematic of the confessional urge felt by non-disabled people in the field and speaking about a certain type of identity performance. Brian was not endorsing this urge, simply drawing a young researcher's attention to the dangers of avoidance.

I have had a troubled and changing relationship to my embodiment, and have been affected by others’ reactions to it. When I started working on the project, I imagined that the participants would, like me, have had to consider their own non-normative embodiment, but obviously in different ways. I choose not to compare experiences, because my experience differs in central respects, to the relationship to bodies of the participants. Primarily, because anorexia nervosa is (and, in my case, has been, largely) remediable. Secondly, because – at least in the beginning – it moves the person living with it closer (and not further) towards an acceptable aesthetic (and, even when one is repellently thin, reactions of others often convey a sort of thinly-veiled admiration, rather than pure discomfort).

I am, however, acutely aware of the impacts and limits of pity, and so the qualitative survey aspect of this study – which dealt with non-disabled peoples’ often pity-laden reactions to disability – angered me. Fortunately, I was able to rely on the tempering influence of my supervisor, fellow coders, and the broader team with whom I worked, so that my indignation was not disproportionately conveyed in the write up.

I am also intensely interested in the dynamics of looking, not only as a result of having an eating disorder which paints on the body a protest to feeling invisible, but also because I am a woman. The importance of being seen, viewed and visually acquired was central to much of my socialisation. Anorexia is an exercise in managing looking. It takes to its logical extreme society’s imperative for women to be objects of a gaze – a gaze which demands mastery over unruly curves. It invites looking which is perverted – is asks for staring as an acknowledgement in achieving a spectacle worthy of fear, admiration and disgust.

Looking and sexual looking – being recognised as a sexual being, as alluring, and as a kind of visual novelty which invites hunger from men, or women – disappears with the progression of the disorder. One is demanding, and must be managed. The other threatens to intrude, but also affirms. I have been the object of both types of looking, and am fascinated by their limits and effects. I am interested in the objects' agency in managing others' looking.

This, and my background in media (I am a journalist), drove my particular interest in, and the subsequent growth of, the photovoice segment of this study. It is the reason that when I upgraded my Masters to a PhD, I expanded the scope of the work to include further room for theorisations of representation and self-presentation, and examination of managing others' gazes.

Finally, I am extremely sensitised to the functioning of disgust in intra- and interpersonal dynamics. As such, I found it difficult, at times, to manage interactions where participants expressed disgust about themselves, or to be "objective" about data where non-disabled people were clearly disgusted by the prospect of romantic proximity to people with different-than-average embodiment. Again, my team (particularly Prof Swartz), as well as Brian Watermeyer, were open to exploring my thinking and reflections on the subject, and tempered my inclination to look away when disgust was at hand.

There end the ways in which I feel my personal corporeal and psychic history impact on the present work. My social reality, however, also bears mention.

I am White, young, and come from an economically well-to-do family. These factors, I think, perhaps equal to my own relationship to embodiment, struck me continuously during the course of the project.

Firstly, if I were to encounter some of the barriers to reproduction which affected many of the women with whom I worked, I would have the economic means to circumvent them. I would have access to IVF. I have the educational background to challenge doctors who prescribe to me – as happened to one participant – a 'fertility enhancing treatment' which actually rendered her sterile. I could have – with money – insulated myself from some of the effects of an injury. This is not to claim that it is always and inevitably easier to live (in every sense of the word, including psychologically) with a disability if one is wealthy. It is simply to say that it is easier to address some of the functional limitations engendered by a disability if one has the requisite resources to do so. This struck me during the course of the project. It has led to my focus in subsequent work (Hunt & Watermeyer, 2017; Watermeyer, Hunt, Swartz, & Rohleder, under review) on the relationship between socioeconomic status (SES), disability, and various facets of suffering/coping/thriving.

Secondly, the women, and particularly the men, with whom I worked over the course of this project, often had their femininity or masculinity, respectively, loudly called into question by their communities due to their disability. South Africans' notions of masculinity and virility, particularly, are, as many scholars have argued (Boonzaier & de La Rey, 2003; Jewkes & Morrell, 2010; Leddy, Chakravarty, Dladla, de Bruyn, & Darbes, 2016; Shai, Jewkes, Nduna, & Dunkle, 2012; Shefer, Kruger, & Schepers, 2015), mainly narrow, inflexible, and brittle to the point of absurdity when brought up against an impediment (which is what disability is seen to be). But this is applied differently, depending on the communities from which men came. Higher SES, well-educated men were able to equip themselves with the "compensatory" resources of which participants spoke in Publication 4.[11] Equally, attacks on others' sexuality are socially proscribed on university campuses and in affluent suburbs, perhaps more so than in communities where traditional gender roles, and virility, still hold substantial sway. The limits of politeness are clear – higher SES participants were still often aware that their sexuality was being called into question, but it was implied rather than announced (whether this is a good or bad thing is worth thinking about). Still, the differential impact of cultural norms, gender roles, and expectations for fulfilling ideals of masculinity and femininity, according to SES, culture and education, were noticeable. This

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[11] I have elaborated on this thinking in a paper with Brian Watermeyer, which is currently under review.

was noted in Publications 2 and 4 (and in depth in Watermeyer et al., under review). It will also be expanded on in the proposed book stemming from this project.

However, I was also made aware of the limits of cultural and social exceptionality. In a project such as this, which deals with a universal (sexuality) in a specific context (South Africa), I had to balance competing findings of relativism and specificity on the one hand, and common humanity on the other. I found at times that journals required specificity – rejected "experiences of the universal body" – due to the context of the study. This is a difficult demand to manage – the requirement to perform cultural specificity where the data suggests little exists. This is a subject in academia which bears further exploration, but is beyond my scope presently.

It is my hope that this section does not read as the kind of performance of which Kulick (2015) spoke. Rather, I hope that it frames my position within this study, and the manner(s) in which my history and current way of being may have been brought to bear on the present work. I now move to a precise description of the methods and analyses used in the study. These methods and analyses were largely predetermined by the rest of my team in the original proposal to our funder. However, I conducted much of the data collection and analysis for the data used in this study (my contribution is explicated in Appendix B.

3.2 Methods and Analyses, Précised

The present section provides a brief overview of the methods and analyses employed in the present work. Further details are outlined in Publications 1-6.

3.2.1 Research design

The present study entailed cross-sectional survey, photovoice, and interview components. The survey was administered amongst the general population, whilst the photovoice project was conducted by participants with physical disabilities. The photovoice participants were trained in photovoice methodology, and then followed up at five months for an interview and a discussion of their photographic data. An additional interview was conducted with one of the participants, although the data gathered were not used for publications in the present dissertation.

3.2.2 Procedure and participants

3.2.2.1 A survey of general attitudes towards the sexuality of people with physical disabilities

An online survey (see Appendix C) explored the knowledge and attitudes of the “general” population about physical disability and sexuality (here, “general” implies a diverse sample, as opposed to a representative sample, and so due caution was applied when interpreting results for their applicability to the wider South African context). The survey included questions measuring prevailing myths about disability and sexuality, and attitudes about the sexual and reproductive health rights of people with physical disabilities. Questionnaire items were identified through focus group discussions with people with physical disabilities (invited with the assistance of the Southern Africa Federation of the Disabled (SAFOD), the largest network of disabled persons organisations in the region) and from a literature review. The survey items were checked with the focus group participants prior to the survey being finalised. The survey was translated into isiXhosa, isiZulu, and Afrikaans, and was available online in these languages, as well as in English.

The survey respondents were recruited through the use of social media (such as through a dedicated Facebook page) and other social networks, and was advertised on two of South Africa’s top news sites. Permission was obtained from the institutional planning departments of Stellenbosch University, and the University of Johannesburg, to distribute the survey amongst students. The survey was also administered by hand by trained data collectors in Langa and Khayelitsha. This was to avoid biasing the sample towards educated, literate persons with access to computers. The pen-and-paper respondents were selected at convenience by the data collectors who recruited respondents for the survey from busy areas (markets, taxi ranks, and through their own social networks) in the respective locations.

All respondents had to be at least 18 years of age or older in order to complete the questionnaire (due to the sexual nature of some of the content). The survey was completed by 1989 individuals.

3.2.2.2 The experiences of people with physical disabilities

This section of the study made use of Photovoice (Wang & Burris, 1997) techniques. Photovoice is a participatory research technique in which participants are trained as co-researchers and photographers. Participants are asked to take photographs that represent their everyday experience, and are then invited to provide narrative discussion in relation to illustrative images (Vaughan, 2014). The photographs are used as both visual data and as stimuli to elicit personal narratives.

A group of 13 people with physical disabilities (8 females and 5 males) were recruited via the networks of SAFOD (these individuals were also participants of the focus group involved in the survey design). Each participant was provided with a digital camera and asked to take photographs which symbolised his/her experiences of sexual relationships, sexuality, and sexual and reproductive health care. Training was provided as to what was expected in terms of their photography. I requested that participants not take photographs that were explicitly sexual, but rather photographs which represented and were symbolic of their everyday experience.

Participants were asked to take part in an individual interview five months later. They selected up to five photographs that they felt most represented their experience. These photographs were used as discussion prompts in an individual interview. The interviews explored participants' experiences of their sense of sexual self, intimate relationships, and engagement with sexual and reproductive health care. Interviews were tape-recorded and transcribed.

3.2.3 Measures

3.2.3.1 A survey of general attitudes towards the sexuality of people with physical disabilities

Survey: Following the workshop discussed above, the survey for the present study was designed with the intention of eliciting general population attitudes towards sexuality amongst people with physical disabilities. The questions posed in the survey were done so with a desire to provoke responses concerning both the areas highlighted as important by the co-researchers (the people with physical disabilities who had taken part in the workshop), as well as ones considered to be relevant by the research team, based on past literature.

The survey included questions measuring attitudes about the sexual and reproductive health rights of people with physical disabilities, and attitudes towards various facets of sexuality amongst people with physical disabilities. It also contained a demographic questionnaire to establish the general characteristics of the sample. In addition, the survey included measures of prejudice (Social Dominance Orientation, SDO), respondents' prior contact with people with physical disabilities (the quantity of this contact, the quality of this contact, and whether or not it had been romantic in nature), the respondents' inclination to avoid social proximity with people with physical disabilities (social distance), all of which have proven useful in explaining individual variation in attitudes towards outgroup members in the past (in the present research, people with physical disabilities are the “outgroup”, whilst the non-disabled respondents are the “ingroup”’). Only a subgroup of these scales was included in the analyses for the present study, given the scope of my role in the study, and the specific objectives of my work.

3.2.3.2 Photovoice

Semi-structured interview: Following the completion of their photographic work, each participant was interviewed regarding their selected images and what they symbolised, and their experiences of photovoice as methodology. As part of this interaction, the research team (Dr Rohleder, Dr Braathen, and I) conducted semi-structured interviews with participants. These interviews included questions regarding the participants’ experiences of sexual and reproductive health services and intimate relationships. The interview schedule can be found at Appendix D.

3.2.4 Analysis

3.2.4.1 A survey of general attitudes towards the sexuality of people with physical disabilities

The survey, as noted, included both closed- and open-ended items, and was thus analysed by means of statistical analysis (using SPSS) for the quantitative data and thematic analysis (using Atlas.ti) as outlined by Braun and Clarke (2006) for the qualitative data.

3.2.4.1.1 Quantitative analyses

The quantitative analyses proceeded along two main lines: descriptive statistics, and inferential statistics. Descriptive statistics were used to generate a description of the sample from the demographic items. Following this, Cronbach's alpha was calculated for each of the scales, and composite measures were generated for the various sections of the survey.

To investigate the underlying factor structure of the measured items, an exploratory factor analysis was first conducted. Specifically, we employed a direct oblimin rotation.2. Subsequently, Dr Carew, the project statistician, tested whether a significant difference existed between respondents' beliefs about the sexual and reproductive rights, and benefits of sexual and reproductive health services, of people with physical disabilities, compared to the non-disabled population. On an exploratory basis, we also tested whether these beliefs varied according to participant gender. Specifically, we ran two mixed ANOVAs with participant beliefs (i.e., concerning either rights or benefits of sexual and reproductive health care) about each target group as the repeated measures factor, and gender (male, female) as the between subjects factor.

3.2.4.2 Qualitative analyses

Wilkenfeld and Ballan (2011) note that open-ended, qualitative questioning is useful for exploratory research, in part because such methods provide investigators with access to others' thoughts and understanding through their textual responses. These textual responses provide insights which the investigator can use to inform their understanding of the attitudes and beliefs in question.

The open-ended questions in this study invited respondents to answer free-response questions (provide a list of adjectives which they associate with people with physical disabilities), and complete vignettes as they best saw fit. In one instance, they were also asked to explain why they chose to complete the vignette narrative in the manner that they did. This meant that I could gain insights not only into the content of attitudes about sexuality and disability of people with physical disabilities (as these informed the respondents' completion of the narrative), but also the respondents' motivations for their attitudes and beliefs – the thinking underlying their attitudes towards sexuality and disability. The free-response items gave a sense of the dominant stereotypes in relation to people with physical disabilities.

I employed thematic analysis (Braun & Clarke, 2006) to arrive at a textured understanding of the qualitative survey responses. To achieve this end in the present inquiry, the qualitative responses in isiXhosa, isiZulu and Afrikaans were translated by professional interpreters. Each translation was then checked by a second, independent translator. The translated transcripts, as well as the transcripts from the English survey, were coded by me, as well as by two assistants on the project.

The use of three independent coders is imperative because, as Braun and Clarke (2006) highlight, reliability is a concern in thematic analyses (because a certain amount of interpretation goes into defining the codes as well as applying the codes to the text). Having two researchers identify codes which represent the most salient categories into which the data cluster independently, is a way of ensuring greater reliability within this sort of qualitative work (Miles, Huberman, & Saldana, 2013). The coding of the data involved a close examination of the textual data, but also its categorisation into more coherent themes through which conclusions could be reached regarding the content of the participants' responses (Aronson, 1995).

3.2.4.2.1 The experiences of a sample of people with physical disabilities

In the photovoice component of this study, conducted with the group of 13 people with physical disabilities, participants were asked to take photographs that represented their everyday experience, and were then invited to provide narrative discussion in relation to illustrative images (Vaughan, 2014). The photographs were used as both visual data and as stimuli to elicit personal narratives. These photographs were used as discussion prompts in individual interviews. The interviews were conducted by either Dr Poul Rohleder, Ms Stine Hellum Braathen, or me. The interviews explored participants' experiences of their sense of sexual self, intimate relationships, and engagement with sexual and reproductive health care. Interviews were tape-recorded for later transcription. Transcripts were analysed using thematic analysis (Braun & Clarke, 2006). Analysis was conducted primarily by Dr Rohleder, and me.

3.3 Introducing the Publications

Given the relative novelty of the dissertation-by-publication format in South Africa, it is worth briefly reflecting on why this mode of study and presentation was selected for the current project. I do this here. I also make some comments regarding the influence which this process has had on the final dissertation, and on the evolution of the project as a whole. This latter reflection provides some framework through which the reader may better understand the interplay between the different works which follow.

The present research is amongst the first to examine the attitudes of a general population sample, from a Global South country, towards the sexuality of people with physical disabilities. It is also one of few in South Africa to explore experiences of sexual and reproductive health, and sexuality, amongst people with physical disabilities. The topic is as yet in very large part unstudied in sub-Saharan Africa, and the potential contribution which research outputs could make to thinking about disability, sexuality, and human rights, is considerable. Thus, there is a certain urgency regarding the dissemination of findings. These findings might usefully shed light on some of the attitudinal barriers which are believed to underlie the exclusion of people with physical disabilities from sexual and reproductive health care specifically, and from enjoying full sexual citizenship, more broadly.

Further, a large portion of this research involves participatory action research. The issue of participation by people with disabilities in knowledge production regarding disability, is a global priority in disability studies. The publications arising from this study would be some of the first in South Africa to provide a space in which the lived experience, and self-representation of sexuality and physical disability, could be explored and reflected on. These publications could potentially begin the process of cleaving open discursive space for a more inclusive conception of sexuality than that which currently prevails.

However, this is not simply a presentation of publications on a given topic, and the publications are intended to hang together as a cohesive whole. As such, each publication is intended to stand alone, but also speak to the greater narrative of the project as a whole. The focus of the present dissertation is two-fold, and so the publications deal either with an individual facet, or with the relationship between, the two spheres of this study (Diagram 1, below, displays the publications, and their relationship to the data generated in the two arms of this survey).

Firstly, this study represents one of the first attempts in South Africa to establish the nature of the public's thinking about sexuality amongst people with physical disabilities. The first three publication[12] which constitute this dissertation deal, respectively, with the general public's thinking about the rights of people with physical disabilities to access reproductive and sexual health care, dating people with physical disabilities, and popular gender stereotypes of people with physical disabilities.

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[12] Publication 1: The sexual and reproductive rights and benefit derived from sexual and reproductive health services of people with physical disabilities in South Africa: beliefs of non-disabled people (Hunt, Carew, Braathen, Swartz, Chiwaula, & Rohleder, 2017)
Publication 2: Dating persons with physical disabilities: the perceptions of South Africans without disabilities (Hunt, Swartz, Carew, Braathen, Chiwaula, & Rohleder, 2017)
Publication 3: Withdrawn, strong, kind, but de-gendered: Non-disabled South Africans' stereotypes concerning persons with physical disabilities (Hunt, Swartz, Carew, Braathen, & Rohleder, in press)

These three publications provide the social backdrop against which the people with physical disabilities-generated data are explored and interpreted. The data – both narrative and photographic – generated by people with physical disabilities then constitute a "speaking back" to the findings presented in the first half of the dissertation. That is, the photographs and narratives expressing the self-claimed sexuality of people with physical disabilities provide a counter-point to the misrepresentations thought to be rife amongst the general population. These are presented in the latter three publications.[13]

These publications will deal with the self-representation and experiences of sexuality of a group of people with physical disabilities, with self-representation as an act of resistance for people with physical disabilities, and – finally – my theoretical contribution to thinking about representation as a research method and activist activity.

The dissertation as a whole, then, establishes:

- One of the first accounts of South African attitudes and representations of sexuality amongst people with physical disabilities, by non-disabled people; and
- How people with physical disabilities self-claim and self-represent sexuality, and how these lived experience accounts speak to, or are elided by, popular conceptions.

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[13] Publication 4: Physical disability and sexual life: Experiences of people with physical disabilities in a photovoice study from South Africa (Hunt, Braathen, Swartz, Carew, & Rohleder, 2017)
Publication 5: Shooting back and (re)framing: Challenging dominant representations of the disabled body in the Global South (Hunt, Swartz, Braathen, Carew, Chiwaula, & Rohleder, in press)
Publication 6: (Re)presenting the self: Reflections on a photovoice project with people with physical disabilities in South Africa (Hunt, Swartz, Braathen, & Rohleder, in press)

Diagram 1: Publications

Survey of community sample of non-disabled South Africans

Publication 1: The sexual and reproductive rights and benefit derived from sexual and reproductive health services of people with physical disabilities in South Africa: beliefs of non-disabled people (Hunt, Carew, Braathen, Swartz, Chiwaula, & Rohleder, 2017)

Publication 2: Dating persons with physical disabilities: the perceptions of South Africans without disabilities (Hunt, Swartz, Carew, Braathen, Chiwaula, & Rohleder, 2017)

Publication 3: Withdrawn, strong, kind, but de-gendered: Non-disabled South Africans' stereotypes concerning persons with physical disabilities (Hunt, Swartz, Carew, Braathen, & Rohleder, in press)

Photovoice project with volunteer sample of people with physical disabilities

Publication 4: Intimacy, intercourse and adjustments: Experiences of sexual life of a group of people with physical disabilities in South Africa (Hunt, Braathen, Swartz, Carew, & Rohleder, 2017)

Publication 5: Shooting back and (re)framing: Challenging dominant representations of the disabled body in the Global South (Hunt, Swartz, Braathen, Carew, Chiwaula, & Rohleder, in press)

Publication 6: (Re)presenting the self: Reflections on a photovoice project with people with physical disabilities in South Africa (Hunt, Swartz, Braathen, & Rohleder, in press)

Yet, as the reader may well know, the task of coming to publish a peer-reviewed piece of work is a multifarious one. The “by publication” format, then, brings its own forces to bear on the work concerned. This is due to three interrelated forces: the first is reviewer voice, the second is journal requirements, and the third has to do with exposure to alternative ways of seeing.

Firstly, reviewers add voices to a piece of work. Sometimes these voices and viewpoints differ to those of the writer. Although in the process of responding to reviewers, I have made every attempt not to capitulate to perspectives with which I disagree, one must at times yield. This, then, is intended to prime the reader to the discrepancies between publications (where, for instance, social constructionism is underlined in one publication, and sexual script theory in another). The content is not the result of the reviewers’ comments, nor is its interpretation, but the emphasis placed on certain work and not others often had to do with the advice – often extremely apt – of a given reviewer.

Secondly, each journal has its own conventions and quirks, and so if these differ, the publications differ in tone and phrasing and terminology. This observation, too, is intended to prime the reader to possible discrepancies – not so much in emphasis, but rather in language.

Each encounter with a new reviewer or editor set in motion an encounter with new work, different perspectives, and – ultimately – spurred me to a re-encounter with the data. This has been one of the most valuable things which this manner of dissertation has bestowed on me. I am indebted to my reviewers. Still, this process is also reflected in the work – at each encounter (or point of growth in my research and thinking), I developed new ways of thinking about my topic, often gaining insights which necessitated a refining or revising of prior thinking; at times, I rued that a theory encountered on revising Publication 3 had not been employed to illuminate findings from Publication 1, and so forth. I do not think this detracts from the publications as they stand, but it may explain the different theories or paradigms employed to engage with similar findings over the chronological course of the publications.

Finally, it is worth flagging for the reader that this mode of dissertation depends on the scholar working recursively between this large document, and the publications, throughout the course of the research and write up. Literature encountered in reviews for the introductions to publications was included in the literature review of this broader document. Similarly, methodology, definitions and certain pieces of discussion crafted for this dissertation were included in the publications. For ease of reading, overlap and duplication has been minimised, but it is worth noting at the outset that there will be repetition between the large literature reviews which frame this whole project, and the smaller introductory sections of the publications.

Publication 1: The sexual and reproductive rights and benefit derived from sexual and reproductive health services of people with physical disabilities in South Africa: beliefs of non-disabled people (Hunt, Carew, Braathen, Swartz, Chiwaula, & Rohleder, 2017)

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The sexual and reproductive rights and benefit derived from sexual and reproductive health services of people with physical disabilities in South Africa: beliefs of non-disabled people

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RESEARCH ARTICLE

REPRODUCTIVE HEALTH matters

The sexual and reproductive rights and benefit derived from sexual and reproductive health services of people with physical disabilities in South Africa: beliefs of non-disabled people

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Abstract: *There is a body of theoretical work, and some empirical research, which suggests that non-disabled people assume people with physical disabilities are not suitable romantic partners, do not have sexual drives or desires, or are not sexually active. It has also been proposed that people with physical disabilities face barriers to sexual healthcare access which are structural as well as social. The present paper explores non-disabled South Africans' beliefs concerning the degree to which non-disabled respondents enjoy sexual and reproductive rights, and benefit from sexual and reproductive healthcare, compared to people without disability. Using a survey, we asked 1989 South Africans to estimate the degree to which people with physical disabilities and people without disability have sexual rights, and benefit from sexual and reproductive healthcare services, respectively. Respondents were more likely to support the idea that the population without disability were deserving of sexual rights compared to people with physical disabilities. Respondents were more likely to rate the degree to which people with physical disability benefit from sexual and reproductive healthcare as less than that for people without physical disabilities. These findings provide some of the first empirical support that non-disabled people perceive people with physical disabilities as having fewer sexual and reproductive rights, and deriving less benefit from sexual and reproductive health services, than the population without disability. To have diminished sexual rights, and benefit less from sexual and reproductive healthcare, we suggest, evinces a negation of the sexual and reproductive needs and capacity of people with physical disabilities.* DOI: 10.1080/09688080.2017.1332949

Keywords: persons with physical disabilities, sexuality, sexual and reproductive health rights, sexual rights, reproductive healthcare, access, disability studies, South Africa

Introduction

There is a body of theoretical work, and some research, which suggests that non-disabled people assume that people with physical disabilities are not sexual or sexually active.[1–10] Simultaneously, access to sexual and reproductive health services for people with physical disabilities is largely neglected, and people with physical disabilities are generally excluded from sexual and reproductive health education.[11,12]

Since the 1970s, the disability rights movement has fought for equality, access, and recognition for people with disabilities.[13] Today, as authors such as Addlakha[14] note, there is a recognition of the need to enhance educational and employment opportunities for people with disabilities, to address their exclusion from society, services, and

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Supplemental data for this article can be accessed at https://doi.org/10.1080/09688080.2017.1332949.

institutions, and – amongst disability rights activists – to speak back to the dominant discourses of the non-disabled which have for too long portrayed people with physical disabilities unfavourably. Only in the past few decades, however, have the issues of sexual and reproductive health for people with physical disabilities been addressed in disability scholarship[9,15–17] and, even more latterly, in relation to public health.[18,19]

Indeed, recent years have seen a growing recognition of the sexual and reproductive rights of all people, which, since the World Report on Disability,[20] and the UN Convention on the Rights of People with Disabilities[21] includes people with disabilities. In the years subsequent to this report, increased international attention has been given to issues of sexual and reproductive rights, and health, amongst people with disabilities, including people with physical disabilities. Indeed, amongst people with physical disabilities, issues of sexuality and sexual rights are inextricably linked with human rights and so should form a focus of disability activism: as Shakespeare[22] notes, work around disabled sexuality:

> *"should form part of a revisioning of the disability movement's mission which encompasses identity and solidarity and rights and respect in every area of the lives of disabled people, and which builds an inclusive community of disabled and non-disabled individuals."*[22]

The drive for the inclusion of people with physical disabilities in contemporary efforts to improve sexual and reproductive health access is underlain by the prevailing wisdom in disability scholarship that the sexuality of people with physical disabilities has hitherto been nullified, with people with physical disabilities systematically excluded from conceptions of sexuality, from sexual health services, and generally considered to be – and treated as – lacking sexuality.

Past work has used the term asexuality to describe this state of affairs. The word asexual in this literature has been used to describe the assumption that people with disabilities experience a "relative absence or insufficiency of sexual interest, biologically and socially described function, and interpersonal sexual engagement".[4] Recently, important research and campaigning has resulted in the recognition of asexuality as a sexual orientation, and this recognition must lead us to qualify our use of the term in the present paper. People with disabilities are generally seen as not having any sexuality, including sexual agency or choice, drives or desires, rather than having made the choice to identify as asexual of their own volition. Thus, we limit our use of the term asexuality in the present paper. Instead, we refer to the described lack of sexuality which societies tend to ascribe to people with physical disabilities.

Although there is some empirical research evidencing that people with physical disabilities are considered by non-disabled people to be less sexual, we know of little research investigating if they are viewed as having diminished sexual rights. (Important work has been done with samples of healthcare providers, see for instance Lee et al,[23] and Rueda, Linton and Williams,[24] but none that we know of with the population without disability.[20]) In the main, the literature concerning societal attitudes towards the sexuality of people with physical disabilities suggests that people with physical disabilities are viewed as less sexual than non-disabled people.[10,25–29] The beliefs, and the consequent attitudes, of the non-disabled have been proposed to have consequences for people with physical disabilities.[30–33] These include reticence to date people with physical disabilities, and so negative romantic appraisals of people with physical disabilities by non-disabled people,[5,27,29,34–36] the exclusion of people with physical disabilities from family planning clinics,[7] and possibly even increased risk for sexual violence against people with physical disabilities.[37] Indeed, there is much evidence of an elevated rate of sexual violence perpetrated against women with physical disabilities when compared to non-disabled women.[38] One of the reasons put forward for this sorry fact is that – again, due in no small measure to societal attitudes – women with physical disabilities lack social experience and sexual education.[26] Further, and ironically, Hanass-Hancock[8] found that in South Africa, women with physical disabilities are particularly vulnerable to HIV through the threat of sexual abuse precisely because they are perceived to be asexual and virgins. It is thus proposed that people with physical disabilities not only face barriers to sexual and reproductive healthcare access which are structural (such as inaccessible healthcare provider offices), but also those which are social (such as attitudes).[39]

Some work has suggested that it is the negation of the sexuality of people with physical disabilities that results in a lack of sex education for people with physical disabilities. Several studies have shown that the misconception that people with physical disabilities lack sexuality (including sexual agency or choice, drives or desires) and so are sexually inactive, has resulted in a paucity of sex education for students with disabilities.[12,40] Two additional South African studies have found that educators lacked the knowledge and – particularly – confidence to successfully teach sexual education to adolescents with disabilities,[41,42] whilst another has drawn attention to the fact that almost nothing is known about how, or even if, the HIV and sexual health promotion strategies implemented in South Africa are implemented amongst youth with disabilities.[43] More generally, access to sexual health services for people with physical disabilities is largely neglected, often due to attitudinal barriers encountered by people with physical disabilities, including towards women with physical disabilities trying to access reproductive healthcare services, and contraception.[15,44–51] Yet more work has suggested that people with physical disabilities, especially women, have greater unmet health needs than women without disability, and reduced access to health information, screening, prevention, and care services in the realm of sexual and reproductive health.[2,52–54] The exclusion of people with physical disabilities from sex education,[11,12,55] and sexual and reproductive healthcare, is a human rights as well as a public health issue. Empirically investigating whether people with physical disabilities are indeed considered by the population without disability to have fewer sexual rights is imperative. It is equally important to explore whether it is generally believed that people with physical disabilities will benefit less from sexual and reproductive healthcare than will members of the population without disability.

The present study

As noted, many have argued that people with physical disabilities face daunting attitudinal barriers in their attempts to realise their sexual and reproductive rights and to benefit from sexual and reproductive healthcare. It is especially important to explore attitudinal barriers (if these do, in fact, exist) in the African context. In this context, where healthcare services are already often scant or oversubscribed, any additional barriers faced by people in their attempts to derive benefit from sexual and reproductive health services might be insurmountable. There is almost no empirical evidence for these attitudinal barriers in Africa, although their existence could have dire consequences for people with physical disabilities, including increased risk for HIV. The present article examines a sample of non-disabled South Africans' estimations of the degree to which people with physical disabilities enjoy sexual and reproductive rights, and benefit from sexual and reproductive healthcare services, compared to members of the population without disability.

Hypotheses

On the basis of past research,

1. we hypothesise that participants would estimate that people with physical disabilities have fewer sexual and reproductive rights than the population without disability and
2. we hypothesise that participants would estimate that people with physical disabilities benefit less from sexual and reproductive healthcare than the population without disability.

Method

Research design

The present study entails a cross-sectional survey, administered amongst the population without disability.

Materials

We measured participant beliefs regarding the sexual and reproductive health rights and benefit derived from sexual and reproductive healthcare services of people with physical disabilities and people without disability, using a survey administered to members of the population without disability. In the introduction to the survey, a person with a physical disability was defined as "someone with a physical impairment that has a substantial and long term adverse effect on the person's ability to perform normal day to day activities e.g., walking, eating, going shopping" (p.4).[56] Questionnaire items were identified through focus group discussions with people with physical disabilities and from a literature review. People with physical disabilities (invited with the assistance of the Southern Africa Federation of the Disabled (SAFOD), the umbrella body for national disabled people's organisations in the region) took part in focus group discussions during a planning workshop at the start of the project. These groups focussed in part on identifying and formulating questions to be included in the survey, and survey items were checked with participants prior to the survey's being finalised. The survey was translated into Xhosa, Zulu, and Afrikaans, and available online in these languages, as well as in English. All translations were back-translated by home language speakers, to ensure accuracy.

The survey included demographic questions (age, gender, race, home language, and education). The Washington Group Short Set of questions, which is being used in many contexts globally,[57,58] was used to identify people with disabilities amongst the survey participants. These items include questions regarding the respondent's functioning in terms of seeing, hearing, ambulating, cognition, self-care, and communication. The survey included open and closed questions measuring beliefs about disability and sexuality, and attitudes about the sexual and reproductive health rights and healthcare, of the two populations: people with physical disabilities and the population without disability. This paper reports on findings primarily from this last measure. There are substantial qualitative data from the open-ended questions, which are reported on in detail elsewhere.[59]

We employed a continuum of percentages to elicit respondents' beliefs about different facets of the sexual and reproductive rights and degree to which benefit was derived from sexual and reproductive healthcare services, of people with physical disabilities. Respondents were requested to move a sliding button (online), or point to a spot (pen and paper) on a continuum from 0% to 100% to indicate what percentage of people with physical disabilities certain statements apply to. These items are described below. Each item was prefaced by the statement "Please indicate what % of people with physical disabilities the following statements apply to. You can do this by marking on the line below the number between 0 and 100 that best represents your view."

(1) [indicate the] % of people with physical disabilities that are capable of expressing sexuality.
(2) [indicate the] % of people with physical disabilities for whom expressing sexuality is a basic human need.
(3) [indicate the] % of people who have physical disabilities that should be allowed to have children
(4) [indicate the] % of people with physical disabilities who benefit from sexual healthcare services (e.g., HIV testing) in your area.
(5) [indicate the] % of people with physical disabilities who benefit from reproductive healthcare services (e.g., pregnancy screening) in your area.
(6) [indicate the] % of people who benefit from sexual education services (e.g., classes providing information about HIV) in your area

At a later point in the survey, respondents were asked to respond to the same set of items, but regarding their beliefs about the sexual and reproductive health rights and benefit derived from sexual and reproductive healthcare services of the population without disability. The rights items were constructed to tap into respondents' beliefs (expressed as an estimation) about who should or could potentially have sexual and reproductive rights. The items concerning benefit derived from sexual and reproductive healthcare, and were designed to elicit the respondent's perception about the needs and benefit to be derived from the access of people with physical disabilities to services. Taken together, they paint a coherent picture about (a) whether people without disability believe people with physical disabilities should be less sexual, but also (b) whether people without disability believe that people with physical disabilities *do or should* benefit less from sexual and reproductive health services (see Supplementary data).

Sampling

The survey respondents were recruited through social media (such as a dedicated Facebook page) and other social networks. A *Qualtrics* survey link was also advertised on two of South Africa's top news sites, one which caters mostly to Xhosa- and Zulu-speaking readers,* and has over 1,274,856 unique users, and one which caters to English-speaking readers, and has over 3,104,185 unique users.[61] Permission was also obtained from the institutional planning departments of two large urban universities in South Africa, in

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*isiXhosa and isiZulu are two of South Africa's 11 official languages. These indigenous languages are spoken mostly by Black South Africans. isiXhosa is the home language of 22.7% of the population, and isiZulu, 16%, making them the two largest language groups in the country.[60]

Gauteng and the Western Cape, to distribute the survey amongst students.

The survey was also administered by hand-trained data collectors in two peri-urban settlements in the Western Cape, Langa, and Khayelitsha. This was to avoid biasing the sample towards educated, literate people with access to computers. The pen-and-paper respondents were selected at convenience by the data collectors who recruited people for the survey from busy areas (markets, taxi ranks, through their own social networks) in the respective locations. All respondents had to be at least 18 years of age or older in order to complete the questionnaire (due to the sexual nature of some of the content).

Analytic strategy

To investigate the underlying factor structure of the measured items, an exploratory factor analysis was first conducted. Specifically, we employed a direct oblimin rotation.[†] Subsequently, we tested whether a significant difference existed between respondents' beliefs about the sexual and reproductive rights, and benefits of sexual and reproductive health services of people with physical disabilities, compared to the non-disabled population. On an exploratory basis, we also tested whether these beliefs varied according to participant gender. Specifically, we ran two mixed ANOVAs[‡] with participant beliefs (i.e., concerning either rights or benefits of sexual and reproductive healthcare) about each target group as the repeated measures factor and gender (male and female) as the between subjects factor.

Sample

The sample consisted of 1989 respondents. One hundred and twenty-five respondents who met the Washington Group criteria for having a disability using the recommended cut-off i.e., a response of "a lot of difficulty" or "cannot do at all"[58] on any question were excluded, so the remaining group were people who were not disabled, according to the Washington Group methods. The mean age of the remaining 1864 respondents was 26 years (SD = 9.23), and the age range was 18–76 years old. There were approximately equal numbers of males (44%) and females (56%). Racially, the sample consisted of 45.1% Black African, 40% White, 8.6% Coloured, and 4.5% Asian or Indian, people, as well as 1.8% who self-identified as "other". Of the participants, 51.5% held a school leaving certificate. In South Africa (total population estimated at 54,490,000), 67.5% of the population identify as Black and only 21.6% as White. In terms of education, according to the South African Census,[63] the percentage of people aged 20 or older with a school leaving certificate is 28.5%. Therefore, our sample has a higher number of White respondents and is better educated than the general population.

Our final sample contained 1741 respondents who participated in the survey online, while 123 filled out the pen-and-paper versions. The survey was open from March 2016 until September 2016.

We ran the below analyses separately for each sub-group and found that the results were not significantly different. Therefore, we report findings for the total sample below.

Results

The mean and standard deviations of the beliefs items are summarised in Table 1.

Factor structure of the beliefs items

The factor analysis with direct oblimin rotation created two distinct factors (eigenvalues of 2.838 and 2.319; criteria to retain factors are eigenvalues of >1, and the clustering of items into factors were easily interpretable.[64] That is, items 1, 2, and 3 loaded onto one factor ("sexual and reproductive health rights") and items 4, 5, and 6 loaded onto a second factor ("benefit from sexual and reproductive health services"). Table 2 shows the factor loadings, which are the strength of association between each factor and the measured items. The same two-factor solution was apparent in the non-disabled population items and the correlation between factors was medium in size, $r = 497$, which confirmed that the direct oblimin rotation was appropriate.

[†] Factor analysis is a data reduction technique used to group measured items into a few latent (unobserved) easily interpretable factors. Factor rotation is a technique used in factor analysis to discriminate between the factors. The type of rotation applied here, direct oblimin, is advised when factors are expected to correlate.[62]

[‡] ANOVA is a technique used to analyse differences between group means.[62] The type of model is mixed, because participants give repeated observations on our dependent variable ("beliefs"), while, concurrently, we also wished to examine if these beliefs differed between two independent groups (males and females).

Table 1. Means and standard deviations of belief items

Item	People with physical disabilities (%)	Non-disabled population (%)
Capacity to express sexuality *[indicate the] % of people with physical disabilities that are capable of expressing sexuality.*	61.47 (*SD*= 30.47)	72.49 (*SD*= 26.21)
The need to express sexuality *[indicate the] % of people with physical disabilities for whom expressing sexuality is a basic human need.*	66.21 (*SD*= 31.00)	73.03 (*SD*= 26.81)
The right to reproduction *[indicate the] % of people who have physical disabilities that should be allowed to have children.*	74.22 (*SD*= 29.99)	74.38 (*SD*= 27.34)
Benefit from sexual healthcare *[indicate the] % of people with physical disabilities who benefit from sexual healthcare services (e.g., HIV testing) in your area.*	61.80 (*SD*= 34.25)	70.25 (*SD*= 29.42)
Benefit from reproductive healthcare *[indicate the] % of people with physical disabilities who benefit from reproductive healthcare services (e.g., pregnancy screening) in your area.*	59.04 (*SD*= 34.32)	69.60 (*SD*= 29.41)
Benefit from sexual education services *[indicate the] % of people who benefit from sexual education services (e.g., classes providing information about HIV) in your area.*	60.26 (*SD*= 35.47)	69.07 (*SD*= 30.92)

Given that two clear factors were observed (the higher numbers for each item clearly lay in one column, and not the other), we subsequently averaged the rights and benefit from services items together for each target group (i.e., people with physical disabilities and the non-disabled population) to create four constructs. These constructs indicated good reliability ($\alpha = .75–.91$) and were found to be normally distributed (i.e., skewness <1.16 and kurtosis <1.47; below respective the cut-offs of 3 and 8 recommended by Kline.[65]

ANOVAs: difference in beliefs between people with disabilities and the non-disabled population

With a sufficiently large sample size, inferential tests will almost always produce significance, even when these differences are too small to have practical relevance.[66] Therefore, in considering the below results, we also interpret the effect size (partial η^2; i.e., the magnitude of the difference), according to Cohen's[67] criteria (small: .0099; medium: 0588; large: .1397.[68]

Sexual rights beliefs

There was a significant difference in attributions of sexual rights to each group, F (1, 1862) = 141.89, partial $\eta^2 = .07$. Specifically, participants believed 67.28% of people with physical disabilities have sexual rights, compared to 73.30% of the non-disabled population. There was also a significant gender difference F (1, 1862) = 16.75, $p < .001$, partial $\eta^2 = .009$, with male participants attributing less sexual rights ($M = 68.02\%$) to both target groups, compared to females ($M = 72.01$) and a significant interaction was also observed between attributions of sexual rights and gender, F (1, 1862) = 4.01, $p = .046$, partial $\eta^2 = .002$. However, as the

Table 2. Factor loadings of the items

Item	People with physical disabilities		Non-disabled population	
	Rights	Benefit	Rights	Benefit
Capacity to express sexuality	.800		.880	
The need to express sexuality	.884		.854	
The right to reproduction	.552		.389	
The benefit derived from sexual healthcare		.888		.893
The benefit derived from reproductive healthcare		.934		.904
The benefit derived from sexual education services		.858		.841

magnitude of these differences (i.e., the effect size) are too small to be practically relevant (i.e., both partial $\eta^2 \leq .0099$; Cohen, 1969; see above) we do not probe the interaction further.

Benefit of sexual and reproductive healthcare beliefs

There was a significant difference in attributions of the benefit of sexual and reproductive healthcare to each group, F (1862) = −252.77, $p < .001$, partial $\eta^2 = .120$, with participants reporting that 60.36% of people with physical disabilities benefit from sexual and reproductive healthcare services, compared to 69.62% of the non-disabled population. There was a significant gender difference, F (1, 1862) = 9.12, $p = .003$, partial $\eta^2 = .005$, with male participants attributing less benefit of sexual and reproductive healthcare services (M = 62.82%) to both target groups compared to females (M = 66.64%). However, according to Cohen's (1969) criteria the magnitude of the effect size is too small to be practically relevant (see above). There was no interaction between attributions of benefit to be derived from services to sexual and reproductive healthcare and gender, F (1, 1862) = .502, $p = .479$, partial $\eta^2 < .001$.

Discussion

We hypothesised that non-disabled respondents would estimate the sexual and reproductive rights, and degree to which individuals benefit from sexual and reproductive healthcare, of people with physical disabilities to be less than those deemed appropriate to the population without disability.

We found that respondents estimated the sexual and reproductive rights of the population without disability to be greater than those appropriate to people with physical disabilities, and were more likely to estimate the degree to which people without disabilities benefit from sexual and reproductive healthcare services as greater than that of people with physical disability.

Given the size of the dataset in the present study, we expected that even negligible effects would obtain significance. It is therefore imperative to interpret the effect sizes for each test. The magnitude of the observed difference in sexual rights beliefs and benefit from sexual and reproductive healthcare services were medium. The size of these effects suggest a practically meaningful difference in the estimations of South Africans without disability of the sexual rights and benefit derived from sexual and reproductive healthcare of people with physical disabilities and the population without disability (Cohen, 1969). There were small, statistically significant differences between genders, but these were too small in terms of effect size to be practically meaningful and so are not discussed in depth (i.e., <.0099; Cohen 1969). However, it is noteworthy that, while past work has indicated that females tend to have more positive attitudes towards people with physical disabilities when it comes to dating and relationships than do males,[35,60,69] it does not appear that these differences hold for beliefs about sexual rights and the degree to which individuals benefit from sexual and reproductive healthcare services.

Simply put, there is a significant medium effect for the differences between means of respondents' estimation of the sexual rights of people with physical disabilities and the population without disability. There is also a significant large effect for the differences between means of respondents' estimation of the degree to which individuals benefit from sexual and reproductive healthcare services for people with physical disabilities and the population without disability.

With respect to rights, the findings can be interpreted against the backdrop of the work of such authors as Kim,[70] Crawford and Ostrove,[26] and many more[2,5,6,71–73] concerning the so-called myth of asexuality amongst people with physical disabilities, as well as that of Kim[70] concerning societal anxiety about reproduction amongst people with physical disabilities. (This phrasing has been used in past work. We interpret its meaning as lacking sexual agency and desire, and being less sexual than non-disabled people, rather than ascribing to asexuality as a sexual orientation and identity.) If we return to the items of which this construct is composed, this empirical and theoretical frame becomes useful in making sense of the sentiments which might be underlying this finding.

In 2003, Crawford and Ostrove[26] reported on a variety of prejudicial beliefs held by non-disabled people, which people with physical disabilities experienced. These included beliefs amongst non-disabled people that people with physical disabilities were "universally intellectually challenged", lacking sexuality, and helpless and incompetent.[26] These beliefs well encapsulate both facets of our findings concerning the sexual rights of people with physical disabilities: firstly, people with physical disabilities are *desexualised* (with fewer sexual needs and diminished sexual capacity, items 2 and 1), and secondly, people with physical disabilities are considered unlikely, even incapable or unsuitable, parents (item 3). However, the findings of Crawford and Ostrove's[26] study were based on accounts from women with physical disabilities of stereotypes which they had encountered. A subsequent study by Nario-Redmond[25] drew on the accounts of non-disabled people, but the sample was smaller than that of the present research. Our findings also support these authors, and further suggest that people with physical disabilities are seen as having diminished sexual rights.

According to Kim,[70] the perception of people with physical disabilities as lacking sexuality and the denial of the rights of people with physical disabilities to have children are underpinned by a single social representation with its roots in fear and prejudice. Kim[70] argues convincingly that people with physical disabilities are popularly desexualised, a process which is built upon societal discomfort with the idea of disability "reproduction and contamination" (483).[70] That is, societal fear regarding the "abnormal" sexuality of people whose bodies are not typical underlies the imperative to desexualise people with physical disabilities, for fear that their sexuality – if it were to be acknowledged – would be somehow monstrous and uncomfortably different, and their offspring somehow genetically or otherwise tainted. The sexuality, and offspring, of people with physical disabilities cannot be normal, and people with physical disabilities, therefore, must not be sexual and must refrain from child-bearing. Such social representations of people with physical disabilities as desexualised and unsuitable or unlikely parents might very well underlie the significant effects for the differences between non-disabled respondents' estimation concerning the sexual rights of people with physical disabilities and the population without disability.

This study also provided some of the first empirical evidence that people with physical disabilities are believed to derive diminished benefit from sexual and reproductive healthcare compared to non-disabled people. However, we suggest, against the backdrop of the sentiments revealed in the rights questions, these findings reveal an underestimation, or negation, of the sexuality of people with physical disabilities, as identified in the literature. Imposing a lack of sexuality on people with disabilities relies on typifying them as requiring neither reproductive healthcare and contraception, nor sex education; as much as it does believing that they do not have the same rights to bear children. Our findings for people with physical disabilities are relative to the general population. Considering the multitude of ways that people can benefit from sexual and reproductive health services as above, our reading of this finding, in light of the attitudes evident in the rights items, is that the pervading societal attitude is to assume that sexual and reproductive services benefit one group more than another. The implication is that this reflects a differing attitude toward each group.

Anderson and Kitchin[7] note that:

> *"cultural ideologies [regarding the sexuality of people with physical disabilities] work to legitimate material and discursive discriminatory practices, such as exclusion from family planning clinics, sex education and sexual health, by suggesting that current social relations are common sense and natural (rather than constructed and negotiable); that the lifestyles, practices, minds and bodies of non-disabled people are the 'norm' and those of disabled people are deviant and undesirable".*

As people with physical disabilities are taken to lack sexuality, the need for sex education, and sexual and reproductive healthcare services for people with physical disabilities, is overlooked, suggesting that the findings in the present research might be indicative of ideas about the sexuality of people with physical disabilities which underlie this lack.[11,12]

Beyond statistical significance, the findings of the present study make a noteworthy contribution to current understandings of attitudes towards, and beliefs about, the sexuality of people with physical disabilities. A major contribution of this paper is that it presents empirical evidence that non-disabled people consider people with physical disabilities not only to not be sexual, but also to have fewer sexual rights and benefit less from sexual and reproductive healthcare than the population without disability.

Limitations

The present study has three major limitations: the first concerns the representativeness of the sample, the second, the nature of the sample, and the third, the phrasing of the items which constitute the benefit derived from services factor.

Regarding the first, as noted, our sample includes a greater proportion of White respondents, and is better educated than the general population in South Africa. Thus, due caution must be taken in generalising the findings of this research to the population of South Africa as a whole. This study involves non-probability survey research, and so our goal, from the outset, was more accurately described as diversity, as opposed to representativeness. However, despite our attempts to sample from different sectors of the South African population, including individuals without access to computers, and people from different language groups and provinces, our sample still suffers from over-representation of the country's minority (well-educated Whites). As such, we did not analyse our data by race or education as it was unlikely that the findings would reflect differences within the true population. Still, given the exploratory nature of the study, the lack of strict generalisability does not diminish the contribution made by the findings here: that a substantial difference exists between a sample of non-disabled South Africans' beliefs concerning the degree to which individuals benefit from sexual and reproductive services for people with physical disabilities, and the population without disability, and that this difference implies a negation of the sexuality of people with physical disabilities. It should be noted that a convenience sample is also prone to selection bias, and so our pen-and-paper sample could be biased towards people known to the data collectors. However, during training of the data collectors, emphasis was placed on approaching as random a selection of people as possible from busy areas in their communities, rather than from their social networks.

Conclusion

We examined the difference between non-disabled people' estimation of the sexual and reproductive health rights, and benefit derived from sexual and reproductive healthcare services, of people with physical disabilities. Non-disabled respondents showed greater endorsement of the sexual and reproductive rights of the population without disability than those of people with physical disabilities, and were more likely to rate the benefit derived from sexual and reproductive healthcare of the population without disability as greater than people with physical disabilities. In synchrony, these findings, we propose, are attributable to non-disabled people's beliefs about the sexuality of people with physical disabilities: that people with physical disabilities are seen as having diminished sexual needs and diminished benefit to be derived from accessing sexual and reproductive healthcare services, and that reproduction amongst people with physical disabilities is deemed less desirable and less possible than reproduction amongst non-disabled people.

Examining the content of societal beliefs about the sexuality of people with physical disabilities in South Africa yields important insights into why issues of access to sexual and reproductive healthcare services for this population continue to go unaddressed: if people with physical disabilities are desexualised, their need and capacity for sexuality diminished in the eyes of the public, and their suitability/ability for reproduction called into question, it is little surprise that they may encounter neglect in service provision.

This paper is the first of which we know to examine whether non-disabled people think people with physical disabilities possess the same sexual rights and benefit from sexual and reproductive healthcare in the same way as the population without disability. Our findings suggest that they do not, and, in fact, may perceive people with physical disabilities to be less sexual than non-disabled people. This latter possibility, raised by the present findings, calls for qualitative inquiry into the beliefs of non-disabled people about the sexuality of people with physical disabilities. Such work, which would explore the constructions of sexuality amongst people with physical disabilities, their capacity to be partners, parents, and sexual agents, would yield clarifying insights which would add nuance to the findings presented here.

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Résumé

Une somme de travail théorique et quelques travaux de recherche empirique donnent à penser que les personnes non handicapées supposent que les personnes avec un handicap physique ne sont pas des partenaires amoureux, n’ont pas de désirs sexuels ou n’ont pas de vie sexuelle. Pour ce second groupe, l’accès aux services de santé sexuelle et génésique est un défi : les personnes avec un handicap physique rencontrent des obstacles à l’accès aux soins de santé sexuelle qui sont structurels (comme l’impossibilité pratique de se rendre dans les bureaux des prestataires de soins) et sociaux (comme des prestataires qui suggèrent que les personnes avec des handicaps physiques ne devraient pas procréer). L’article étudie les croyances des Sud-Africains concernant le degré auquel les personnes avec un handicap physique et les personnes sans handicap ont des droits sexuels et génésiques et bénéficient des soins de santé sexuelle et génésique. Avec une enquête, nous avons demandé à 1989 Sud-Africains d’estimer dans quelle mesure les personnes avec un handicap physique et les personnes sans handicap ont des droits sexuels et bénéficient de services de soins de santé sexuelle et génésique, respectivement. Les répondants avaient davantage tendance à soutenir l’idée que la population sans handicap méritait des droits sexuels, par comparaison avec les personnes ayant un handicap physique. Les répondants avaient aussi plus de probabilités d’estimer que les personnes avec des handicaps physiques bénéficient de soins de santé sexuelle et génésique à un degré inférieur que les personnes sans handicap physique. Ces conclusions fournissent les premières données empiriques montrant que les non-handicapés voient les personnes

Resumen

Existe un conjunto de trabajo teórico y algunas investigaciones empíricas que indican que las personas no discapacitadas suponen que las personas con discapacidad física no son parejas románticas adecuadas, no tienen deseo sexual, o no son sexualmente activas. El acceso de este último grupo a los servicios de salud sexual y reproductiva es un reto: se ha propuesto que las personas con discapacidad física enfrentan barreras para obtener servicios de salud sexual que son estructurales (tales como consultorios inaccesibles) y sociales (tales como cuando profesionales de la salud sugieren que las personas con discapacidad física no deberían procrear). Este artículo examina las creencias de personas sudafricanas no discapacitadas respecto a en qué medida tienen derechos sexuales y reproductivos las personas y en qué medida se benefician de los servicios de salud sexual y reproductiva las personas con discapacidad física y aquéllas sin discapacidad. En una encuesta, pedimos a 1989 sudafricanos que estimaran en qué medida las personas con discapacidad física y aquéllas sin discapacidad tienen derechos sexuales y se benefician de los servicios de salud sexual y reproductiva, respectivamente. Las personas encuestadas eran más propensas a respaldar la idea de que la población sin discapacidad es merecedora de derechos sexuales comparada con las personas con discapacidad física. Además, eran más propensas a estimar en qué medida las personas con discapacidad física se benefician menos de los servicios de salud sexual y reproductiva, comparadas con aquéllas sin discapacidad física. Estos hallazgos figuran entre los primeros en corroborar de manera empírica que las personas sin discapacidad perciben a aquéllas con discapacidad física como que tienen menos derechos sexuales y reproductivos, y como handicapées physiques comme ayant moins de droits sexuels et génésiques, et retirant moins d'avantages des services de santé sexuelle et génésique que la population sans handicap. À notre sens, le fait d'avoir des droits sexuels diminués et de bénéficier moins des soins de santé sexuels et génésiques révèle une négation des besoins et des capacités sexuelles et génésiques des personnes avec un handicap physique.

que se benefician menos de los servicios de salud sexual y reproductiva, comparadas con aquéllas sin discapacidad. Sugerimos que tener menos derechos sexuales y beneficiarse menos de los servicios de salud sexual y reproductiva pone en evidencia la negación de la capacidad y las necesidades sexuales y reproductivas de las personas con discapacidad física.

Linking narrative 1: Publication 1 and Publication 2

Publication 1 sketches – broadly – the kinds of beliefs held, and assumptions made by, non-disabled people about the degree to which people with physical disabilities have sexual rights, and benefit from sexual and reproductive health care services. The findings seem to suggest that people with physical disabilities are seen as having fewer sexual and reproductive rights, and that they derive less benefit from sexual and reproductive health services, than the population without disability. I read this finding as suggesting a tacit negation of the sexual and reproductive needs and capacity of people with physical disabilities, by non-disabled others.

However, the estimation of rights and access does not (a) illuminate the reasoning underlying these assumptions and beliefs, nor (b) necessarily activate affect. In the latter respect, what I mean is that, while it is possible to endorse an individual's rights, to, say, have children or have sex, one may still hold prejudicial attitudes which mean that one would not want to have any part in facilitating either activity with the target. I may think people with physical disabilities may have sex, but I would not willingly engage in sexual intercourse with a person with a disability.

Publication 2, presented next, deals with attitudes in relation to people with physical disabilities at a closer degree of social proximity: romantic relationships. Where the previous publication dealt with estimations of sexual and reproductive rights and service use, the question posed in the second publication taps into more closely-held views of people with physical disabilities as sexual subjects: how would a potential dating scenario, between a non-disabled person and a person with a physical disability, play out, and *why*?

The journal was chosen purposively because it is not a disability journal. Part of the broader project of this dissertation is to mainstream thinking about disability in relation to sexuality. That is, I want readers of sexual and reproductive health journals, and scholars interested in sexuality and gender and sexual rights, to encounter disability as an intersectional identity worthy of further thought.

Publication 2: Dating persons with physical disabilities: the perceptions of South Africans without disabilities (Hunt, Swartz, Carew, Braathen, Chiwaula, & Rohleder, 2017)

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Dating persons with physical disabilities: the perceptions of South Africans without disabilities

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ABSTRACT
There is good reason to believe that the attitudes of persons without disability towards dating a person with a physical disability might be unfavourable. However, in general, and in the Global South in particular, there is a dearth of research in this area. This study sought to take the first step in addressing this lack of enquiry, by surveying the attitudes of a general population sample in South Africa towards dating people with physical disabilities, using a vignette. Data from 1723 survey respondents were analysed thematically. Findings reveal largely negative attitudes towards people with physical disabilities. Respondents without disability perceived numerous barriers to dating a person with a physical disability, including social stigma, anxiety and concerns about the burden of care they believed such a relationship would place upon them. However, there was some evidence to suggest that some positive attitudes do exist, and a few respondents were open to dating a person with physical disabilities. Findings contribute to a nuancing and expanding of the 'myth of asexuality' among physically disabled people by showing that people with physical disabilities are actively desexualised by persons without disability. Future research is needed to explore how the inclusive attitudes, of which we did find evidence here, can be further cultivated.

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Introduction

Historically, people with disabilities have often been excluded or pitied by persons without disability in their communities, and by able-ist society as a whole. Disability has commonly been seen by persons without disability either as a personal tragedy to be borne with bravery or a medical anomaly to be cured (Goodley 2011).

Sexuality has long been deemed the purview of the nubile normate[1] (Garland-Thomson 1997), evident both in attempts to 'cure' sexual dysfunction and lack of desire (Bancroft and Graham 2011; Basson 2005) and in popular culture's emphasis on sex as a site of achievement (Attwood 2009; Swami, Diwell, and McCreary 2014). In the societies in which they live, people with disabilities have variously been infantilised and desexualised or – when they do express

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their sexuality – often viewed as 'oversexed perverts' (Brown 1994, 125). Research suggests that the former stereotype is often applied to persons with physical disabilities and the latter to persons with intellectual disabilities (Kim 2011).

In the former case, disability and sexuality are positioned as antithetical to one another: if one lacks ability (has a physical impairment), one cannot be sexual, and – equally – if one is not sexual, one has an impairment. One manifestation of the belief that disability negates sexuality exists in the form of negative attitudes towards the sexuality of people with physical disabilities, specifically regarding dating people with physical disabilities. In the South African context, much of the evidence on societal attitudes towards the sexuality of people with physical disabilities tends to be anecdotal or inferred from the international literature. There has been an emergence of literature looking at disability and sexuality from the perspective of persons with disabilities themselves (e.g. Chappell 2016). The study reported on in this paper addresses a gap in the research literature by looking at the attitudes of non-disabled people regarding dating people with physical disabilities.

In the following sections, we outline key theorising about disability and sexuality. Thereafter, we briefly review studies that have examined attitudes towards the sexuality of people with disabilities, focussing on beliefs about dating people with physical disabilities. We highlight the gaps in current knowledge, which the present study aims to fill, and why it is important to do so in South Africa. Finally, using qualitative data, we examine the views of people without disability about dating people with physical disabilities.

Deviance-by-association and harmful stereotypes

Negative societal attitudes towards the sexuality of people with physical disabilities can have negative sequelae for people with physical disabilities, including obstacles to maximising their sexual potential and barriers to accessing information regarding sexual health (O'Dea, Shuttleworth, and Wedgwood 2012). Specifically, there is evidence that people with physical disabilities encounter barriers in their sexual relationships, and when such relationships do occur, they may be problematic. Recent research in Malawi has indicated that some men without disability actively pursue women with physical disabilities for sexual relations, but due to the stigma that surrounds disability, hide their sexual relationships with the women and often mistreat their 'lower status' partners (Kvam and Braathen 2008).

There is also evidence of an elevated rate of sexual violence perpetrated against women with physical disabilities (Stromsness 1993). Furthermore, as a consequence of negative societal attitudes regarding the sexuality of people with physical disabilities, women with physical disabilities who experience sexual violence seldom disclose the violence (Astbury and Walji 2014), possibly because they would rather avoid the discomfort of inept medical and legal services (Kemp and Mallinckrodt 1996).

Against such a backdrop, attitudes towards the sexuality of people with physical disabilities are worthy of exploration (especially in contexts as marred by sexual violence as South Africa, see Meinck et al. [2017]).

A burden of care, discomfort and social distance

Research suggests that people with disabilities are often not seen as suitable partners by persons without disability (in the case of physical disability, see Marini et al. [2011], Olkin and Howson [1994], Trieschmann [1988] and Yoshida [1994]; in the case of disability more generally, see Hergenrather and Rhodes [2007] and Miller et al. [2009]). Whereas many people without disability would pursue friendships with people with disabilities, far fewer would consider romantic relationships (Hergenrather and Rhodes 2007; Marini et al. 2011; Miller et al. 2009). Not only might people with disabilities be regarded as lacking in sexuality, but also people without disability may feel awkward and uncomfortable if in a dating relationship with them, fearing being stigmatised by association based on their closeness with a person with disabilities (Fichten et al. 1991; Gill 1996; Gordon, Minnes, and Holden 1990; Olkin and Howson 1994).

A number of factors may affect people's beliefs about what it would entail to date people with physical disabilities (Scotti et al. 1996; Wolfe 1997). This includes the belief of non-disabled individuals that it would be too much work, that it would be awkward socially, that they would not be sexually satisfied by a partner with a physical disability (Marini et al. 2011) and that the partner would be too dependent (Esmail et al. 2010). Attitudes towards people with physical disabilities may be worse than those towards persons with less visible disabilities (Esmail et al. 2010). For instance, writers such as Fiduccia (2000) and Siebers (2012) suggest that the societal inability or disinclination to reconcile disability with sexuality is particularly strong for people with physical disabilities.

Approximately 80% of all people with disabilities reside in the Global South (Hershey 2000; World Health Organization 2011), and there are over 2,870,130 people with disabilities in South Africa (about 7.5% of the population) (Statistics South Africa 2014). In this context, dominated as it is by low- and middle-income nations, issues of access to basic services, healthcare and education often take centre stage in disability research. Given the urgency triggered by the HIV epidemic in South Africa, research concerning disability and sexuality has mostly concerned itself with illness (Groce et al. 2013; Hanass-Hancock 2009), although there are notable exceptions (Chappell 2016; McKenzie 2013).

There has been a dearth of research regarding the social facets of sexuality and disability in Global South contexts, including in South Africa (Lynch and Clayton 2016; Sofika and van der Riet 2016). Our study therefore sought to address this lack of enquiry by surveying beliefs about and attitudes of a general population sample in South Africa towards dating people with physical disabilities.

Methods

Study design

This project involved the analysis of qualitative data from story-completion vignettes completed by 1723 respondents (Kitzinger and Powell 1995). The vignettes formed part of a larger mixed-methods survey on societal attitudes towards people with physical disabilities in South Africa. The survey included questions exploring perceptions of different facets of physical disability and sexuality, as well as a demographic questionnaire. In the introduction to the survey, a person with physical disabilities was defined as 'someone with a physical impairment that has a substantial and long-term adverse effect on the person's ability to perform normal day to day activities, for example walking, eating, going shopping'.

Gender-matched vignettes were employed to elicit participant beliefs about, discursive practices used, and ways of thinking about, dating a person with physical disabilities. The vignettes were constructed in consultation with a group of people with physical disabilities who worked with the authors on the project. The vignette read as follows for respondents who identified as female (with the equivalent for those who identified as male in brackets):

> Jane (John), who is non-disabled, meets John (Jane), who has a physical disability, at a party. They have a nice chat together and seem to get along really well. At the end of the evening, John (Jane) tells Jane (John) that he really likes her, and invites her to go out on a date the following weekend. How does Jane (John) react to this? How might she (he) respond to John (Jane)? Why might Jane (John) react in this way? What are her (his) thoughts and feelings about the situation?

Projective techniques, such as this story completion vignette, are an attempt to elicit views, beliefs and attitudes indirectly. Barriers to admissibility, including the social undesirability of certain views or attitudes, make this technique useful when researching taboo subjects. As suggested by Kitzinger and Powell (1995), we employed this method as a means of gaining access to respondents' ways of thinking about the topic at hand (Kitzinger and Powell 1995). The survey, including the vignette, was translated into isiXhosa, isiZulu, and Afrikaans[2], and respondents could choose to answer the questions in any of these languages, or in English.

We focussed this study on beliefs about the sexuality of persons with *physical* disabilities for two reasons. Primarily, in the case of examining perceptions of the suitability of people with physical disabilities as dating partners, we wanted to limit the number of factors that could influence respondents' answers. By focussing on physical disabilities, we sought to identify impairment-specific reactions and reactions to difference. We thus isolated an example of disability that allowed people in the vignettes to be adult, able to communicate and fully capable of consent. Secondly, it has been suggested that individuals with visible disabilities face more stigma and social limitations (Esmail et al. 2010).

In designing our study, we were also concerned about respondents answering qualitative questions in a socially desirable manner, which may be particularly pertinent in South Africa where there is an acute awareness of the country's exclusionary history and ongoing inequality (Swartz 2007). Consequently, a largely online and anonymous survey using indirect measures seemed a suitable way to attempt to circumvent this form of social desirability in the present study, insofar as is possible.

Participants and procedure

The survey, administered through *Qualtrics*[3], was advertised widely, including through a dedicated Facebook page and two of South Africa's largest news sites, *The Sowetan and TimesLive*. We obtained permission from the institutional planning departments of two large urban universities – the University of Johannesburg in Gauteng and Stellenbosch University in the Western Cape – to advertise the survey. It was also administered by hand by trained data collectors in two peri-urban settlements in the Western Cape, Langa and Khayelitsha[4]. This was to avoid biasing the sample towards persons with access to computers. The pen-and-paper respondents were selected at convenience from busy areas in the data collectors' respective locations. All respondents had to be at least 18 years of age (due to the sexual nature of some of the content). Ethical approval for the study was granted by the University of East London and the University of Stellenbosch.

The sample consisted of 1990 valid survey responses for the qualitative data, and 125 respondents who met the Washington Group criteria[5] for having a disability using standard cut-offs were excluded, so the remaining group were people without disability, according to the Washington Group criteria. Of the remaining 1865 responses, 1723 provided valid qualitative data (i.e. did not have missing or nonsensical responses, such as 'fggg'). The mean age of the remaining respondents was 26 years (*SD* = 9.15) and ranged from 18 to 76 years. There were fewer men (43.3%) than women (57.7%). Racially, the sample consisted of 42.8% Black African, 42% White, 8.9% Coloured and 4.5% Asian or Indian persons, as well as 1.7% who self-identified as 'other'. Of the participants, 51.2% held a school leaving certificate. In South Africa (total population estimated at 54,490,000), 67.5% of the population identify as Black and only 21.6% as White. In terms of education, according to the South African Census (StatsSA 2012), the percentage of people aged 20 or older with a school leaving certificate is 28.5%. Therefore, our sample had a higher number of White respondents and was better educated than the general population.

Analysis

As in the study of Kitzinger and Powell (1995), we treated the story completion vignette data as one would interview data. Respondents were able to give as long a response as they wished, the majority of responses ranging from 10–150 words. The responses were analysed using thematic analysis (Braun and Clarke 2006). Responses written in isiXhosa and isiZulu were translated by professional translators, while those written in Afrikaans were coded by the first author, who is a speaker of the language. A random sample of the translations was then checked by an independent translator.

All transcripts were coded using Atlas.ti by the first author, as well as two research assistants on the project. In the first round of coding, we used Atlas.ti's open coding function, independently coding the same 100 responses. Following discussion, a code book was developed. The remaining responses were coded using this code book, although allowance was made for emerging codes. Coding was conducted until a point in analysis at which no new information was emerging (after 1000 responses). Having three researchers identify codes independently is a way of ensuring greater reliability within this sort of qualitative work (Saldana 2013).

The extracts were coded not only for semantic content, but also for dynamics within the responses (for instance, noting when respondents changed track half way through their response) and for the manner of responding (how they narrated the end of the story). In each case, the dynamic of responding was examined for what it revealed about the respondents' views concerning dating a person with physical disabilities, and this was coded (as suggested by Clarke, Braun, and Wooles [2015]). The codes, and their associated extracts, were then examined by the first author and themes developed, which were then discussed as a team.

Results

All the themes identified are listed in Table 1.

The responses may reflect respondents' assumptions regarding dating a person with physical disabilities, possibly in lieu of any personal experience of doing so. Thus, our results also illuminate a plethora of stereotypes and misconceptions that the respondents either

Table 1. Themes.

Response dynamics	Inclusive attitudes Pity and condescension
	Moralising
	Need to overcompensate for disability
Reactions	Disgust
	Ambivalence and uncertainty
	Disability an insurmountable obstacle
	Sex concerns and desexualisation
Influential factors	Disability-dependent
	Contact
	Adjustments and accommodations
	Curiosity/openness

held or were aware of in relation to romantic relations with people with physical disabilities, in spite of potentially never having dated a person with physical disabilities.

Response dynamics

Inclusive attitudes

We used a single theme to encapsulate positive views about dating people with physical disabilities. Responses coded here were those that conveyed positive attitudes towards dating people with physical disabilities, either because they limited reference to the disability status of the potential dating partner in the vignette, or because disability status was not seen as a barrier to dating. Example quotes include: '[The woman without disability] feels excited to go out with him, as with any other boy' and '[The person with physical disabilities] is a possible romantic companion, and if they've gotten on well so far, why not pursue the relationship to see if he might be a compatible partner.'

Pity and condescension

A large segment of responses implied or explicitly stated pity for, or condescension to, people without disability towards people with physical disabilities. Coded extracts conveyed an urge to protect the feelings of people with physical disabilities against 'inevitable' rejection but, equally, gestured towards an unequal power dynamic that people without disability felt manifested between themselves and people with physical disabilities. For instance some respondents indicated that the motivation for the person without disability's acquiescence to a date would be pity. One respondent wrote that: '[the person without disability] goes for one date out of sympathy for him but unfortunately does not return his calls afterwards.'

Manifestations of pity included using deception, with respondents stating, for instance, that: '[The person without disability] would probably not want to offend [the people with physical disabilities] and could say yes and go on the date. Alternately [the person without disability] may decline the invite and provide some excuse as to why.'

Another instance of condescension was in some respondents' indication that they were 'proud' of the courage of people with physical disabilities to try to date a person without disability, stating, for instance, that: '[The woman without disability] is deeply impressed by [the man with a physical disability's] confidence. Not only did he overcome the general fear of being rejected as a suitor, but he also overcame fears of being reduced to the stigma attached to disabilities.'

Moralising

Much of the data were prescriptive in tone (responses that contained the word 'should' or its variants, in relation to appropriate behaviour towards people with physical disabilities, were common). Responses included: 'The disability is not supposed to be a factor as [both] are human beings who could go out if they wish' and '[The people with physical disabilities'] disability should be secondary to his personality and character.' The general prescriptiveness of these responses hints at a paternalistic sense of how to 'deal' with people with physical disabilities, pointing to some of the moralistic ways of thinking underlying people without disability's relationships with people with physical disabilities.

Emanating out of the dynamics above, most respondents without disability indicated that the nature of the relationship between the person without disability and the person with physical disabilities would depend entirely on the character of the person without disability, such as the need for magnanimity on the part of potential partners of people with physical disabilities, as seen in responses such as: '[The person without disability] was brought up in a decent home and did not judge someone on their outer looks.'

Need to compensate for disability

This theme highlighted a particularly interesting facet of the data: that people without disability believed people with physical disabilities should compensate, in some manner, for their disability. What is conveyed in these data is the idea that, for people with physical disabilities to 'qualify' as dateable, they need to exceed the expectations placed upon people without disability, by being exceptionally funny or charming, so as to 'make up for' what they 'lack' in physical desirability. This is exemplified in responses such as: 'If the conversation and [the people with physical disabilities'] company were exceptional then [the person without disability] will certainly react positively and respond with the affirmative. If not, she can reserve her right to refuse [the people with physical disabilities'] invitation.'

Reactions

Disgust

Some responses seemed to suggest powerful negative affect – such as recoiling, revulsion and fear. This included shock and offense that a 'lower status' romantic candidate would approach the character without disability. As one respondent wrote: '[The woman without disability] might say that she isn't interested or feel offended that he could think that she would go on a date with [the person with physical disabilities].' These codes were clustered into a distinct theme due to their negative valence, as evidenced by statements such as: '[The woman with disability] might respond with disgust due to his disability and tell John it's her reason not to pursue anything with him.'

Disability as an insurmountable obstacle

This theme encompasses responses from two dominant sub-themes, namely 'anxiety and complicated feelings' and 'stigma'. The sub-theme 'anxiety and complicated feelings' is evident in responses that conveyed discomfort (the word uncomfortable and its variants occurred frequently), as evidenced in responses such as: '[The person without disability] might have a problem with John's disability, perhaps the prospect of being intimate with [the person with physical disabilities] given his physical condition makes her feel uncomfortable. In this case, she may pretend not to like him although she does, because she is uncertain about the situation.'

Respondents conveyed a fear of being regarded as prejudiced, indicating that the sense of duty to be good to people with physical disabilities might originate from a desire to do the right thing. For men, this took on a gendered tone, with comments such as: 'He should be a gentleman and say yes. He should take her out on another date if he doesn't feel uncomfortable with [the person with physical disabilities]. He should just say yes.'

The complicated-feelings facet of this sub-theme refers to the fact that a number of the responses conveyed a somewhat mediated reaction on the part of respondents – that is, the response would change tack mid-way through or would convey guilt about holding socially undesirable views, as exemplified in quotes such as: '[The person without disability] may not feel comfortable or have a certain view point where she sees no future with [the person with physical disabilities] because he has a disability … may be a pity date which will lead to more hurt.'

The sub-theme 'stigma' encapsulates one of the most prominent sentiments recurring throughout the data-set. Stigma was coded as either being 'other' or 'self' – that is, the respondents either conveyed a fear of stigma by association whilst not explicitly stating their own views about people with physical disabilities or expressed stigmatising and prejudicial views themselves.

In the first instance, responses included: '[The person without disability] will probably tell [the person with physical disabilities] that he is a nice person but he is not her type. This may be due to the fear of what the society might say about her' and '… depends on [if the person without disability is] prejudiced and the way handicapped are seen in his culture. He might accept or decline (*sic*).'

In other cases, the respondents expressed these feelings as their own, noting their desire to conceal their romantic involvement with a person with physical disabilities: 'Unfortunately, when [the woman without disability's] friends see them together, she still feels ashamed.'

Finally, extracts included here framed the people with physical disabilities' impairment itself as too great an obstacle to allow for the possibility of romantic involvement. Amongst women, this often included a fear that the burden of caring for the person with physical disabilities would fall on them. As one respondent stated: 'It might depend on what type of disability John has. If he has a "time-consuming" disability, Jane must be very sure before agreeing to a date and sparking a real romantic interest.'

Sex concerns and desexualisation

Of special interest were those responses that conveyed respondents' sexual concerns about dating a person with physical disabilities, or that desexualised the people with physical disabilities in the vignette, writing, for instance, that: '[The person without disability] might have a problem with disability; perhaps the prospect of being intimate with [the person with physical disabilities] given his physical condition makes her feel uncomfortable.'

In contrast to women's concern with intimacy, broadly defined, the codes included in this theme from male respondents mainly constituted worries about physical limitations on sexual activity (narrowly-defined as heteronormative penetrative sex), with respondents stating, for instance, that: 'There might be a deal breaker in terms of disabilities, as in if she is paralysed from the waist down and does want someone sexually active then he wouldn't want to date her, but at the least they would be friends.' This not only reflects a focus on the mechanics of the sexual act, rather than intimacy more broadly, but also reinforces the observation of Esmail et al. (2010) and Tepper (2000) that restrictive understandings of what counts as sex contribute to disableism and perpetuate the myth of asexuality amongst people with physical disabilities.

Ambivalence and uncertainty

Related to, but distinct from, the 'anxiety and complicated feelings' sub-theme, 'ambivalence and uncertainty' encapsulates data that conveyed ambivalence and uncertainty about romantic contact with people with physical disabilities.

Respondents often showed ambivalence about dating people with physical disabilities, stating, for instance, that: '[The person without disability] is going to be nice to [the person with physical disabilities] because he cannot bring himself to "disappoint a disabled girl"; he might feel guilty for "leading this girl on and giving her ideas" while all he meant was being nice out of pity.' Despite the fact that this ambivalence could have a negative valence, it also sometimes signalled a hint of inclusivity. This can be seen in responses such as: '[The woman without disability] is really surprised and a little uneasy about how to respond, but since they had such a nice conversation and she doesn't want him to be upset, she agrees to go on a date with him.'

Influential factors

Contact

Respondents often motivated negative responding on the part of the character without disability by referring to the latter's lack of familiarity and past contact with people with physical disabilities. Statements such as: 'There might be some apprehension if [the woman without disability] has never had a personal or intimate relationship with a person who has a disability' exemplify this. This lack of contact was framed as a barrier to romantic interactions with people with physical disabilities.

Adjustments and accommodations

Responses to the vignettes from female respondents evinced a strong longitudinal perspective on the scenario. Respondents pointed to concerns about the future burden of care in a relationship with a person with physical disabilities, making comments such as: '[The woman without disability] may not feel comfortable or have a certain view point where she [sees] no future with him because he has a disability.' Women also made more reference to adjustments that would need to be made over time in pursuit of a relationship with a person with physical disabilities, including: 'Googling [the man with a physical disability's] disability.'

Curiosity/openness

When respondents did show openness to the idea of dating a person with physical disabilities, their motivation was often curiosity. As one respondent wrote: '[The person without disability] smiles as she eyes [the person with physical disabilities'] prosthetic legs, "The more adventurous, the better".'

The degree to which the curiosity displayed in many responses is not problematic is debatable – such sentiments might be seen to be fetishising/using people with physical disabilities as an opportunity for personal growth. However, they may reflect simple interest and openness, as suggested by such responses as: '[The woman without disability] accepts the invitation with an open mind.'

Disability-dependent

A prominent theme throughout the data-set was the idea that the romantic suitability of people with physical disabilities depended on the nature of their disability. Respondents suggested that greater functional impairments would foreclose on the possibility of dating, whilst less severe impairments might be manageable, writing, for instance, that: 'If Jane is severely disabled (quadriplegic, for instance) she might require intense care, and John might not want to take the relationship further …. With lesser amounts of disability, possibly lost a leg or a hand, the person will require less physical assistance, after which John would be much more open to further the relationship.'

Discussion

This discussion must be prefaced by an acknowledgement that vignettes are but one means of gaining some access to the ways of thinking about, perceptions and social constructions of the respondents concerning dating people with physical disabilities, and it is with this in mind that the following discussion is undertaken (Agunbiade and Ayotunde 2012; Kitzinger and Powell 1995). Further, as noted before, it must be borne in mind that our sample had more White respondents, fewer men, and respondents with a higher degree of education than the South African population at large. This limits the generalisability of our findings. Thus, what follow are our observations regarding attitudes of some South Africans towards dating people with physical disabilities.

We found that the views of our sample of South Africans without disability about a dating scenario involving a person with a physical disability were dependent on the nature and severity of the disability, and characterised by pity for people with physical disabilities and fears about stigma and dependency. Notably, however, we also found evidence of inclusive attitudes, characterised by responses that did not focus on the disability status of the dating target or that expressed openness to dating a person with physical disabilities. It is important to note that answers characterised by ambivalence and uncertainty also convey potentially inclusive attitudes, indicating the potential for meaningful relating. Taken together, these facets of our data suggest that there are some positive attitudes towards dating people with physical disabilities in South Africa.

However, we also found that there is a perception amongst people without disability that lack of contact between people without disability and people with physical disabilities causes the former to feel anxious in the presence of the latter. Research on attitudes has consistently suggested that people without disability perceive there to be a hierarchy of disability acceptability, where severe and visible disabilities are ranked as less acceptable than less visible and less disabling conditions (Olkin and Howson 1994; Strohmer, Grand, and Purcell 1984). Based on our findings, it appears that this hierarchy holds for partnering with people with physical disabilities.

The motivations behind this hierarchy appear to be twofold: firstly, people without disability may fear the accommodations necessary to pursue a sexual relationship with a person whose physicality differs from their own. Secondly, this finding appears to support what

Davis (1995) calls the 'enforcement of normalcy', which is the tendency of people to exclude persons based on their deviations from their criteria for normalcy.

Social psychological research has for some time explored anxiety in interactions between non-stigmatised and stigmatised persons (Hebl, Tickle, and Heatherton 2000; Stephan and Stephan 2000; Hebl and Dovidio 2005). Writing from the psychoanalytic tradition, Watermeyer (2006) suggests that this nervousness is due to our imaginings about what it would be like to be stigmatised ourselves, and our fantasies about the life and internal world of the other.

Many of our findings mirror those of past studies. Pity played a large role in many respondents' narratives. Past work has suggested that people with disabilities encounter condescension and pity from people without disability (Crawford and Ostrove 2008). Our respondents without disability also expressed awkwardness about interactions between people without disability and people with physical disabilities, mirroring the findings of Marini (2012) and Marini et al. (2011).

We also found evidence that people without disability actively desexualise people with disabilities. 'Desexualisation is a process that separates sexuality from disabled bodies', writes Kim (2011, 483), 'making it irrelevant to and incompatible with them because [people without disability] are supposedly undesirable in society and because disability is believed to lead to sexual incapacity.' The findings of the present study provide tentative evidence that the myth of asexuality amongst people with physical disabilities (noted in the Introduction) may be underlain not only by beliefs, but also by people without disability's active desexualisation of people with physical disabilities in interactions.

There was evidence of gender differences in responding to the dating scenario. For instance moralising about the 'right' way to react to the scenario was framed by male respondents as a matter of 'being a gentleman', and men were more concerned with physical intimacy than were women. Women were more likely to refer to making adjustments over time to accommodate disability. However, gender did not emerge as a major axis down which the data were split. Future work in this area could potentially conduct a more purposeful gender analysis of attitudes towards dating people with physical disabilities. The present study seems to suggest that gender does not directly determine the valence of attitudes.

In the South African context, specifically, however, two of our findings have particular relevance. Firstly, our finding that more women than men feared the burden of care, which could be placed upon them in a relationship with a person with physical disabilities, makes sense in context. Recent work in South Africa suggests that women bear the majority of the burden of hidden care work (Akintola 2006; Nnko et al. 2000; Steinberg et al. 2002). In higher-income contexts, professional or paraprofessional care workers may be available to assist people with physical disabilities with specific care needs. There is a dearth of such services in low- and middle-income settings. It stands to reason, then, that women without disability in such contexts might be more reticent to partner with a person whose care they feel they might become tasked with.

Secondly, it is relevant that we found evidence that suggests that some inclusive attitudes do exist. Even where persons without disability appeared to be ambivalent about the romantic suitability of people with physical disabilities, some expressed openness to exploring a romantic relationship with a person with physical disabilities. This is a notable finding in South Africa, where the numerous barriers faced by people with physical disabilities mean that evidence of positive attitudes towards them should be seized upon and explored.

Indeed, the evidence of inclusive attitudes towards dating people with physical disabilities warrants further enquiry, given that so little is known about the antecedents of inclusive attitudes in this area.

Conclusion

The findings presented in this paper have implications for future research and work in the field, which should – our data suggest – concern itself more with detailed exploration and analysis of the beliefs and attitudes of people without disability that underlie their willingness to date people with physical disabilities. The promotion of full inclusion, and the sexual rights, of people with disabilities is a central goal of the Convention on the Rights of Persons with Disabilities (UN General Assembly 2007). Further enquiry and activism is urgently required if we are to begin to explore and explode some of the attitudes and beliefs that underlie negative attitudes found in the present work.

Some of the work that must be done may involve creating more opportunities for contact between people with physical disabilities and people without disability on an equal basis every day, in higher education institutions, places of employment and public spaces. In South Africa, and in the Global South in general, there are many barriers to contact likely to foster and support relationships and intimacy (Goodley and Swartz 2016). But it is clear that a much more complex politics of intimacy and desire is at stake here, not only contact. In the context of disability and sexuality, much remains to be done. However, the positive attitudes we did find in our sample suggest that fertile ground exists for this work to occur.

Notes

1. Garland-Thomson (1997) coins a particularly useful term, 'the normate', to refer to the imagined identity position held by those unmarked by identifiers of difference (including disability).
2. isiXhosa and isiZulu are 2 of South Africa's 11 official languages. These Indigenous languages are spoken mostly by Black South Africans. isiXhosa is the home language of 22.7% of the population and isiZulu, 16%, making these the two largest language groups in the country. Afrikaans is the home language of 13.5% of the population, making it the third largest language group in the country (Statistics South Africa 2012).
3. *Qualtrics* is a survey-management platform.
4. Langa and Khayelitsha are two large, peri-urban settlements on the outskirts of Cape Town in South Africa. Their inhabitants are largely Black African and Xhosa-speaking.
5. The Washington Group Short Set of questions, which is being used in many contexts globally, was used to identify people with disabilities amongst the survey participants. These items measure disability in functional terms and include questions regarding the respondent's abilities in terms of seeing, hearing, ambulating, cognition, self-care and communication. Response options range from 1 = 'No – no difficulty, 2 = 'Yes – some difficulty', 3 = 'Yes – a lot of difficulty' and, finally, 4 = 'Cannot do at all'.

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Linking narrative 2: Publication 2 to Publication 3

The two foregoing publications (Publication 1 and Publication 2) go some way toward sketching the nature of non-disabled people's thinking and feeling about the sexuality of people with physical disabilities. Thus far, we have accumulated evidence which suggests that people with physical disabilities are desexualised by non-disabled people.

The reader may recall, however, that I am also interested in non-disabled people's representations of the sexuality of people with physical disabilities. The impetus behind the following publication (Publication 3) was to gain some preliminary ideas about what kinds of representations underlie the attitudes apparent in the previous two publications. Methodologically, the publication is simple; I employ free response analysis to generate basic descriptions of men, and women, with physical disabilities, by non-disabled people. However, what this publication sets out to do is of fundamental importance; to illuminate the ways in which disability is thought about generally, and – specifically – in relation to gender. In so doing, this publication contributes a further level of evidence for my case that people with physical disabilities are seen as disabled, first, and gendered or sexual, second. Further, the work presented in this piece begins to move our consideration of physical disability and sexuality in the direction of representations, providing a useful background against which we may silhouette the subsequent work in this dissertation.

Publication 3: Withdrawn, strong, kind, but de-gendered: Non-disabled South Africans' stereotypes concerning persons with physical disabilities (Hunt, Swartz, Carew, Braathen, & Rohleder, in press)

Withdrawn, strong, kind, but de-gendered: Non-disabled South Africans' stereotypes concerning persons with physical disabilities

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Points of interest

- People with disabilities have often been the subject of a number of problematic stereotypes held by people without disabilities.
- People with physical disabilities have been found in the past to be stereotyped in a manner which characterises them as less sexual than people without disabilities.
- This paper presents one of the first accounts of stereotyping in relation to physical disability and sexuality in South Africa.
- A free response methodology was used to examine the content of non-disabled people's stereotypes concerning men and women with physical disabilities.
- We found evidence of stereotypes regarding physical disability and femininity which could place women with physical disabilities at risk of negative attitudes.
- The findings in the present paper suggest that stereotypes of people with physical disabilities are not overwhelmingly de-sexualising, but *are* undifferentiated by gender.

Background

Stereotypes, readers of this journal well know, are sets of qualities which people are assumed to share based on their perceived or real membership to a social category (Ashmore & Del Boca, 1981). When applied to others we perceive different to ourselves, stereotypes morph into images of personhood we expect those others to enact. Functionally, stereotypes create expectations and beliefs which hold with remarkable endurance (Foddy, Platow, & Yamagishi, 2009; Kao, 2000; Tiedens, Ellsworth, & Mesquita, 2000).

When applied to marginalised groups, stereotypes can cause harm (via prejudice). When held by the majority, stereotypical images of marginalised persons often have problematic implications for the latter group, perpetuating their marginalisation (Hubbard, 1998; Manthorpe, Bowes, Innes, Archibald, & Murphy, 2004). This, we suggest, is the case for people with disabilities (PWD).

PWD have often been the subject of a number of problematic stereotypes held by non-disabled people. One such stereotype, most often applied to people with physical disabilities (PWPD), is that they lack sexuality. Some work seems to support the claim that PWPD are seen as less sexual than non-disabled people (Nario-Redmond, 2010); however, no research has yet examined stereotyping in relation to physical disability[1] and gender in the Global South, a context in which, for reasons discussed presently, such stereotypes might have dire consequences for PWPD (especially women). The present paper sets out to address this gap

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[1] There is debate in the field of disability studies over the terminology by which people with impairments are referred to. In this article, we employ 'person first' language, where, conceptually, personhood is given primacy over disability identity, hence, 'person with a physical disability' (this derives from an American school of thought). There are scholars, however, who prefer the term 'disabled people', in order to recognise and value disability identity (this derives from the Social Model school of thought). The former terminology was selected to make the article coherent. We also use the term 'disability' over the word 'impairment', in acknowledgment of the social model, and its emphasis on disablement as a social process (which is of relevance to the present inquiry).

by reporting findings from a large survey of stereotypes about PWPD and gender, conducted amongst non-disabled people in South Africa.

Concerning stereotypes

The study of disability as a social construct began in the 1940s (Asch & McCarthy, 2003). In this work, disability is examined as a group categorisation based on homogenising representations applied consistently by the majority of society to PWD (Asch & McCarthy, 2003). Such representations are stereotypes which are used as a social heuristic to define groups in ways which distinguish them from others (McCauley & Stitt, 1978).

Recent work by Dixon (2017) deftly elaborates the manner in which claims about stereotype inaccuracy have led scholars to falsely dismiss all stereotypes as problematic. Some stereotypes, however, *are* derived from fact, and Dixon (2017) argues that 'accepting that groups differ, and that their differences are often validly perceived by members of a society, is a necessary first step on the path to social justice'. Dixon (2017) presciently argues for a shift in how the relationship between stereotyping and social perception is interpreted – an examination of how our construction of social reality is produced by interactions with the world out there, and our internal meaning-making systems 'in here', rather than attempting to quantify whether what we may believe about others is justified. In critical disability studies there is an important position taken in challenging stereotypes about 'vulnerability' or 'capacity' or 'dependency'. What Dixon's (2017) work does allude to is that this does not mean that these stereotypes are necessarily baseless, for some PWD these issues may be areas of concern or actual experience.

In the vein of Dixon (2017), we do not assume that all stereotypes are inaccurate, nor entirely distorted. We have evidence that some are inaccurate, and that non-disabled people are invested in the pervasiveness of this inaccuracy. We also suggest that some stereotypes create a performative expectation for PWD, which may lead to a cyclical reification and enactment of the stereotype by non-disabled people and PWD, respectively. In line with Dixon (2017), we work from the perspective that ‘stereotyping is not a matter of (mis)perceiving or (mis)representing the already existing qualities of individuals or groups. Rather, it is a matter of actively constructing those qualities and indeed the very nature of social categories that are deemed applicable within a given context’ (2017, 18). However, we take a political line in emphasising the characteristics of disablist dynamics which hold problematic constructions – often inaccurate – in place.

Arguments regarding the function or accuracy of stereotypes aside, we do know that stereotypes concerning PWD exist. Researchers have attempted to understand stereotyping in relation to persons with disabilities by establishing whether disabled people are viewed in consistent ways (Nario-Redmond, 2010). This research is based on the premise that, while most people hold a unique set of personal beliefs and frame of reference for understanding social groups, these views and beliefs are often influenced by socialisation and so reflect broader cultural stereotypes. Thus, consistency amongst individual views and beliefs reveals the nature of cultural stereotypes (Schneider, 2005). What studies in this area have revealed is that such stereotypes do exist (Abrams, Jackson, & St Claire, 1990; Braathen & Ingstad, 2006; Coleman et al., 2015; Fiske, Cuddy, Glick, & Xu, 2002; Hanass-Hancock, 2009; Kvam & Braathen, 2008; Maras & Brown, 1996).

Regarding PWPD in particular, cultural studies work has examined how PWPD have been portrayed using certain tropes or stereotypes. These include the PWPD as Freak (Garland-Thomson, 2009), the medical anomaly (Condrau, 2007; Garland-Thomson, 2009; Reeve, 2012), and the inspiration or SuperCrip (Grue, 2016; Shakespeare, 1994).

Indirect evidence of stereotypes of PWPD can be gleaned from other sources, not least of which the reports of PWPD themselves. In a study by Crawford and Ostrove (2003), women with physical disabilities (WWPD) noted encountering beliefs from non-disabled others which characterised PWPD as ‘universally intellectually challenged’, lacking sexuality, helpless, and incompetent (Crawford & Ostrove, 2003, 186). Similar findings were reported by Kvam and Braathen (2008) and Braathen and Ingstad (2006).

To date, work involving the direct measurement of disability stereotypes is scarce in the Global South. This despite the fact that research on the homogenising ways of thinking about PWD would make a notable contribution to our knowledge of the underpinnings of attitudes towards PWD in contexts outside of the Global North (recent work by the authors has noted the importance of examining possible antecedents of attitudes towards PWPD) (see Author et al., 2018).

In the sections which follow, we will outline why this tendency to draw on stereotypes to guide social expectations is of particular import for thinking about stereotypes concerning disability – particularly, stereotypes concerning physical disability and sexuality, and gender.

Concerning attitudes towards PWPD

As Sechrist and Stangor (2001) note, identifying the contents of societal stereotypes is important as this content influences when and how the stereotypes are used, with far-reaching consequences for those who are stereotyped. An individual without disability’s awareness of societal stereotypes can influence their reactions to PWPD in stereotype-congruent ways (Bargh, 1999). In the case of sexuality, as Wood and Nario-Redmond (cited in Nario-

Redmond, 2010) note, stereotypical representations of PWPD as lacking sexuality can influence perceptions, judgements and expectations for PWPD amongst people without disability, even when the latter discredit the veracity of the stereotypes (Crawford & Ostrove, 2003).

Problematic attitudes towards PWPD, particularly as pertains to their gender, sexuality, and suitability as romantic partners, are prevalent (Hergenrather & Rhodes, 2007; Marini, Chan, Feist, & Flores-Torres, 2011; Miller, Chen, Glover-Graf, & Kranz, 2009). It appears that some of this is due to negative social constructions and stereotypes concerning PWPD. However, in general, and in the Global South in particular, we lack evidence of these stereotypes. In the section which follows, we will briefly discuss the necessity of such work, particularly in South Africa, and why an examination of stereotypes concerning PWPD should also incorporate gender.

Concerning gender and disability

Usually, gender is a primary marker of identity, one of the first features of a person which meet our attention in interaction with them. It is thus one of the first features of a person which would be subject to our deployment of stereotypes in interaction with them.

According to writers such as Rich (2014), however, disability is an identity which *supersedes* gender (Goffman 1959). As gender roles are enacted through the performance of certain activities, activities which disability may make impossible (either in reality, or in the eyes of others), disability can ‘trump’ a PWD’s gender identity in the eyes of others (Banks, 2010), the former working to negate the latter (in the eyes of society at large).

Past work has shown that PWD are characterised as less sexual than non-disabled people, and unattractive (Nario-Redmond, 2010). In essence, the stereotypes concerning PWD appeared to exist in direct opposition to the traditional characteristics of their respective gender group (Schlesinger, 1996; Tilley, 1996).

In South Africa, there is reason to believe that the intersection of gender and disability stereotypes has particularly dire consequences for women with disabilities. In the KwaZulu-Natal province, Hanass-Hancock (2009) notes that disability and gender are both associated with myths and stereotypes that exacerbate the vulnerability of PWD to HIV/AIDS, particularly women. The prevalent idea that PWD are lacking sexuality, virgins, sexually overactive, cursed, dirty or clean, all contribute to their vulnerability to sexual abuse and, subsequently, HIV/AIDS in this context (Hanass-Hancock, 2009).

Over and above risk of abuse and HIV, intersections between gender and disability stereotypes mean that WWPD in particular are seen as unable to fulfil traditional roles, and are liable to be seen as 'lucky' if a person without disability 'sees fit' to have sex with them, regardless of their own desire (Kvam & Braathen, 2008).

When these three strands of thinking are taken together, the relevance of examining societal stereotypes concerning men and WWPD becomes apparent: stereotypes are likely to be desexualising or at least de-gendering for PWPD; stereotypes guide attitudes; desexualising attitudes, when encountered by PWPD, are harmful.

Concerning stereotypes of sexuality and disability

Stereotypes about PWPD which appear to be particularly prevalent, are those which concern their sexuality – or, rather, characterise PWPD as lacking sexuality. In relation to disability and sexuality specifically, Nario-Redmond (2010) elicited students' stereotypes regarding men and women with disabilities, and contrasted them with stereotypes regarding non-disabled men and women. Only non-disabled women and men were stereotyped along traditional gender lines, whereas persons with disabilities were characterised as asexual and unattractive (Nario-Redmond, 2010). Traditional male and female gender stereotypes were found only for non-disabled targets, and the stereotypes of male and female targets with disabilities were characterised as more similar to one another, and, overall, as less gendered. Further, men and women with disabilities were seen as uniformly dependent, incompetent, and asexual (Nario-Redmond, 2010). This buttresses the point, made earlier, that common myths relating to PWPD are constructed in opposition to the traditional gender characteristics of a group (Schlesinger, 1996; Tilley, 1996).

Nguyen, Liamputtong, and Monfries (2016) noted that stereotypes about physical disability resulted in a lack of knowledge about reproductive health of PWPD, and that PWPD, especially women, faced stigmatising stereotypes which portrayed them as asexual, de-gendered, unattractive, and unsuitable for motherhood.

The above work has important implications for considering how non-disabled people may think and feel about the sexuality of PWPD. Stereotypical representations of PWPD as asexual can influence the perceptions, judgements and expectations of PWD, even amongst non-disabled participants who discredit the veracity of the stereotypes themselves (Coleman et al., 2015; Nario-Redmond, 2010; Wood & Nario-Redmond cited in Nario-Redmond, 2010). For instance, as Nario-Redmond (2009) explains, non-disabled people who do not actively express the assumption that WWPD are not sexually active, might still be surprised to discover that a woman with a physical disability has a child.

PWPD have been very widely argued to be subject to rigid and relatively unremitting processes of desexualisation by society at large. This desexualisation, the literature suggests, is sustained by stereotypes which characterise PWPD as infantile, dependent and 'de-gendered'.

By examining the stereotypes which a sample of non-disabled South Africans employ in describing PWPD, we hope to shed light on how such stereotypes might contribute to some of the problematic attitudes and sequelae of attitudes encountered by PWPD.

Method

Participants and procedure

Cross-sectional data for the present study were gathered using an online survey examining the attitudes of people without disability towards different facets of sexuality and disability. The survey (hosted on *Qualtrics*) contained two free response items. The survey was translated into three South African languages – isiXhosa, isiZulu, and Afrikaans[2] – and participants could choose to respond in any of these languages, or in English. The survey was advertised on social media, as well as on two prominent South African online news sites.[3] We obtained permission from the institutional planning departments of two large urban

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[2] isiXhosa and isiZulu are two of South Africa's 11 official languages. These indigenous languages are spoken mostly by Black South Africans. isiXhosa is the home language of 22.7% of the population, and isiZulu, 16%, making them the two largest language groups in the country. Afrikaans is the home language of 13.5% of the population, making it the third largest language group in the country (Statistics South Africa, 2011).

[3] *The Sowetan* and *Timeslive*.

universities, one in the Western Cape and one in Gauteng, to advertise the survey amongst their students. The survey was also administered by hand by trained data collectors in Langa and Khayelitsha,[4] two large peri-urban settlements in the Western Cape. The pen-and-paper survey participants were selected at convenience by the data collectors, who were residents of the areas in question. Due to the sexual nature of some of the items in the questionnaire, all participants had to be at least 18 years old to be included in the study. After five months, the survey was closed, the pen-and-paper collection finished, and the qualitative data entered into Atlas.ti.[5]

Materials

The survey included questions measuring attitudes towards different facets of physical disability and sexuality, as well as a demographic questionnaire (findings from the quantitative data produced by these items will be published elsewhere, see Author et al., in press). In the introduction to the survey, a PWPD was defined as ‘someone with a physical impairment that has a substantial and long term adverse effect on the person’s ability to perform normal day to day activities e.g. walking, eating, going shopping’ (Government of United Kingdom, 2010). As part of this survey, we assessed stereotypes using free-response items.

Free response analysis

Free-response items are based in a free association technique which elicits participants’ spontaneously-activated traits in relation to a target group. The questions request participants

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[4] Langa and Khayelitsha are two large, peri-urban settlements on the outskirts of Cape Town in South Africa. Their inhabitants are largely Black African and Xhosa-speaking.

[5] ATLAS.ti is a computer programme used in qualitative data analysis. For more details, see http://atlasti.com/product/

to state three traits that come to mind when thinking of men who have physical disabilities, and three which come to mind when thinking of women who have physical disabilities.

This methodology has been used in previous research into attitudes towards men and women with disabilities (Nario-Redmond, 2010). In the present study, free-responses were limited to three descriptive points per target, per respondent, based on recommendations from prior research (Nario-Redmond, 2010; Niemann, Jennings, Rozelle, Baxter, & Sullivan, 1994).

Analysis

The data for the free response questions were imported into Atlas.ti. Responses were then coded by two research assistants on the project, as well as the first author. During this process, the three traits listed by each respondent in each item were assigned a homonymous code. If a response was longer than one word, for instance, ‘physically limited’ or ‘less than they could have been’, then, for ease of analysis, the coders assigned it a synonymous, single- or two-word code. Codes were kept separately by gender.

We coded the responses until saturation was reached, and no new traits were emerging. The first author then randomly selected a sample of the remaining questionnaires, checking whether these responses contained any novel traits. They did not. In the final code lists, there were 598 codes (traits) for male targets, and 546 codes (traits) for female targets. Each code corresponded to a trait. All frequencies spoken about in the sections which follow are expressed as a percentage of the total number of the total responses for a gender.

We first calculated the relative frequencies for each individual trait. We then clustered the traits, with their associated frequencies, into stereotypes. In a manner similar to the formation of themes in thematic analysis, this process entailed the categorisation of codes into larger, discrete groups which encapsulated something novel about the data, in this case, novel images of PWPD. We then calculated the rank of each stereotype, by summing the frequencies of traits associated with it. We could thus rank the stereotypes in terms of prominence according to what percentage of responses cohered within it (for instance, 27.8% of all codes for men with physical disability (MWPD) fell under the ‘withdrawn and dependent’ stereotype for men).

We arranged the traits within each stereotype in terms of rank (so, for instance, for MWPD, insecure was the most common trait cited under the ‘withdrawn and dependent’ stereotype). Finally, we highlighted the five highest ranked traits, independent of stereotype, for MWPD and WWPD.

Results

Sample

The sample consisted of 1,990 valid survey responses for the qualitative data. One hundred and twenty-five participants who met the Washington Group criteria for having a disability using standard cut-offs were excluded, so the remaining group were people without disability, according to the Washington Group criteria (Madans, Loeb, & Altman, 2011). These items measure disability in functional terms, and include questions regarding the respondent’s abilities in terms of seeing, hearing, ambulating, cognition, self-care and communication. They have been used in numerous contexts (Altman, 2016; Madans & Loeb, 2013). The response options range from 1, ‘No- no difficulty’, to 2, ‘Yes- some difficulty’, to 3, ‘Yes- a lot of difficulty’, and, finally, to 4, ‘Cannot do at all’. People are considered to have a disability if they score 3 or 4 to any of the questions. Of the remaining 1,865 responses, 1,723 provided valid qualitative data (i.e., did not have missing or nonsensical responses, such as 'fggg'). The mean age was 26 years (SD = 9.15), and ranged from 18 years to 76 years. There were fewer males (43.3%) than females (57.7%). The sample consisted of 42.8% Black African, 42% White, 8.9% Coloured, and 4.5% Asian or Indian people, as well as 1.7% who self-identified as 'other'. Of the participants, 51.2% held a school leaving certificate. In South Africa (total population estimated at 54,490,000), 67.5% of the population identify as Black and only 21.6% as White. In terms of education, according to the South African Census (Statistics South Africa, 2011), the percentage of people aged 20 or older with a school leaving certificate is 28.5%. Therefore, our sample has a higher number of White participants and is better educated than the general population.

Stereotypes Regarding Men With Physical Disabilities (MWPD)

In the analysis, the individual traits were clustered into relatively discrete stereotypes. Stereotype prominence was calculated by summing the total prevalence of traits associated with that stereotype. There were seven such stereotypes concerning MWPD. The present section, then, will consider these homogenising images of men with disability first. Thereafter, we list the five most prominent individual traits, independent of the stereotype from which they hail.

The most prominent stereotype was of MWPD as 'withdrawn and dependent'. The top five traits within this stereotype were insecure, shy, weak, dependent, and introverted. The second most prominent stereotype was the 'SuperCrip' – a cluster of traits which positioned MWPD as somehow superhuman, ultra-capable, and heroic. The top five most prevalent traits associated with this stereotype were strong, determined, brave, independent, and intelligent.

The third most prominent stereotype for men was that of a ‘nice guy’ – an image of a person who was optimistic, kind, happy, and friendly. The top five most prevalent traits associated with this stereotype were friendly, kind, funny, positive, and patient.

Next, in order of total prevalence, was a group of traits which did not indicate a homogenising view of MWPD, but instead cited traits related to the physical impairments which participants associated with MWPD. These included mobility-impaired, physically limited, blind, hearing-impaired, and visually-impaired. Next, MWPD were often portrayed as ‘angry’. The image of thwarted masculinity which this cluster of traits pointed to was salient. The top five most prevalent traits associated with this stereotype were frustrated, stubborn, short-tempered, grumpy, and defensive.

The penultimate stereotype concerning MWPD portrayed these men as ‘lacking sexuality’. The top five traits associated with this stereotype of the sexual man with a physical disability were impotent, emasculated, unattractive, ‘can’t perform sexually’, and asexual. The last, lowest-scoring category of traits were those which were not strictly traits, but rather the absence of specific characteristics or markers of difference. This category thus included responses such as ‘everyone is different’, ‘same as able-bodied’, and ‘disability doesn’t define a person’.

Of these seven groups of traits, five were counted as stereotypes proper, and two as mere trait clusters (clusters of traits which did not so much create a coherent image of PWPD, but instead reflected types of characteristics associated with them).

Further to the stereotypes proper and trait clusters, and their respective rankings, we also calculated the individual traits in terms of relative frequency. For MWPD, the top five most prevalent individual traits cited were strong, funny, insecure, weak, and determined.

When we separated these individual traits by respondent, we found that female participants most commonly called MWPD strong, insecure, determined, shy, friendly, and brave (in that order). Meanwhile, male participants most commonly called MWPD strong, insecure, determined, friendly, weak, and kind (in that order).

Stereotypes Regarding Women With Physical Disabilities (WWPD)

There were also seven stereotypes concerning WWPD. The most prominent stereotype was of WWPD as withdrawn and dependent. Similar to the same stereotype concerning MWPD, the top five traits associated with this stereotype were insecure, shy, dependent, quiet, and sad (the notable difference being the inclusion of a depressive trait).

As in the case with MWPD, the SuperCrip stereotype ranked second overall for WWPD. Here, the most prevalent traits associated with the female SuperCrip were strong, determined, independent, brave, and courageous.

The female corollary of the nice guy stereotype concerning MWPD also ranked third in cumulative trait score for women with disabilities. The top five traits associated with this image of WWPD as ‘nice ladies’ were kind, friendly, positive, intelligent, and caring.

Next, in order of total prevalence, was a group of traits which related to the physical impairments which participants associated with WWPD. The five most prevalent traits were mobility-impaired, blind, hearing-impaired, physically limited, and paralysed.

Next, for women, was a cluster of traits which did not so much point to a stereotype of WWPD, but instead, revealed inclusive attitudes on the part of participants, or were traits indistinguishable from those usually associated with women, regardless of impairment. The top five most prevalent traits in this image of the WWPD were ‘everyone-is-different’, beautiful, human, normal, and female.

Next, WWPD were portrayed as ‘irritable and aloof’. The top five traits in this stereotype were frustrated, short-tempered, unfriendly, aloof, and angry.

The least prominent stereotype concerning WWPD concerned sexuality – that they were sexually undesirable. Unlike men, for whom the sexuality stereotype ranked above that which characterised MWPD as normal, for women, this stereotype was not as desexualising and did not appear as prominent in the minds of participants. The top five traits which were associated with this stereotype were unattractive, ineligible, asexual, ‘difficulties with reproduction’, and ‘bad mothers’.

Of these seven, five were counted as stereotypes proper, and two as trait clusters. Aside from the overall stereotypes, and their respective rankings, we also calculated the individual traits for WWPD in terms of relative frequency. The top five most prevalent individual traits cited were strong, insecure, shy, kind, and friendly.

When we separated these individual traits by respondent gender, we found that female participants most commonly called WWPD strong, shy, insecure, friendly, and determined (in that order). Meanwhile, male participants most commonly called WWPD insecure, kind, friendly, strong, shy, and dependent (in that order).

Limitations

Self-report measures are sensitive to social desirability concerns. Consequently, a largely online and anonymous survey using indirect measures seemed a suitable way to attempt to circumvent social desirability in the present study, insofar as is possible. However, there could have been a priming effect in the present study, as the free-response items were situated near the end of a survey with questions about disability and sexuality, which may have influenced replies. Given that stereotypes concerning sexuality were not very prevalent in the present data set, there does not seem to be much evidence of a priming effect here.

Discussion

A promising interpretation of our findings is offered by stereotype content model research. Fiske, Cuddy, Glick, and Xu (2002) argued that there are two dimensions organising most group stereotypes: warmth (traits denoting emotional qualities of a group) and competence (traits denoting intellectual/capability qualities of a group). Research has shown that stereotypes are often mixed. When called on to spontaneously describe an Other, we often cite traits which are positive on one of these dimensions and negative on the other (Cuddy, Norton, & Fiske, 2005; Eckes, 2002; Rohmer & Louvet, 2012).

In a paper published in 2012, Rohmer and Louvet (2012) noted that such ambivalent stereotype contents are supposed to be due to a conflict between prejudice and societal pressures against prejudice (as seen in the work of, for instance, Judd, James-Hawkins, Yzerbyt, and Kashima (2005)).

Working from the premise that such mixed stereotype content is the result of a compensation process based on social norms, these authors hypothesised that ambivalent stereotype content observed with explicit measures of stereotypes would not manifest itself with implicit measures, as the latter are less affected by social demand characteristics (Rohmer & Louvet, 2012). As in the case of most low-status groups, PWD (including PWPD) are often rated, by non-disabled people, as high in warmth, but given low ratings in competence (Cuddy, Fiske, & Glick, 2007; Louvet & Rohmer, 2010).

Seeing PWPD as high in warmth could stem from the motivation to appear unprejudiced by non-disabled people, given that they are actively inclined to rate PWPD as low in competence (Dambrun & Guimond, 2004; Louvet, Rohmer, & Dubois, 2009). In their study, Rohmer and Louvet (2012) found that there were discrepancies between responses obtained using implicit and explicit measures, with responses at the explicit level revealing positive and negative stereotype content, and implicit measures revealing consistently negative stereotype content; when non-disabled people are deprived of the capacity to socially moderate and control their responses, their stereotypes of PWD are more likely to be consistently negative. This offers a useful frame for interpreting the general lie of the land of our results. However, it is also worth exploring, in depth, the nature and implications of individual stereotypes.

As in past research, we found marked consistency between stereotypes of PWPD of both genders (Nario-Redmond, 2010). The prominence of overall stereotypes for men and women was the same: withdrawn and dependent, SuperCrip, nice guy/girl, angry/irritable and aloof, and lacking sexuality/sexually undesirable. However, for women, the trait cluster for inclusive or neutral traits, or traits more characteristic of ‘ordinary’ gender stereotypes, ranked higher overall than this trait cluster did for men. For men, such neutral or inclusive traits were least prevalent. And, for women, the stereotype asexual ranked lowest, whereas for men it ranked second-last (followed by the inclusive or neutral trait cluster). For both genders, the fourth most prominent image of disability was the trait cluster concerned with physical impairment.

Our findings support those of past work which found that MWPD and WWPD are stereotyped in consistent ways across genders (Nario-Redmond, 2010; Schlesinger, 1996; Tilley, 1996). However, while Crawford and Ostrove (2003, 186) found that people without disability believed all PWD, including PWPD, to be ‘universally intellectually challenged’, lacking sexuality, and helpless and incompetent, these traits, aside from helplessness, were not very prominent in the present study. Instead, MWPD and WWPD were seen as strong, funny, insecure, shy, and determined, traits which appeared to arise from participants’ drawing on stereotypes of MWPD as withdrawn and dependent, SuperCrips, or nice.

It is worth exploring these stereotypes both from a psychodynamic, individual-level perspective, as well as from a more sociological perspective, as both interpretations hold weight.

Withdrawn and dependent

Concerning the image of PWPD as withdrawn and dependent, it is worth turning to the individual traits cited for possible explanations for the prominence of this stereotype. For men, these traits were insecure, shy, weak, dependent, and introverted; for women, they were insecure, shy, weak, dependent, and introverted. What might be seen to be at play here are a process of projection (psychodynamic), and a process of binary opposition (sociological).

In the first instance, we can see possible evidence for projection. Projection, in psychodynamic terms, is the process by which people defend against their own unconscious impulses or qualities (often those which they find unpleasant) by attributing them to others – for instance, perceiving one’s spouse to be angry when one is angry oneself. A critical psychoanalytic view of disablism (Marks, 1999; Watermeyer, 2013) proposes that PWD are ‘psychically exploited’ (Author & Author, under review, 2) by the dominant majority, as containers for the projection of unwanted human characteristics such as shame and vulnerability. In the present study, by constructing a stereotypical image of PWPD as weak and dependent, participants may be projecting onto disability all of their fears and fantasies about what it would mean to have a physical impairment, as has been suggested in past work (Shakespeare, 1994). They imagine, perhaps, that they would feel powerless and dependent, and would withdraw.

This projection, however, is not an enactment of the purely imagined. Some PWPD do have substantial care needs. Thus, rather than merely projecting the feared sequelae of disability, and what physical impairment represents, these responses may actually reflect a projective identification with the real care needs of another, as representing something feared and disavowed in the self. Projective identification takes projection a step further; the individual does not simply project their disavowed feelings or attributes onto another, but actually strives to induce those feelings or attributes in another (in the example earlier, actively acting in a manner which will likely anger one's spouse in order to validate one's perception of them as angry). Projective identification could lead non-disabled people to actively seek out the dependency, for instance, which they fear in their selves and project onto PWPD, and foster it amongst PWPD whom they encounter.

In the second, sociological interpretation, these traits point to the opposite of the 'ideal of able-bodiedness': if we can conceive, as Garland-Thomson (1997) does, of a non-disabled norm against which the disabled other is constructed, then what we have here is evidence of this process in relation to an image of people without disability as secure, outgoing, strong, independent, and extroverted. If these can be considered the hallmarks of ability and success, we can see how participants may be aware of social constructions of disability in opposition to this ideal. Such images are perpetuated in charity advertising (Grue, 2016).

Taken together, though, it seems that participants are drawing on images of PWPD circulating in popular consciousness. As Schneider (2005) notes, consistency amongst individual views and beliefs about a group of people will reveal the nature of cultural stereotypes. We found such consistency, and thus evidence of a cultural stereotype. Whether this stereotype leads to the citing of the traits we found, or if the process of binary opposition and projection leads to the formation of a stereotype, is not possible to ascertain here – in fact, it is likely a synergistic effect of both together, the one mirroring on the social level (binary opposition), the other (projection). However, what is interesting to note is that the presence of this stereotype does reflect a certain construction of disability which bears little resemblance to constructions of the capable normate.

SuperCrip

In terms of the SuperCrip stereotype, there are, again, two interpretations – one psychodynamic, and one sociological. Considering the first, Watermeyer (2009, 2013) proposes that the SuperCrip stereotype epitomises the imperative of being 'un-disabled' – a form of enforcing 'compulsory able-bodiedness' (McRuer, 2010). Author and Author (under review) note that the media phenomenon of the 'supercrip' is an extreme instantiation of stoic reassurance. In this process, PWPD perform stoicism in order to prove their capacity to resist or contain others' projections. PWPD may take on superhuman tasks, purportedly in an effort to disprove denigrating stereotypes. In so doing, they become part of a media machine which perpetuates stereotypes of PWPD as needing to perform exceptional tasks in order to qualify as 'able-bodied enough'.

However, on a broader level, certain contextual interpretations of this finding can be made. South Africa's most famous disabled person is the athlete Oscar Pistorius, who has been the subject of both idealising and extremely denigrating media attention, especially after he killed his girlfriend. There was, for example, a temporary television channel devoted solely to Pistorius' murder trial. For this reason, the SuperCrip image (with all its ambiguities) may be especially accessible for South Africans. The SuperCrip image may be even more salient in South Africa, where disability and PWD are more hidden from view than in countries where there are higher degrees of integration of PWD (Stadler, 2006).

Nice guy/Nice lady

The prominence of traits associated with a 'nice guy' or 'nice lady' PWPD provides evidence for the sort of enforcement of happiness and humour on PWPD of which past authors have written (Shakespeare, 1999). Ascribing traits such as friendly, kind, funny, positive, caring and patient to PWPD could be evidence of people without disability's reference to an over-compensatory standard of self-presentation to which PWPD often feel themselves held. Media and other portrayals of disability often portray PWD as cheerful and easy going – somehow compensating with congenial personalities for what they lack physically, or simply protecting people without disability from difficulties associated with physical impairment which the latter may find off-putting.

Author and Author (under review), as well as Watermeyer (2009, 2013), reflect on the creation (or, in this case, enforcement) of a persona of easy-goingness on PWPD to the imperative of being 'un-disabled'. PWPD need to – must be – cheerful and happy in order to reassure non-disabled people that their needs and difference are manageable and not threatening.

However, reference to these positive traits may also reflect inclusive attitudes towards PWPD. By ascribing positive traits to PWPD, participants may simply be indicating positive attitudes towards PWPD. This interpretation is supported from findings from the same sample which found inclusive attitudes towards dating PWPD (see Author et al., 2018).

Gender

Finally, we need to consider what our findings mean for thinking about gender and disability, precisely because gender did not appear as an important axis of stereotyping in the present study. In the introduction to this paper, we noted that problematic attitudes towards PWPD, particularly as pertains to their gender, sexuality, and suitability as romantic partners, are prevalent, and that some of this appears to be due to negative social constructions and stereotypes concerning PWPD.

Drawing on Schlesinger's (1996) assertion that disability disrupts traditional ideologies regarding gender identity, we noted that past work has found that common stereotypes relating to MWPD and WWPD are constructed in opposition to the traditional gender characteristics of men and women (Tilley, 1996).

In our study, we found some evidence that stereotypes of MWPD are constructed in opposition to male gender identity, where the latter is traditionally constructed around notions of sexual prowess, physicality and productivity. MWPD were seen as strong, funny, insecure, shy, and determined. Although strength is stereotypically associated with men, the fact that participants also cited this trait in relation to WWPD points to the fact that it was not activated in relation to an underlying gender stereotype for men, but rather an underlying stereotype for PWPD.

We failed to find evidence that stereotypes of WWPD are constructed in opposition to those normally associated with women: women with disabilities were conceived of as strong, insecure, shy, kind, and friendly in our study, and none of these attributes are particularly at odds with stereotypes of femininity.

However, it is important to note that for neither WWPD nor MWPD were the top cited traits particularly masculine nor particularly feminine. Instead, they seem to reflect gender-neutral disability stereotypes. This provides evidence, we argue, that disability trumps gender in terms of salience in stereotype activation: people without disability are likely to stereotype PWPD according to their disability status prior to their gender. This supports Rich's (2014) assertion that disability is a primary hallmark of identity: an identity which supersedes gender.

Finally, recalling the work cited in the beginning of this paper, which proposed that the intersection of gender and disability stereotypes has particularly dire consequences for women with disabilities, as they are seen as lacking sexuality, virgins, sexually overactive, cursed, dirty or clean, we did not find these traits to be prominently associated with WWPD. This stems from the fact that sexuality traits constituted a small proportion of the overall traits cited for PWPD in this study.

However, the following two important points are worthy of further consideration in research. Firstly, the stereotypes concerning PWPD's sexuality for women was less prevalent than its counterpart for men (2.04% versus 5% of all traits cited). This, perhaps ominously, points to the fact that physical disability is not seen as a barrier to sex (conceived of narrowly as penetrative heterosexual sex) for WWPD, as it is with men. Although apparently positive, this may also point towards a problematic understanding of what it means to be sexual, and also reinforces the idea that women can be passive recipients of sex, rather than active participants; if participants think that a state of being would disqualify men from participating in sexual activity, but not women, then what does this say about their understandings of the rules of engagement in the sexual act?

Secondly, if we do reflect on the traits included in the sexuality stereotype for women (unattractive, ineligible, asexual, difficulties with reproduction, and bad mothers), we can readily see why these may have negative consequences for WWPD (they also portray these women as undesirable partners, rather than as lacking sexuality). They may not be prominent, but they are highly problematic. With rates of sexual violence against women in the country being as high as they are, stereotypes of WWPD which portray them as unlikely sexual partners may work, as Hanass-Hancock (2009, 40) suggests, to make them likely targets of such violence: ‘sexual abuse or exploitation was sometimes interpreted as a blessing such as that the person with disability can “count herself lucky” to have sexual intercourse’.

Conclusions

Although we found marked incongruity at the individual level between non-disabled people’s ascription of traits to PWPD, we found evidence of the consistency amongst our sample’s views and beliefs about a target group which Schneider (2005) asserts to be evidence of stereotypes.

The most prominent stereotypes in the present study were those which characterised PWPD as withdrawn and shy, SuperCrips, or happy, funny, and kind. These stereotypes can be read in both psychological and sociological terms, but – regardless of origin or function – seem to be extremely similar between genders of PWPD.

We proposed that it is relevant to examine societal stereotypes concerning MWPD and WWPD: stereotypes are likely to be desexualising or at least de-gendering for PWPD; stereotypes guide attitudes; and such attitudes, when encountered by PWPD, are harmful.

The findings in the present paper suggest that stereotypes of PWPD are not overwhelmingly de-sexualising, but *are* undifferentiated by gender. The latter point seems to evince a de-gendering of PWPD by people without disability. It would appear, then, that – as proposed by Rich (2014) – disability does trump gender in the eyes of non-disabled people, when it comes to primacy of identity: stereotypes in our study were activated primarily in reaction to disability, and latterly in relation to gender, when it came to men and women with disabilities. However, when examined specifically, we did find evidence of stereotypes regarding physical disability and femininity which could place WWPD at risk of negative attitudes, and even, as Hanass-Hancock (2009) proposes, sexual violence.

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Conflict of interest

No conflict of interest.

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Linking narrative 3: Background Publications to Publication 4

In the three preceding publications (Publication 1, Publication 2, and Publication 3), I have sketched the outline of the attitudinal context in relation to sexuality and physical disability, adding texture and colour with qualitative accounts of physical disability and dating and gender, from non-disabled people. I found that non-disabled people seem to desexualise people with physical disabilities, are reticent about dating people with physical disabilities, and stereotype the latter group in a number of ways, most of which subtly, or not-so-subtly, negate the sexuality of people with physical disabilities.

In the following publication (Publication 4), I begin to explore the obverse of this image: the manner in which people with physical disabilities navigate their experiences of sexuality in such an attitudinal context. This publication incorporates some, but not all, of the photovoice work generated through the qualitative branch of the project, in which 13 adults with physical disabilities participated. This publication draws on data gathered during interviews conducted with these participants as they discussed questions of sexuality and sexual experience. The photos are not central to this piece of work, but, rather, provide a segue by which the participants could begin to speak about the topic at hand.

This publication underwent three rounds of review (the last of which was primarily an exercise in copy editing). In the first two rounds, however, the reviewers’ comments centred on my need to incorporate sexual script theory as a paradigm through which to understand the gendered accounts of sexual activity. The reviewers also recommended further explanation of the colloquial language and euphemism employed in order to discuss sexual behaviour by the participants.

Publication 4: Intimacy, intercourse and adjustments: Experiences of sexual life of a group of people with physical disabilities in South Africa (Hunt, Braathen, Swartz, Carew, & Rohleder)

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Intimacy, intercourse and adjustments: Experiences of sexual life of a group of people with physical disabilities in South Africa

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Abstract

There is a growing recognition of the sexual and reproductive rights of people with disabilities, and since the World Health Organisation's World Report on Disability, increased international attention has been given to these issues. Past research, however, suggests that this group encounter barriers to sexual and reproductive rights, which are both physical and attitudinal. Against this backdrop, this article employs a sequential mixed qualitative methodology to explore the practical and subjective experiences of 13 people with physical disabilities in South Africa, with regard to their sexual lives and experiences of sexuality. These experiences were marked by concerns about their 'fitness' as sexual beings and indicated that social forces were key in shaping their expectations for their own sexual life.

Keywords

photovoice, physical disability, sexual and reproductive health, sexual script theory, sexuality

Background

The disability rights movement has fought for equality, access and recognition for people with disabilities (Hurst, 2003), with issues of education and employment forming a key focus of activism (Addlakha, 2007). Recently, however, issues of sexual and reproductive health (SRH) have arisen as key concerns (Gibson and Mykitiuk, 2012; McKenzie, 2013; Shuttleworth and Mona, 2002), as noted in the United Nations Convention on the Rights of Persons with Disabilities and highlighted in the World Report on Disability (World Health Organization (WHO), 2011). Disabled people have in the past been excluded from sexual health services due to attitudinal barriers such as service providers assuming that they are asexual, or physical barriers, such as inaccessible clinics. Furthermore, disabled people are often stereotyped as either sexually voracious and perverse or, more commonly, as lacking sexuality (Grabois, 2001; Kim, 2011; Milligan and Neufeldt, 2001).

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The societal desexualisation of people with disabilities may pertain particularly to people with physical disabilities (Kim, 2011; Milligan and Neufeldt, 2001; Nario-Redmond, 2009) who may be seen to experience a 'relative absence or insufficiency of sexual interest, biologically and socially described function, and interpersonal sexual engagement' (Kim, 2011: 480). The reasons for this erroneous ascription stem, first, from an assumption that physical difference excludes one from sexuality and, second, from a discomfort with the idea of differently abled sexuality (an enforcement of normalcy). Cultural ideologies surrounding disability (Anderson and Kitchin, 2000), as well as the hegemony of heteronormative sexuality (Esmail et al., 2010; Siebers, 2012), play a role in the tenacity with which this fallacy of the desexualised person with a physical disability endures.

Social constructionist theory provides a useful paradigm for understanding the uncertain sexual status which disabled people hold in the eyes of non-disabled others, specifically sexual script theory (Simon and Gagnon, 1969, 1971). Sexual script theory proposes that sexuality and sexual behaviour among humans are social processes, determined by an individual's internalisation of prevailing ways of 'doing' gendered performances of erotic behaviour (Carpenter, 2010; Gagnon and Simon, 2005; Simon and Gagnon, 1986, 2003; Wiederman, 2005). It constitutes an important lens through which to frame any inquiry into human sexuality, albeit an incomplete account of it (Sakaluk et al., 2014).

Sexual scripts instruct members of a society as to appropriate behaviour and the meanings to attach to certain courting and sexual behaviours (Wiederman, 2005). When internalised, sexual scripts may also constitute a force through which gendered performances of sexuality are played out, and these have a bearing on gendered understandings of disability (Baumeister, 2001; Okami and Shackelford, 2002; Oliver and Hyde, 1993). For instance, male sexual scripts depend on male physicality (Muehlenhard and Shippee, 2010; Sakaluk et al., 2014), and there is an ever-present emphasis on sex as a site of achievement (Gilfoyle and Wilson, 1992). Women, in line with traditional notions of appropriate feminine behaviour, are held to sexual scripts which require that they embody attractiveness and desirability (Eaton and Rose, 2011; Ménard and Cabrera, 2011), rather than overt sexual desire (Wiederman, 2005). This places an implicit primacy on men's ability to display physical prowess and sexual skill (centred on penetrative sex), and women's capacity to embody normative standards of feminine beauty. Men and women with physical disabilities may not be seen to conform to norms for their gender and thus be seen as less gendered than non-disabled people (Hunt, Swartz et al., 2017; Hunt et al under review).

Powerful sexual scripts, underpinned by medicalised understandings of sexuality, have led to an unprecedented emphasis on 'curing' disability or illness induced 'sexual dysfunction', as evidenced by the rise of sex medications such as Viagra (Marshall, 2002; Tiefer, 1995, 1996). Medicalised framings of 'abnormal' sexual behaviour as dysfunction have led to a further valorisation of re-attaining heteronormative standards of sexual ability post-disability (Hawkes, 1996: 71). This is particularly for men whose experiences of disability and illness are heavily influenced by definitions of masculinity, characterised by stoicism and sexual prowess (Gordon and Cerami, 2000; Huggins, 1998), characteristics at odds with embodied experiences of, for instance, spinal cord injury. Thus, in the case of people with physical disabilities, who may not conform to normative standards of ability or embodiment, the enactment of such scripts can be frustrated, and the desire for medical assistance in achieving 'normality' fuelled.

Within this context, the growing empirical literature concerning societal attitudes towards the sexuality of people with physical disabilities has found that individual members of societies view people with physical disabilities as less sexual than able-bodied people (Hunt, Swartz et al., 2017). Indeed, in recent work that we (the authors of this article) have undertaken, a large survey of nearly 2000 non-disabled South Africans revealed a range of problematic attitudes towards the sexuality of people with physical disabilities (Hunt, Carew et al., 2017; Hunt et al., 2017; Hunt et al., under review). Non-disabled respondents were more likely to support the idea that people without disability were deserving of sexual rights compared to people with physical disabilities and to rate the degree to which people with physical disability benefit from sexual and reproductive health care as less than that for people without physical disabilities.

These findings provide some of the first empirical support that non-disabled people perceive people with physical disabilities as enjoying fewer sexual and reproductive rights (even in a society like South Africa where, officially, non-discrimination against disabled people is enshrined in the constitution), and deriving less benefit from SRH services, than the population without disability (Hunt, Carew et al., 2017).

Discriminatory beliefs and attitudes held by non-disabled persons have consequences for the lives and experience of people with physical disabilities (O'Dea et al., 2012; Sakellariou, 2006; Sakellariou and Algado, 2006; Siebers, 2012). The latter are excluded from SRH education (Cheausuwantavee, 2002; Seidel et al., 2014), and SRH services (Rohleder and Swartz, 2012) experience barriers in their sexual development (Howland and Rintala, 2001; Stohl, 1996) and are at increased risk to be victims of sexual violence (Astbury and Walji, 2014). In sub-Saharan Africa in general, and South Africa in particular, negative attitudes towards the sexuality of this group of persons – largely negating that any such sexuality exists – have been suggested to put people with physical disabilities at increased risk for HIV, hinder their accessing SRH services, hamper their sexual expression and diminish their sexual self-esteem (Groce et al., 2013).

Yet, in past research with people with physical disabilities, most have identified as sexual beings (Bahner, 2012), with a sexual orientation (Ostrander, 2009); sexual needs (Bahner, 2012; Siebers, 2012); and the desire for intimacy, intimate relationships (Li and Yau, 2006) and children (Nosek et al., 2001). There are exceptions, and we are not suggesting that asexuality is not a valid sexual orientation – it is. But the imposition of a non-sexual identity onto people with physical disabilities is problematic and potentially damaging.

Among people without disabilities, multinational, aggregate data have shown that all aspects of the sexual experience are important to men and women (Mulhall et al., 2008) and that the importance of sexual activity endures into middle age and beyond (Nicolosi et al., 2004). Sexual dissatisfaction, among non-disabled people, is greater among women (Haavio-Mannila and Kontula, 1997). There is an established relationship between sexual satisfaction and marital satisfaction. Fewer studies have examined the association between sexual satisfaction and relationship satisfaction among unmarried people. However, those which have have also found a link between sexual satisfaction and relationship satisfaction (Sprecher, 2002), as well as other indicators of relationship well-being, including love (Yela, 2000) and commitment (Sprecher et al., 1995; Waite and Joyner, 2001).

However, there is a dearth of norms and understanding regarding the experiences of sexual activity among people with physical disabilities. In the Global South in particular, little work has examined the experiences of SRH, and sexual relationships, of people with physical disabilities. If the vision of SRH rights to be shared equitably by all (WHO, 2006: 5) is to be realised, then the voices of those whose sexuality is seen to be marginal must be heard. Indeed, disability activism is also about the politics of voice – it is important that disabled people speak back to the dominant discourses of the able-bodied which have for too long portrayed people with disabilities unfavourably. With this imperative in mind, our aim in this article is to explore the practical and subjective experiences of people with physical disabilities in South Africa, with regard to their sexual life (including experiences of sexual intimacy, intercourse, and other sexual activity).

Method

This article analyses qualitative interview data collected from 13 adults with acquired or congenital physical disabilities. The qualitative interviews were conducted as part of a photovoice[1] project with the same group of adults. We present here our analysis of the interviews which were guided by a semi-structured interview guide exploring SRH. The analysis of photographs and some of the accompanying narratives are presented elsewhere (Hunt et al., under review). However, some photographs, pertaining to SRH, are included in this article, as illustrative instances of themes we address (Table 1).

Table 1. Table of themes.

Theme	Exemplary quote
Difficulties having satisfying sex	'A physically-challenged person is more likely to end up in a short-term relationship due to their challenges and intimacy'.
The need to satisfy a lover	'You are the guy who is going to be the one that needs to perform the whole time'.
Finding sexual mutuality	'I think in some ways you become a better lover when you can't move because you have to rely on talking and other things that you can do in that sense'.
Sexual self-esteem	'For me it was very affirming, although it was a bit of a shock that another female would be able to see me as not only attractive as a partner but attracted that sex could be pursued'.

Sample

A sample of 13 people with physical disabilities (demographics described in Table 2) were recruited via the networks of the Southern African Federation of Disability Organizations and the South African authors (X.H. and L.S.), as well as through mailing lists of local disability networks. All participants were identified as heterosexual and cisgender.

Table 2. Participant demographics.

Gender	Male: 5
	Female: 8
Race	Black African: 5
	Coloured[a]: 4
	White: 4
Disability	Acquired: 8
	Congenital: 3

[a]The term 'Coloured' refers to a South African census racial group. Historically of mixed European, African and Asian ancestry, self-identifying Coloured people constitute about 8.9 per cent of the population (Statistics South Africa, 2011).

Procedure

All individuals who responded to the advert were invited to a workshop held in Cape Town, South Africa. During this meeting, the theme of the project, its goals and methods were discussed with all participants. Participants were trained in the photovoice element of the project, each participant being provided with a digital camera and asked to take photographs which symbolised his or her experiences of sexual relationships and sexual and reproductive health care.[2] Participants were given at least 3 months to collect photographs. If participants were not able to use the digital cameras themselves, they were invited to ask a friend or carer to take the photographs under their instruction. Participants could take as many photographs as they chose.

Following this process, all participants were asked to take part in an individual interview. Participants could select up to five photographs which they felt most represented their experiences. These photographs were then used as discussion prompts in one section of the interview, and a semi-structured schedule guided the second section. The interviews were conducted by X.H., S.H.B. or P.R. The semi-structured section explored participants' experiences of their sense of sexual self, intimate relationships, sex and SRH. Interviews were voice-recorded for transcription by a professional transcriber. This article includes three of the photovoice photographs in order to illustrate themes; however, the present analysis centres on textual qualitative interview data. We focus in this article on themes related to the actual sexual lives of participants (including experiences of sexual intimacy, intercourse and other sexual activity). Themes related to stigma, identity, relationships and dating will be presented in a forthcoming article.

Analysis

The qualitative responses in this study were analysed using thematic analysis (Braun and Clarke, 2006). As described by Namey et al. (2008), in their chapter on the subject, 'thematic analyses move beyond counting explicit words or phrases and focus on identifying and describing both implicit and explicit ideas within the data, that is, themes' (p. 140). Thus, this method proved useful for arriving at a textured understanding of the interview responses.

The aim in the present analysis was to provide a rich thematic description of the entire data set. Braun and Clarke (2006) note that such a method is usually employed when the research topic is one for which there is little existing research, such as is the case in this study. This goal – to provide a clear overview of the experiences of the sample of the sexual lives of participants, while not neglecting detail and nuance within these accounts – guided the present analysis.

In this study, coding proceeded through two rounds. First, P.R. read and re-read all the transcripts, highlighting salient transcripts. Thereafter, these codes were named, examined and coalesced into broader themes by P.R. and X.H. The themes in the present analysis represented patterns of meaning – cohering or contrasting – which recurred throughout the coded data set. These themes were then discussed with the team, who were familiar with the data set. The themes were then refined and are presented below.

Ethical considerations

Ethical approval for this study was obtained from Stellenbosch University and the University of East London. Written informed consent was obtained from all participants, and all participation was entirely voluntary.

Results

From our analysis of the data, we present four overarching themes related to sex and the sexual life of participants. These are difficulties having satisfying sex, the need to satisfy a lover, finding sexual mutuality and sexual self-esteem.

A detailed discussion of each theme is presented below. Thereafter, we reflect on the overarching ways of making sense of the sexuality in the context of disability reflected in these themes.

Difficulties having satisfying sex

Among the respondents, men more often commented on the physical limitations which they encountered in trying to sustain a sexual relationship. For Nick, a male with an acquired disability, this was perceived to strain intimate relationships: 'A physically-challenged person is more likely to end up in a short-term relationship due to their challenges and intimacy', he explained.

In some cases, these challenges were often met with ingenuity and creativity. Nick explained that he 'use[d] equipment or I have to use some medication to give me that stamina, that feeling back, that energy back, to be intimate with a partner'. However, such a reliance on mediation was met with ambivalence. As Nick explained, 'Sometimes, for example, I can't afford to get that specific treatment, then I'm stranded, which makes my partner stranded, and that same strandedness will make the partner look for someone else to fulfil her wants and needs'. On one hand, Nick describes medication and equipment (sexual aids), to make him feel 'energised', which is framed here both as literal sexual stamina and perhaps as confidence to perform sexual acts for longer durations. Meanwhile, in the latter quote, the term 'stranded' describes his dependence on medication to engage in sexual activity in the manner which he desires: when the medication is not available, he felt powerless and unable to satisfy his partner.

However, finding a solution to the 'problem' of their sense of sexual incapacity was described as a great relief by the male respondents. As Edward, a male with an acquired disability, explained,

> [When] I started trying the Lavitra [a medication for erectile dysfunction]. I followed the dosage. It worked for me. It worked for me from the first time. I used it once for the first night and it worked for me. Then I felt like, okay, I'm back to normal now because it's working now for me.

For some of the participants, the difficulties which they experienced with sexual activity, fear of others' negative appraisals of them as partners and flagging sexual self-esteem led to diminished sexual expression and unsatisfactory sex.

For Nick, this was due to his frustration at having a limited capacity for engaging in the kind of sex which he would like to. He explained,

> Sometimes you get bored. You get frustrated. Then the next partner also wants a different position or a different type of tactic [way of engaging in sex], if I can say that, to go about and make it more exciting as a relationship. It can be boring, like I mentioned, for him or for her. Partners. Problems. That's when it can become a problem at the end of the day. That is what I have experienced in life.

Nick explained that the limitations on ingenuity in the bedroom which he felt to be engendered by his disability, not only made him fear that his partner would get bored but also that they frustrated and bored him.

For Erica, a female with an acquired disability, the loss of sensation associated with her impairment was responsible for the initial diminishment of her sexual expression post-injury. Recalling an incident with a past partner, she explained,

> We had sex very occasionally … but we were having sex and it was going on, and I remember saying to him, no, just get it done, get it over with. I could see he was totally put off. But I mean, I was not a sexual being, I was a dead piece of body, you know, lying there like a piece of meat, and it seemed almost sacrilegious to do that!

Despite these feelings, Erika's desire for inclusion in the sexual order of things led her to continue to engage in sexual activity despite her diminished inclination to do so. Erica explained that her diminished sexual expression stemmed from the fact that she was only just beginning to adjust to her impairment. 'I was also very … I would say much more disabled than I am now. So sex was terrible'.

The need to satisfy a lover

A prominent theme among our male participants was the emphasis which they placed on sex as a site of achievement; a space in which they could prove their worth as a lover by satisfying their partners. The satisfaction being referenced, in the main, implied 'pleasuring a female partner' – often in the form of penetrative or oral sex (a fact which can be derived from the men's focus on needing Viagra or similar medications in order to be able to sustain an erection during penetrative heteronormative intercourse). Further to this, the men simply expressed a desire to be able to engage in unspecified but somehow unattainable levels of sexual ingenuity and variety. Part of this may simply reflect an amplification of existing sexual scripts for men among disabled men: in light of not being able to engage in all manner of sexual acts at will, the

Figure 1. Photograph of Liam and his girlfriend (we have blurred the image to protect identity, although permission was granted to use the photograph).

men were perhaps more inclined to view such sexual ingenuity as necessary to a healthy sex life. As noted in the introduction to this article, male sexual scripts, and contemporary thinking about male sexual performance, centre on male physicality (Sakaluk et al., 2014). Sex is framed as a site of achievement (Gilfoyle and Wilson, 1992). The participants might thus be more concerned about exclusion from performances of sexual prowess.

Some respondents expressed frustration at feeling unable to access as wide a range of sexual positions and techniques as they wanted to. However, for the majority of the men, their experiences of satisfaction with their sex lives centred on their sense of having to prove themselves as worthy partners. ‘You are the guy who is going to be the one that needs to perform the whole time’, explained Simon, a male with an acquired disability, adding that he perceived this need to be imposed on him in order to ‘compensate’ for his disability. ‘What I have found, there’s this thing of trying to prove yourself in trying to satisfy your partner. Ja, it’s a strange issue’, he added. Simon also related a similar concern, linking it to ideas around gender. ‘You know males, they have this problem of will I be able to satisfy [my partner]? That is the male mind in our society’.

For many of the men, their thinking about sexual pleasure centred on the pleasure of their partners. Liam, a male with an acquired disability, explained that ‘feeling like a man’, for him, centred on being able to satisfy his partner sexually, again, echoing broader research concerning male understandings of erotic behaviour. Discussing a photograph (Figure 1) of himself and his girlfriend sitting on his bed, he explains,

> You can see I feel like a man. You can see the amount of confidence and satisfaction that I have on my face there. You can also see how happy she is there, so we people with disabilities, we can also make our women feel good sexually. You can bring out the best in them. We can still be romantics as well if we want to.

Ryan, a male with an acquired disability, quite succinctly explained the relationship between this reframing of his conceptions of sexual pleasure and his sense of 'coming into' feelings of sexual competence. Here, again, we see echoes of prior sentiment, with his conception of sexual activity centring on his capacity to pleasure a woman. Ryan links this explicitly to the idea of sex as a site of achievement:

> To give a woman pleasure, I can really do that and that's fantastic. You know, that to me is fantastic. Because I think sex is about achievement. It's quite a complex thing, but I think a part of it is about achievement.

'Overcoming' and accommodation

This theme encompassed participants' responses regarding post-disability sexual functioning and their adaptation to it. Initially, several of the participants, particularly the men, spoke about the ways in which their physical impairments could be 'overcome' in sexual relationships or even conferred advantages which non-disabled people might not experience.

For Nick, this was the result of his own limited sexual sensation during intercourse. He explained,

> I think mostly about my partner. You know why I'm saying so? Part of my body has got no sensation, it's got no feeling, so if I have intimacy with my partner I don't feel anything. But I have to think about her needs. I have to fulfil her needs. I don't feel anything, nothing, but she needs to feel. I'm working in her terms now.

Two other male respondents, Ryan and Liam, related a similar sentiment:

> I think in some ways you become a better lover when you can't move because you have to rely on talking and other things that you can do in that sense. I don't know if that makes sense. You become better, but you become more sensitive to what's important and try and understand women I guess, which is still an anomaly for any kind of partner. (Ryan, a male with an acquired disability)

Ryan discussed his becoming disabled as spurring him to focus less on his own sexual needs than on those of his partner. He saw this in a positive light, making him an unusually unselfish lover ('an anomaly').

However, despite taking pride in their capacity to focus on their partners' needs during sex, some respondents noted that they did feel their endeavours towards sexual mutuality and pleasure to be more skewed than mutual:

> I have to make time to give pleasure for my partner to feel at ease and to feel free to do what is necessary for her to do. From my perspective, from my side, I have to go with the flow. Yes, I am feeling free, but not as free as my partner. (Nick)

The men's accounts not only inevitably reflect the lack of mutuality between them and their partners but also focus on heterosexual men's attention to their female partners' sexual pleasure.

Two female respondents, Erica and Ange, both recounted predominantly positive experiences of intimacy within sexual encounters. For Erica, this was achieved through a learning process, in which she and her partner jointly navigated their respective abilities and desires during sex:

> We just had to learn what worked and what didn't work sexually, you know, different positions, what he liked, what I liked, and we were open to be able to explore.

Similarly, for Ange, a female with a congenital disability, communication and openness to express her needs and the accommodations necessary to enable sex to be enjoyable for her were central to her enjoyment of sexual activity. She explained,

> There were times … because remember, I'm cerebral palsy and the muscles contract … then I

Figure 2. Ryan's photograph: water droplets on sand.

> would say to [my husband] how I want it, how to pack the pillows, how to do it. He would do exactly what I told him.

Ange went on to explain that this allowed sexual intercourse to be something which she enjoyed. She felt more able to fully engage in sexual activity which her physical limitations might otherwise have precluded, were it not for the assistance of an accommodating partner.

Central to several of the respondents' discussions of sexual pleasure in relationships was the process of coming to understand and adjust to one's sexuality after acquiring a disability. As Ryan explained,

> When your body starts adjusting to your disability and that type of thing, it changes, and your sensation changes and all those things. Like if you kiss me on my neck or on my ear, I go nuts. It's like, fucking don't do that. Yes, no, no, yes – that type of thing.

Centrally, though, this knowledge needed to be shared. 'It's good for you to know [what you enjoy sexually] and it's good for your partner to know that'. Central, also, to the respondent's discussions of sexual activity was a focus on intimacy, broadly defined, rather than penetrative sex. Liam related that the fact that he had 'very, very little feeling' when having sexual intercourse made him refocus his attention on intimacy in physical relationships. 'I can't feel when I ejaculate, but for me it's about intimacy, about still being able to have sex and to please your female friend'. Exemplary of this sentiment was Ryan's discussion of an image he took of water droplets on sand (Figure 2). He explained,

> I feel that black and white is more open to interpretation, suggestion and imagination. And I think sex is like that, it's an individual thing linked to our desires and imagination … I think a lot of sex is about what's going on in your head at the time. I think a lot of it is imagination. I can touch you in a certain way and it will mean nothing. But I can touch someone else in that certain way and it will mean a lot. At the same time, you might touch somebody else and it will be nothing, but they can touch you and it will mean something as well. So sex isn't just about intercourse but more about intimacy.

Such relational conceptions of sexuality were common in the participants' accounts.

Sexual self-esteem

Self-esteem is a superordinate theme which transects almost all other themes discussed here. In many cases, as will be evident in the foregoing sections, self-esteem and sexual self-esteem were intertwined, with the former being buoyed when the latter was affirmed. As Ian, who acquired a disability at a very young age, explains, being seen to be a sexual being positively influenced his body image, as well as his sexual self-esteem. Speaking about a sexual encounter with a woman he said,

Figure 3. Erica's photograph: femininity.

> She was forthcoming and things like that. For me it was very affirming, although it was a bit of a shock that another female would be able to see me as not only attractive as a partner but attracted that sex could be pursued. It's almost like it wouldn't be bad to be nude or naked, and basically explore without being held back by what society says.

He framed this as a moment in which he came to question some of his assumptions about himself, 'I found that very awakening, the fact that I might be insecure about it, but not everyone thinks of myself like that', he explained.

Erica spoke about how her experience of becoming disabled was marked by a constant fear about how she would be seen. Being treated differently by people only served to confirm her fears and fuelled her inner sense of herself as somehow irreparably altered:

> Not only are people treating you differently, but you yourself are … you know, you see yourself as different. You have a perception of something that's outside your normal environment, and you're having to deal with this change all of a sudden internally as well.

For her, this spurred an interrogation of a previously unexamined assumption about the importance – even primacy – of physical appearance. '[It made me question] What are the values? What are my values? What are people's values and why is physical appearance so very important?'

Participants with congenital disabilities spoke of how growing up with a disability and constantly feeling that 'normal' sexual society was 'not for them' impacted on their sense of self. Ange explained,

> When you are young you need to make love and all of those things. But for me, although I had those aspirations and desires, deep-down I had doubt. How was I going to be accepted? Will it be possible? Will I get hurt?

The impact of the participants' perceptions of others' reactions to their disabilities did not only affect their sense of themselves as attractive but also cut to the very core of their sense of worth as a prospective partner. 'I also didn't have confidence in myself. Because you know when people say negative things about you, you also lose confidence', explained Olivia, a woman with a congenital disability, while Ryan noted that he

> felt like a burden. I'm very attracted to women. I love that idea. But I felt that I didn't want to be a burden to a partner. So I managed for about six years, that's all. I just kind of cut myself off from that.

Finally, Erica, discussing a black and white image she had taken of herself by a photographer (Figure 3), described how reclaiming her sexual identity, after feeling that it had been lost post-injury, marked a moment of self-acceptance:

> I sent [a man I met] a very sexy picture, just of my legs, and these pictures I took many years ago in a competition because I wanted to depict disability as being sexy in a way … I can't hide my flaws and imperfections like other people can. Mine is there for the world to see. In the process of rediscovering my sexuality, I have learned to use what I have to seduce and entice. The silent battles I have fought of self-acceptance and validation has left me with the realisation that I no longer have to hide the naked beautiful truth of who I am … a woman in every essence of the word.

Discussion

Despite the immense depth and diversity of experience evident in the foregoing discussion of themes, three facets of the data are particularly salient. The first concerns the difference between respondents with congenital disabilities' experiences of self-esteem and sexual self-esteem and those of respondents with acquired disabilities. The second concerns the intersection of ways of talking about normalcy, recovery, gender identity and sexuality. The third concerns the gendered differences in the respondents' discussions of sexuality.

Among respondents with congenital disabilities, it is apparent that their self-esteem, particularly their sexual self-esteem and sense of themselves as sexual beings, differed from those of their non-disabled peers, due to undergoing their socialisation as a person with physical disabilities. This impacted on their discussion of sub-themes such as desirability and attractiveness.

Consistent with these findings, MacDougall and Morin's (1979) early study on the subject indicated that young adults with congenital disabilities were limited in their expression of their sexuality. Nearly all the individuals studied were unmarried, and very few had had a serious long-term relationship (MacDougall and Morin, 1979).

The findings of this work are consistent with the notion that there are many factors that seriously limit the expression of sexuality among individuals with congenital disabilities and that when sexual identity development occurs in the context of disability (as opposed to before its onset), the result can be inhibitory on sexual development.

For our respondents with acquired disabilities, their experiences seemed to progress through a predictable pattern of (a) being sexualised in the context of a typical embodiment; (b) having this embodiment disrupted, and with this disruption, feeling their sexuality to be damaged or diminished; and then (c) reclaiming and redefining their sexuality in light of their disability (often with their first sexual encounter marking their re-entry into sexual society). However, a prominent part of these accounts included concerns over their attractiveness following becoming disabled, and doubt over their romantic prospects, mirroring findings from past work (Li and Yau, 2006).

Second, as is clear, for many of the respondents, becoming sexually active was regarded as something which made them feel 'normal'. When probed about this way of seeing sex, 'becoming normal again' seemed to be participants' way of talking about reconnecting with a part of themselves which they had feared lost due to being disabled. Ideas about normality were also intertwined with feeling like a 'real woman' or 'real man', and being initiated (or reinitiated) into sexual society was regarded as something which affirmed their gender identities and sense of themselves as 'normal'.

Indeed, for many of the respondents, there was immense overlap in their discussions of normality, sexual achievement (pleasing a partner) and their gender identity, particularly among men. Authors such as Oliffe (2005) have drawn attention to the manner in which penis-centric conceptions of sexuality held among men can create confusion between men's personhood and their sexual organ, in the sense that when they are unable to maintain an erection and engage in penetrative sex, men experience a subjective loss of their manhood. As physical performance forms the basis for one's construction of sex, men who are unable to perform sexually are affected in deeply gendered ways (Flood, 2002; Tiefer, 1994, 2006).

Past theoretical work has reflected extensively on the overlap in ideas of normality and sexuality, and bodily difference and sexual difference among men *and* women. Essentially, this work states that according to societal norms, sex is for 'normal' bodies, and the bodies of people with physical disabilities do not conform to a prescriptive definition of 'normal' (Kumari-Campbell, 2009; McRuer, 2011). Therefore, they are assumed to be unfit for sexuality. Esmail et al. (2010), for instance, have found that members of the public as well as service providers used concepts of 'naturalness' to describe sexuality and that such narrow descriptions of sexuality (in heteronormative, genital terms) excluded people with physical disabilities. This observation affirms a comment made by Tepper in 2000 that sex is too often taken to be the sole purview of White, heterosexual, young, single, non-disabled people. Thus, it is understandable that the respondents would feel that initiation into one of these (sexuality) would signal an initiation into 'normality', something which many of them had felt excluded from, from the outset. This initiation into normalcy took on a gendered tone, with males focussing on developing a capacity to please women, while women focussed on regaining feelings of attractiveness.

Male respondents tended to focus on heteronormative performances of sexual prowess as 'compensating' for what they might lack in physical ability. Inclusion in sexual society for men centred on their ability to please a partner, as has been found in other work (Tepper, 2000). However, we would go further and suggest that this is largely to do with the men's expressions of needing to compensate for what they 'lack' in normative conceptions of masculinity, by becoming proficient lovers and drawing on women's enjoyment of their sexual behaviour as a source of pride.

It is thus important to note the manner in which discourses and scripts, which are clearly circulating among the non-disabled majority, are accentuated among men with disabilities. It is not that the emphasis on achievement, or as Simon put it, 'performance', is unique to men with physical disabilities. However, Liam's words, 'feel like a man', can be read as implying an experience of prior emasculation. Thus, for men with physical disabilities, performance and pleasing a woman become the benchmark by which they evaluate the majority of their sexual functioning (a normative discourse, exacerbated by the question placed over their general physicality by virtue of having a physical limitation).

Finally, it is worth considering what broader implications such findings as these have for research and practice regarding sexuality and physical disability. The WHO has developed a broad definition of sexual health as encompassing more than just the absence of disease or dysfunction, but as being a positive state of well-being. In the medical sector certainly, and perhaps generally in rehabilitation work with people physical disabilities, the focus and concern is typically on sexual dysfunction, how to 'cure' it and how to restore pre-disability sexual functioning in very normative terms. Less emphasis is placed on the interpersonal, intimacy, mutuality and sexual self-esteem aspects of sexuality in the context of disability. Powerful forces shape what is desired, how desire is expressed and make sexual pleasure and its pursuit not only normative but also compulsory (Karlsen and Villadsen, 2016). Sexuality in the context of disability could provide a dynamic arena in which new conceptions of pleasure, intimacy, mutuality and what it means to be sexual could be explored, and dominant ideas around what is and is not necessary to live a sexual life could be expanded.

Limitations

The limitations of this work exist in the fact that we drew on a volunteer sample; thus, it is possible that those people interested in participating had already given thought to, or were affected by, experiences relating to sexuality. It is possible that the ideas reflected here are not characteristic of the experiences of people with physical disabilities in general, although the fact that many of our findings mirrored those of past work seems to suggest that this is not the case.

Conclusion

This study found evidence that people with physical disabilities' experiences of SRH and sexual relationships were marked by concerns about their 'fitness' as sexual beings, a concern which seemed to find its origins in their ideas about how non-disabled people might view their different-than-average embodiment. Those participants with congenital disabilities described how the attitudes of non-disabled people had impacted on their expectations for their own sexual lives, and future relationships, largely casting a pall on both. Participants with acquired disabilities described having to re-negotiate their sexual functioning in light of their altered embodiment, with many framing their sexual experiences post-disability as moments of 'regaining' a bit of normality.

As noted, past research has suggested that the societal desexualisation of people with disabilities might be particularly the case of people with physical disabilities. A recent study from South Africa suggests that people with physical disabilities are seen as less sexual than non-disabled people. Theoretical work has suggested that the erroneous ascription of asexuality to people with physical disabilities seems to stem, first, from an assumption that physical difference excludes one from sexuality and, second, from a discomfort with the idea of differently abled sexuality (an enforcement of normalcy).

Our respondents seemed to both accept and resist such assumptions. In the first instance, the fact that many saw their re-initiation into sexual society, as it were, as a moment of 'becoming normal again' points to their implicit assumption that there is something abnormal about not being sexual but also that they had feared that disability would negate their sexuality and, with it, their normality. However, the respondents also seemed to resist the desexualising beliefs and ascriptions of others, taking pride in their capacity to engage in different kinds of sexual behaviour and negotiating sexual relationships. This experience, we found, was gendered, with men emphasising sexual activity as a site of achievement.

On one hand then, research suggests that people with physical disabilities are regarded as less sexual than non-disabled people. On the other hand, this work suggests that people with physical disabilities are sexual and sexually active. Advocacy around the SRH rights of people with disabilities is imperative if this disjuncture between attitudes and ascriptions, and lived experience, is to be bridged, particularly given that our work shows that people with physical disabilities' experiences and conceptions of SRH and sexual relationships are actively impinged on by the desexualising attitudes of non-disabled others.

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Notes

1. Photovoice (Wang and Burris, 1997) is a participatory research technique in which participants are trained as co-researchers and photographers. Participants were asked to take photographs that represented their everyday experience and were

then invited to provide narrative discussion in relation to illustrative images (Vaughan, 2014). The photographs are used as both visual data and as stimuli to elicit personal narratives.

2. Training was provided regarding what was expected in terms of their photography. Participants were requested not to take photographs which were explicitly sexual but rather photographs that represented and were symbolic of their everyday experience.

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Linking narrative 4: Publication 4 to Publication 5

In the foregoing publication, I presented the narrative findings (with illustrative pictures), from the photovoice facet of the project. We showed that people with physical disabilities' experiences of sexuality were marked by concerns about their "fitness" as sexual beings, and how the attitudes of non-disabled people impacted their expectations for their own sexual lives, and future relationships, largely casting a pall on both. Our respondents seemed to both accept and resist the assumption of asexuality which non-disabled people foisted onto them. In this publication (Publication 4), however, the focus was on words rather than images – what did the participants say as opposed to what they represented visually. In the next publication, Publication 5 (a chapter for an edited book on sexuality and disability in the Global South), I examine the photographic data more explicitly.

This chapter considers the role of photographs generated through the photovoice project in challenging the ways in which the sexuality and bodies of people with physical disabilities are represented. Drawing on the meanings which these co-researchers speak into their images, I explore this "shooting back" (Hubbard, 1996) at imposed representations of disability, and the participants' co-researchers' reframing of sexuality and their bodies, in their own terms.

Publication 5: Shooting back and (re)framing: Challenging dominant representations of the disabled body in the Global South (Hunt, Swartz, Braathen, Carew, Chiwaula, & Rohleder, in press)

Shooting back and (re)framing: Challenging dominant representations of the disabled body in the Global South

Xanthe Hunt, Leslie Swartz, Stine Hellum Braathen, Mark Carew, and Poul Rohleder

The society in which we live centres on looking and talking – our proclivity to experience through sight inextricably entwined with our desire to talk about what we see, and to see things in the manner in which we have talked, and thought, about them. Humans love to look, and love to talk. But when that looking is perverted – becomes an oppressive gaze or a blind eye – thinking about the subject in question takes on scripted and stereotyped forms which prohibit understanding or simply beget silence.

The visual representation of people with physical disabilities has a long, fraught history. Disabled bodies have been portrayed – on canvas and by camera – as abnormal, abject, or simply concealed. Images prefigure audiences, and so viewers come to interpret disability in the stereotypical, limited ways invited by stereotypical, limited images (Hafsteinsson & Bredin, 2010). These visual representations, and audiences' attitude in relation to them, often mirror social representations concerning the sexuality, bodies, and gender of people with physical disabilities (hereafter "sexuality" denotes sexuality and gender, as our conception of sexuality includes gender and sexual orientation).

According to dominant constructions, bodies which defy societal standards for normality cannot – and must not – be sexual bodies (Campbell, 2009; McRuer, 2011). They are also seen to be de-gendered bodies (Hunt, Swartz, Carew, Braathen, & Rohleder, under review). People with physical disabilities have been desexualised – or their sexuality maligned – in art and media, a process sustained and maintained by their symbolic representation in the public imagining.

Given the parallels in depicting the bodies, and conceiving of the sexuality, of people with physical disabilities, it is little surprise that disability studies has drawn on self-representation as an act of social resistance. Amongst this work, photovoice – a qualitative research method where participants produce photographs as data – has allowed the Othered subject to shoot back at dominant representations of imposed alterity, and challenge dominant discourses of power.

This chapter considers the role of photographs generated through photovoice in challenging the ways in which the sexuality and bodies of people with physical disabilities are represented.

We suggest that self-generated images cleave open a space for an emancipatory politics of representation, one which positions itself well away from the oppressive descriptive and discursive regimes applied to such subjects in the past. Drawing on the meanings which these co-researchers speak into their images, we explore this "shooting back" (Hubbard, 1996) at imposed representations of disability, and the participants' (hereafter, co-researchers) reframing of sexuality and their bodies, in their own terms.

Problematic representation, précised

The "background" sections of the present chapter are centrally concerned with two things:

1. That, historically, the visual representation of people with physical disabilities has been problematic; and
2. That these visual representations often have problematic implications for thinking about the sexuality and bodies of people with physical disabilities.

I précise these categories here. In this section, then, we lay out some “categories” of visual representation and viewership to which people with physical disabilities have been subjected. We outline how each way of representing or viewing such bodies in the visual realm finds its corollary in societal ways of thinking about disability, and how both act to pathologise or negate the sexuality of people deemed physically different.

The Freakshow

In past decades, Freakshows celebrated the alterity of people with different bodies. Bodies which defied dominant constructions of “normality” were paraded and displayed; their difference accentuated. The Freakshow-type spectacle depends on crowds of complicit viewers projecting onto the displayed difference their collective fears. The human-as-prop takes to its logical extreme the idea of objectification: bodies are currency, not subjectivities or selves.

The clinical gaze

The clinical gaze describes the manner in which medical looking can be oppressive. Since its exposition by Foucault (Foucault, 1970), the concept has been much elaborated, including by scholars from disability studies (Condrau, 2007; Garland-Thomson, 2009; Reeve, 2002).

The clinical gaze is the way in which medical professionals and medicalised societies look at the “ill” or “impaired”. The clinical gaze seeks out pathology and categorises it. The concept of the clinical gaze directs our attention to the manner in which looking can exert power and enact violence. Under this inspection, the physical difference of the people with physical disabilities is accentuated. Medicalised bodies are not subjects. As in the Freakshow, they are objects.

Inspiration porn

Inspiration porn is the term coined to describe the representation of people with disabilities in charitable campaigns. Such images are intended to inspire non-disabled people to donate to charities (Shakespeare, 1994). In these campaigns, people with disabilities are held up as exemplary of different virtues, particularly determination.

The images cause as much discomfort as they do admiration (Grue, 2016; Shakespeare, 1994). Shakespeare (1994), drawing on Lacan and Sheridan (1978), has explained this discomfort as originating in pity. These images evoke pity, and pity relies on a power disparity between pitier and pitied. Many of us recoil from this. Further, in inspiration porn, as in pornography, “the gaze is on the body, which is passive and available. In each case, particular aspects of the body are exaggerated: sexual parts, in pornography, or ‘flawed’ parts in charity advertising” (Shakespeare, 1994, p. 288). The combination of pity and objectifying looking puts us ill at ease.

Metaphor and movies

Disability has often been employed as a cipher for metaphorical meanings and moral agendas. In fact, a superordinate way of thinking about the visual representation of people with physical disabilities is that people with physical disabilities are often standing for something else. That is, when they are visually presented, people with physical disabilities are themselves representing something: be it hope, or lack, or oddity.

At any given time, most of us can draw on a trove of disability stereotypes (Barnes & Mercer, 2003; Darke, 2004; C. A. Nelson, 2010; J. Nelson, 1996; Ross, 2011). This is perhaps most apparent in movies and theatre, but is equally pervasive in popular photography.

Media treatments of people with physical disabilities, although as a rule taking an individualised perspective on disability, often imbue impairments with metaphorical significance. Such simplified, de-personalising representations constitute a form of objectification. They create a de-realised spectre of disability as something not quite human, unrelatable and exceptional, yet still undesirable (Grue, 2016).

Concealment and looking away

The final way of representing people with physical disabilities is its lack: the dearth of visual representation of people with physical disabilities. Our everyday visual landscape is characterised by a dearth of difference. In the exceptional instances when difference is represented, it is treated as exceptional: as novelty or visual fetish.

The absence of people with physical disabilities in cultural images conspires to present a narrow perspective of the existence of disability in history (Delin, 2002; Dorn, 1994). Ironically, Garland-Thomson (2009) notes, this absence means that when we are confronted with bodily difference, our reaction to it tends to be aversion. We look away because we are uncomfortable, and we are uncomfortable because we are not used to seeing difference. A visual culture which fails to represent people with physical disabilities, except in problematic ways, is settings its viewers up to have problems seeing people with physical disabilities: it de-normalises disability.

In this chapter, however, we are not only concerned with visual representation. We are also interested in sexuality. What does each of the above categories – of how people with physical disabilities are represented and viewed – mean for thinking about their sexuality?

In answer to such questions, we revisit the key themes of each visual category, thinking through the implications it has for what we think about the sexuality of people with physical disabilities. If distilled, the Freakshow is about objectification. If examined closely, the clinical gaze is about objectification, subjugation and pathologisation. Inspiration porn is about objectification and pity. Seeing disability as a metaphor is about failing to see disability for what it is, and rather seeing it as something flat and symbolic. Concealment and looking away is about failing to see disability altogether. Each of these endpoints of a certain type of representation or way of seeing disability, has negative implications for thinking about the sexuality of people with physical disabilities, or at the very least mirrors a problematic societal conception of sexuality amongst people with physical disabilities.

In all of these modes of representation and looking at (or failing to see) people with physical disabilities, the recognition of the disabled other's sexuality, if not entirely prohibited, is not invited in any egalitarian manner – mutuality, an important facet of meaningful romantic relating, is denied. Most of the representations discussed here foreclose on sexuality, rigorously distancing sexuality from disability, to preserve discourses and ideologies of normality, ability, and sex.

Shooting back at imposed representations: Reframing sexuality for people with physical disabilities in South Africa

The project with which the remainder of this chapter concerns itself occurs against the backdrop of the modes of representation, and their underlying discursive regimes, outlined above. These mutually reinforcing ways of inscribing meaning into, and reading meaning from, bodies, means that people with physical disabilities are not able to reference a representational cannon which is affirming to their sexual selfhood, their reproductive potential, or their personhood. As noted, we focus on representations of sexuality and disability.

Oliver (1990) argues that problematic images (both ideological and visual) of the sexuality of people with physical disabilities can only be rectified if "a social theory of disability … [is] located within the experience of disabled people themselves (p. 11)”. In a similar vein, Freire (Freire & Macedo, 1995) argued that true participation does not involve a subject-object relationship, but rather a subject-subject relationship. In all of the visual and social representations discussed above, what is at play is a subject-object relationship: between thinker and the thought about, between the representer and the represented, between the viewer and the viewed, between us and them. The present project strives to invert this dynamic through participatory methods, into a subject-subject relationship.

The project which gave rise to the images discussed in the following section employed participatory action research methods, specifically, photovoice (Wang & Burris, 1997). Photovoice places control of the camera lens in the hands of the research co-researchers themselves, and draws its data from the images which they produce (Wang & Burris, 1997). This method of research allows not only for co-researchers to create, and share, their own visualised realities, but involves research “subjects” in the process of photography (Lykes, 1997; Wang, 2003).

In the project in question, flyers and word of mouth were used to recruit adults with physical disabilities. Of the 14 co-researchers recruited, four of the participants were included in the present analysis. Given our interest in exploring representation in depth, and the constraints of space, only these co-researchers’ work is included here. Their work was chosen because it was representative of broader patterns reflected throughout the data set.

Once selected, co-researchers were invited to a workshop, at which the research team addressed various facets of photovoice methodology, including how to use a camera, and photography ethics. There was also group discussion regarding the topic of the project, which was simply put to the co-researchers as “sexuality and disability”. Thereafter, co-researchers left, with their cameras, and embarked on their photography project. After at least three months, each co-researcher was interviewed about the project, and asked to pick three to five of their favourite photographs about which they most wanted to talk.

The visual products, as well as the process – and co-researchers' reflections on the process – are the data with which the research concerns itself, ultimately with the hope that the individual or group cultural narratives captured by the photographer in the photograph become a catalyst for reflection, and allow for a tactile reframing of past representations.

The photographer-subject, self-expression, sexuality and disability in pictures

Co-researchers were interviewed about the meanings which they intended to convey in their pictures. These meanings might be at odds with a theoretically-oriented reading of the photographs, informed by the representational cannon described above. As the discussion of problematic representations which began this publication highlights, it is extremely difficult to represent people with disabilities without running into difficulty, and risk re-perpetuating problematic looking dynamics. It is important to note that the authors of this chapter will not be scrutinising the images for signs of representational trouble. Nonetheless, we, like all viewers, bring our own varying awareness of the historical ways of portraying, and ways of looking at, differently bodied subjects. We will attempt a reading of the images which negotiates between these different positions.

The present discussion examines a sample of the co-researchers' photographic data, examining the ways of representing sexuality and disability, in light not only of the cannon of representations concerning people with physical disabilities, sexuality and the body, discussed in preceding sections, but also of the photographers' intended meanings. Particularly, we draw attention to the aspects of dominant discursive and visual representations of disabled sexuality which these photographs can be read against. We examine what shooting back and reframing looks like, and what it does.

This photograph was taken by a male wheelchair user, Nick. Nick explained that he intended to capture in the image the sort of expansive freedom which being in water bestows, explaining that this was a metaphor for that fact that "people who are physically challenged, they also need the freedom to express themselves".

However, discussing the image and his journey in taking it, Nick drew attention to the limits on his freedom: "This lady going into that water freely, jumping in that water: they can do what they want to do in the water … [but in my case, being] at the edge of the water and telling myself I *can* go in that water, *but* how am I going to balance myself; who is going to assist me; who is going to guide me through this whole process where that person physically can contribute his or her help according to my need", he explained, adding that this mirrored his experiences in intimate relationships.

For Nick, then, the image conveyed some of the conflicts of his experience of sexuality. Particularly, the need to access help, and the de-romanticising pragmatics of help when achieving sexual freedom cropped up in many discussions. As the non-disabled woman swans about in the water, so Nick would have to be carried, have to enlist another's help, and in so doing, alter the gentle aesthetic of the image, and, he suggests, a romantic encounter.

Reading Nick’s image against the trove of disablist representational tropes discussed, yields several points of interest. The first concerns objectification. By employing metaphorical representation, Nick denies the viewer the spectacle of bodily difference. Unless contextualised, this image does not concern disability or sexuality. Interestingly, though, the image does invite reading as a metaphor – the impressionistic effect, the colours, the woman’s gestures – all seem to point beyond the image, to some extrinsic meaning. Nick has inscribed, on the non-disabled body, meanings which make it a cipher, inverting the conventions of narrative prosthesis and inspiration porn alike. Secondly, the impressionistic quality of the image, as well as the absence of identifiable disability signifiers within the frame, resist the conventions of inspiration porn, the Freakshow, and the clinical gaze which seek out and foreground markers of difference.

Nick chose to present an image the meaning of which hinges on what he speaks into it: the meaning of this image is disability-neutral, as it were, without his dialogue. This achieves two things: it centralises his voice in making the image about disability, and it disallows for negative readings of disability. However, it also marks an absence of disability, further perpetuating the absence of disability and sexuality from the Global South post-colony.

Considering the centralisation of his voicing in meaning making in relation to this image, Nick “speaks back” to the power imbalances and objectification characteristic of past representations – social and visual – of disabled subjects. His minimal use of “signs” of disability and racial otherness in the image inverts the traditional representational hierarchy, putting him firmly in charge of meaning relating to disability, particularly, in the image. Rather than representing disability and sexuality, he presents something else, and then makes meaning around it. The absence of disability and sexuality, which is a consequence of this strategy, recurs throughout the photographs presented here, and will be attended to in greater detail below.

A second co-researcher, Ian, focussed on the representation of the relational aspects of disability and sexuality. In the first, the image again lacks a human subject, although the presence of a pair is suggested by the two-seater bench which is in the centre of the frame. Ian explained that he "actually wanted a picture of a seesaw", explaining that a seesaw is a metaphor for a romantic relationship. "One can't really enjoy the full benefits of the seesaw unless there's another person on the other side. So you might be in a park full of people with very high spirits and all of that [and] you might go and sit on the seesaw, but it's almost entirely useless until someone sees you as worthy of joining you," he explained.

For Ian, the two-person bench pointed to ideas around participation in sexual engagements. Particularly, he related, the image encapsulated a daunting social barrier to his sexual development: until the person was prepared to "sit" on the metaphorical seesaw with him, he was unsure of his role in romantic encounters. He explained: "Unless that partner is almost on a similar page as me, I'm not going to be able to fully capture that. But at the same time, the biggest challenge is to get to a point where someone is on the same page as you. It's almost like [how to] get over the … how can I say … the barrier of how they perceive you … But now even after we get to a point where we agree for instance to take it to that next step, who is in charge? You know, it almost appeals to power dynamics, if you will."

This image represents the conflict between Ian's own sense of his sexual selfhood, and his feeling of being willing and able – free – to engage in relationships, and yet his knowledge that women and the world "out there" might not feel similarly: they may impose limits on his freedom. As with Nick's images, Ian places emphasis on the relational aspects of disability, instead of the individualistic portrayals characteristic of the cannon.

For Ian, his disability-deprived images are imbued with significance, and encapsulate many of the complexities which he faces in his negotiation of sexuality. Access and the environment are metaphors for the negotiation of social representations and self-representations in terms of his sexuality. Similar to the first image (taken by Nick), the subject is absent, changing the nature of a reading of this picture against the visual and social representational cannon of problematic disability depictions. As in Nick's first image, this suggests a disallowing of dramatic representations of sexuality and disability when the visual is commissioned at the behest of/constructed by people with physical disabilities. This departs from the cannon described earlier which rely, almost parasitically, on "presenting" the disabled body as a signifier for disability. This forecloses on the casual viewer's ability to read disability or related issues from the sign: these can only be given to the image by the photographer. The photographers speak this meaning into their art, and so they are "in charge" of its meaning, in relation to disability.

The above picture, taken by Erika, a female wheelchair user, differs markedly from those of Ian and Nick. Erika explains that she approached a photographer friend of hers to take the pictures, whilst she choreographed them: “A friend of mine [took this]. He was really cool. I mean, I have known him for years. I said, look, this is what I want, can you do it very discretely? I don’t want it to be sleazy or shit or anything, but just like real.”

Real, she explained, entailed the representation of her “normal” sexuality: “What I wanted was to just like show that people with disabilities are just normal. We *flippen* do things, you know, if you can and if it’s possible.”

For this co-researcher, a model prior to her accident, the photographs encapsulate a re-capturing of her pre-disability identity, as a sexual, attractive, confident women, reinscribing these meanings on her own body through the orchestration of these photographs. This was her framing of the process. While she appears to be striving for a normative performance of attractiveness: discrete but intimate photographs, with all the trappings of a lingerie advert – smooth skin, lace, and such – the wheelchair, here, does signify a departure from "normal" performances of sexuality. For Erika, the aesthetics of the image were important: "I love the round wheel and all the angles. It's nice, hey?", she asked, adding that her long hair had been something which she revelled in.

The signs of sexuality are in the setting, her hair, the delicateness of the lighting and angles. For her, they are works of art. They are a point of pride. The wheelchair, whilst not concealed, is not the centre of attention, neither is her impairment. Instead, her body – not itself signified with markers of impairment – is on display, although only in a segment. Whilst a feminist reading might problematise the type of audience prefigured by such an image – in this instance, they appear more as a slice-of-life: the capturing of a moment of intimate alone time between a woman and her body. This markedly contrasts with the aesthetics of inspiration porn and sexual porn in which the impairment/sexual organs of the subject are central to the image.

Erika's legs are the focal point of this image, their angle suggesting movement, their smoothness, traditional femininity. In contrast to medicalised images of disability, no impairment is apparent. We do not know why the wheelchair is there. If our eyes search for signs of difference, we come short. In contrast to the aesthetics of the Freakshow, the signs of impairment are subtle, and the conventions of the image invite us to consider it more as a beauty spread than a spectacle. This image does not invite looking away, nor staring. However, it could be accused of inviting a masculinised gaze.

This latter possibility is the product of a bind in which women such as Erika find themselves when attempting to portray themselves sexually: how to do so overtly, without falling into the trap of perpetuating problematic images of women, or disability. For Erika, this image represented an attempt to reclaim the "normal". In so doing, she prefigures a certain, masculine gaze. However, she actively denies fetishising her impairment (she explained, “I don’t want it to be sleazy or shit or anything, but just like real”), instead catering to a “normative” masculine gaze. She appears to weigh up the pathologising gaze and the sexualising gaze, deems the former the greater devil, and so risks catering to the latter.

The last picture was taken by Edward, a man with an acquired spinal cord injury. Edward, who uses a wheelchair to move around most of the time, but – following years of physical therapy – can walk around, lives in the staff quarters of a large provincial prison. This picture captures the ramp which was built at the entrance to the compound’s gym. Following his use of the space – in order to engage in physiotherapy – Edward can now walk for short distances, and so the image also captures his upright figure in shadow.

For Edward, this image encapsulates the process of his gaining access to a masculine space. It represents attaining a certain masculine ideal of activity. “I told them, firstly, there must be ramps. The first thing is the ramps. So they made a ramp there at the gymnasium. They said, if you are interested to come and do weights and lift weights, there’s a ramp at the back and you can drive up it with your wheelchair,” he explained.

Gaining access to the gym was central to his sense of reclaiming his identity as a "normal man" (Edward's story centred around ideas of progress from "injury" to "capability", an overcoming narrative of which disability scholars are normally critical. In the present project we aim to align our discussion with the meanings intended by the co-researcher. Yet, we are aware of the problems invited by this framing).

For Edward, the ramp was also a sign of the lengths to which his colleagues and institution supported him following his accident. "This is a door that has to be opened for me. I mean, I was like, wow, people have to now revamp the building. They said, no, we wanted to see that you are happy." Mirroring the metaphorical images of Nick and Ian, Edward's image of the built environment holds significance, allowing him to express, in his own terms, the facets of inclusion which matter most to him, only one of which was sexual inclusion: inclusion into the masculine "pack" at the prison was of equal import.

At the outset of this chapter, we discussed how these images would reflect upon sexuality, gender and the body. Concerning the latter, we see in the images of Nick, Ian, and Edward, a denial of the spectacle of bodily difference. Instead, the built environment is used to create narratives which often centre on difficulties encountered in negotiating sexuality, which the co-researchers attribute to bodily difference and functional limitations. In the case of Erika we see the body, inscribed with signs of femininity.

Concerning sexual relationships and sexuality generally, Erika presents a normative image of sexuality, regardless of disability, whilst Ian discusses issues of access to sexual and romantic relationships, drawing on the built environment as metaphor. Concerning gender, Erika and Edward all spoke about reclaiming, or holding onto, aspects of their gender identity in the face of the desexualisation which they felt to be a consequence of their being physically disabled. For Edward, this was framed in terms of reclamation, while for Erika it was a matter of accentuating the traditional trappings of femininity.

For all of the co-researchers, access issues – social and physical – took centre stage. With the exception of Erika’s image, these photographs resist overtly sexual images, and the focus of the majority of these representations are subtle and intersectional. One of the overarching themes, as it were, of the collection of images – across co-researchers – is a focus on the quotidian, bread-and-butter issues of living with an impairment, and negotiating one’s sexuality as a person with a physical disability, particularly in terms of social access. Physical access issues are often used as a metaphor for issues of inclusion and sexual access.

Here representation takes on the form not only of individual self-representation, but also as tool for the expression of lived experience (departing from the individualising representations of sexuality and the body characteristic of the cannon). These images do not strive to represent disability overtly, but – when narrated by the photographer-subject – disability is present in all of them.

All of the images here held metaphorical significance for the photographers. Recalling the work of Shakespeare (1994) and Mitchell and Snyder (2013), it is usually disability which is the metaphor, and “disabled people become ciphers for those feelings, processes or characteristics with which non-disabled society cannot deal” (Shakespeare, 1994, p. 287), and – in the case of idealised images of disability – which society needs to project onto disability in order to make it bearable (Shakespeare, 1994). In the representational cannon, the feelings, processes and characteristics are attributed to people with physical disabilities through the use of disability as metaphor. In the present images, however, the photographers imbue the world out there, particularly the built environment, with the significance of metaphor. Instead of their own selves pointing to a broader meaning, they employ the physical world to perform the same task.

Another facet of the cannon disrupted by these images is categorisation and objectification – the non-disabled viewer’s search for the sign which will reveal the disability.

In most images of people with physical disabilities, we – the viewer – want to see what the difference is: where is the impairment, how does it look, what category of disability does this body before us belong to? In these pictures, this knowledge is denied us, except in the image where the presence of a wheelchair points to mobility impairment. Still the specifics which our eyes demand are absent and withheld.

Further, most of the images bear subtle relation to issues of sexuality and the body. We as viewers need people with physical disabilities to read disability and sexuality from these images. Morley (2003) notes that people produce meanings from the restricted range of cultural resources which their structural position has thus far exposed them to (p. 128). For non-disabled people, conceiving of the sexuality of people with physical disabilities, this range of resources is limited and problematic. This would mean that presenting the viewer with overt signs of disability and sexuality could invite problematic readings. However, by crafting their images such that only their intended meanings and messages about disability and sexuality can be read from their pictures – because they as creator are required to link the image to its topic – circumvents this issue. In our readings of these images, we have, mainly, aligned ourselves with the subject, with power to select their own interpretations of an otherwise relatively uninterpretable image (in relation to the topic, at least), and explore meanings and readings of disability and sexuality which are freed from the dictated meanings encoded into it pictures of disabled bodies by dominant forms of representation.

One final point, however, must be made regarding a defining feature of much of our gallery here: the absence of signs of disability and the general absence of the body. This can be read in a number of ways. All visual representations are built on a cannon of similar representations; perhaps the dearth of representations of disabled sexuality means that our creators are striking out into unknown territory. These images represent the first attempts to make sense of the visual representation of the minoritised subject. The discomfort which confronts many people when viewing overt images of sexuality, and social taboos about disability and sexuality, could make of metaphorical representation an easy entry point into imagining an aesthetic for such a topic.

Alternatively, our co-researchers are unlikely to be unaware of the representational cannon outlined in this chapter, particularly that concerning disability and sexuality. In light of such an awareness, it might be understandable that they would feel frozen in their attempts to portray such a subject. Indeed, given this long and problematic history, it is reasonable that the creators would fall into the trap of thinking that all representation of disability is somehow problematic. A failure of imagination regarding how to represent the unrepresentable is understandable. The use of metaphor could represent a cautious attempt not to perpetuate past representations.

Rethinking sexuality and difference

This chapter represents a first to consider the role of self-representation in challenging the ways in which the sexuality of people with physical disabilities is conceived of. Our examination of photographic data, and our reflections on interviews with our co-researchers regarding photography-as-process, yield broadly two insights. The first concerns the images: our co-researchers' photographs "shoot back" at the dominant aesthetics and their concomitant power imbalances characteristic of past representations – social and visual – of disabled subjects. This occurs largely through a focus on issues of access in relation to sexuality, and the general omission of disability imagery and signs of difference.

Our second conclusion concerns reflections on photography-as-process. The project on which this chapter is based was premised on the idea that photovoice offers a unique opportunity for people with physical disabilities to shoot back at dominant visual and discursive representations of their alterity, and in so doing challenge dominant discourses and ideologies of power. The transformative potential of the process itself, we suggested, could offer a valuable challenge to the moral and social agendas underlying societal thinking about and representing of bodies, sexuality and difference. In this project, our co-researchers have created their own representational frameworks for representing sexuality and disability. These, a counter to dominant systems, largely eschew the representational frameworks of dominant meaning-making systems. These photographers have used their photography to identify and represent, and begin dialogue around, issues important to them, and their communities.

These photographs and the meanings spoken around them challenge the idea that sexuality should be conceived of in purely physical terms, as issues of access take centre stage. They challenge the idea that images of sexuality should be sexual images. They challenge the idea that the cannon of problematic representations means that the sexuality of people with physical disabilities is always held hostage to alterity. They constitute an ideological challenge to dominant cultural ideologies concerning sexuality, and not only a visual challenge to sexuality aesthetics.

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Linking narrative 5: Publication 5 to Publication 6

In the preceding chapter (Publication 5), I propose that images representing the sexuality of people with physical disabilities, taken by people with physical disabilities, can challenge the (largely negative) ways in which their sexuality is conceived of in the public imagining. Photovoice is one method through which such self-representation can be achieved, and the process of photography can be valuable in and of itself.

However, during the crafting of this chapter, and discussions with scholars at conferences where I presented this work, I began to reflect more comprehensively on photovoice as method, and what it might mean for this method to be employed in more research on topics like the sexuality of minoritised groups.

In this next publication (Publication 6), I flesh out this thinking. I consider the ways in which images generated during the course of photovoice projects in reflecting and perpetuating problematic beliefs about the subjects which they represent. Specifically, I consider how some of the photographs taken by participants in this project could potentially be held hostage to interpretations which reify untruths about the people who took them, and about the sexuality of people with physical disabilities.

Publication 6: (Re)presenting the self: Reflections on a photovoice project with people with physical disabilities in South Africa (Hunt, Swartz, Braathen, & Rohleder, in press)

(Re)presenting the self: Reflections on a photovoice project with people with physical disabilities in South Africa

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Photovoice; self-representation; participatory action research; disability studies

Abstract

The way in which something is visually represented both reflects and creates, the way in which we – as members of predominantly visual societies – think about and relate to it. Photovoice is presented as an emancipatory, participatory research method with the potential to put minority subjects in charge of their own representation in the visual realm.

In this article, we consider the possible role of images created as a result of photovoice projects in reflecting and perpetuating problematic beliefs about people with physical disabilities. Reflecting on images from a photovoice study conducted in the Western Cape of South Africa, we argue that – once in the world – the meaning of images is often hostage to interpretations which reify untruths about the subject. We consider how photovoice projects may actually give rise to images that perpetuate the subjugation of their subjects.

We also consider whether the images generated by our participants might cleave open a space for a truly emancipatory politics of self-representation through photography. The process of coming to speak for oneself is central to the development of one’s own political agenda. If a picture speaks a thousand words, then representation – particularly – self-representation, *can* be political. We argue that images of subjects generated by those subjects could constitute a challenge not only to dominant aesthetics, but also to the discursive regimes and ideologies which underlie them.

Photovoice; self-representation; participatory action research; disability studies

Introduction

The way in which something is visually represented both reflects, and sustains, the way in which we – as members of predominantly visual societies – think about and relate to it. The manner in which the world 'out there' is represented is intertwined, inextricably, with how we come to represent it in the world 'in here' of our minds. If something is often portrayed in the visual realm in a manner which is problematic, we may come to harbour beliefs of a negative nature, or emotions of a negative valence, about that thing. Equally, if we harbour negative beliefs or emotions about a thing, we are unlikely to represent it visually in a positive manner. Photos have a life of their own.

In this paper, we consider the role of images created during photovoice projects in reflecting and perpetuating problematic beliefs about the minoritised communities which such work hopes to empower. Drawing on a South African study concerning the sexuality of people with physical disabilities, we tease apart some of the complex issues engendered by the creation of publicly displayed social objects (i.e. photographs). We argue that attention needs to be paid to the complexities of representing minorities, and the possibilities – both positive and negative – of such projects must be considered. Only then might the images generated cleave open a space for a truly emancipatory politics of self-representation through photography. That is, a space in which representing the self in a desired manner can be a political act of empowerment.

Background

The visual representation of any subject is closely aligned with how that subject is understood in a given zeitgeist (in the case of news photographs, for instance), or the attitude of the given representer to their subject (in, say, the case of artistic renderings). However, this dynamic of beliefs-determining-aesthetics works in the reverse too, and so representations may come to influence the manner in which their subject is understood and accepted (or not).

In light of this, activist artists have striven to find new and alternative ways of representing subjects who are traditionally hostage to problematic representational tropes. With the rise of socially conscious activist work in the social sciences and humanities, such self-representation has come to be used in participatory action research, often in the form of photovoice [1]. Photovoice is a participatory methodology in which participants produce photographs as data through which to represent, visually, their thoughts, feelings and ideas about a given topic. Photovoice and its variants are established methods in anthropology and in other disciplines, particularly where participants are 'silenced' minorities – people who are structurally vulnerable.

The idea in such self-representation work is that communities under the thumbs of certain social and/or visual representations at odds with their political ends, may use self-representation as a mode of activism: 'the world out there sees and reads us in this way, and this is not to our benefit, so this is how we choose to present and understand ourselves'. The process of coming to speak for oneself is central to the development of one's own political agenda. If a picture speaks a thousand words, then representation – particularly self-representation – is political. [2]

One group of people who have too often been the subject of extremely troublesome visual representations by others, are people with physical disabilities. Although beyond the scope of this article, both the origins and outcomes of this state of affairs are complex (for further reading, see [2-4]). However, what can be discussed here, albeit briefly, are the kinds of representational tropes used to represent people with physical disabilities, and the implications which these have for thinking about alternative embodiment and one other facet of human experience – sexuality.

As a necessary backdrop to our discussion of photovoice as an emancipatory research methodology, we will briefly outline the following:

1. The relationship between social representations and visual representations;
2. Popular visual representational tropes concerning people with physical disabilities, and the implications of such for thinking about sexuality and different-than-average embodiment;
3. The promise of photovoice for inverting problematic past representational dynamics, and the reason for its employment in the case study on which the rest of this paper reflects.

On representation, disability, and sexuality

Social representations are societal stocks of shared values, ideas, metaphors, beliefs, and practices through which groups and communities make meaning of the social world [5 6]. Described as the collective elaboration "of a social object by the community for the purpose of behaving and communicating" [7], social representations guide behaviour towards, and thinking about, social objects. The given meaning of a social object (for instance, physical disability) within a given society has implications for how that social object is expected to behave, attributes it is expected to have, and which possibilities for engagement with it are appropriate and desired, and which are not.

Stereotypes, myths, and other modes of cultural diffusion share certain characteristics with social representations, predominantly that they guide behaviour towards and thinking about social objects. Social representations of people with physical disabilities tend to characterise them as helpless, dependent, de-gendered and less sexual than non-disabled people [8] [9]. People with physical disabilities are also commonly characterised as insecure, dependant, weak, asexual, or somehow superhuman (more on this below).

Perhaps unsurprisingly given the above context concerning thought and visual representation, these ways of conceiving of disability in the mind's eye mirror popular ways of visually representing people with physical disabilities. Briefly, we will review popular visual representational tropes concerning people with physical disabilities, and the implications of such for thinking about sexuality and different-than-average embodiment.

Historically, people with disabilities have often been marginalised from their communities, pathologised by medical professionals, and been the object of the pity, scorn, or disdain of non-disabled others. As Goodley [10] notes, societal discourses have positioned disability either as a personal tragedy or a scientific anomaly. Sexuality, on the other hand, is conceived of in contemporary discourse as the purview of the able-bodied and the nubile.

In tandem, modes of visual representation of disabled subjects have often relied on outdated, stereotypical, and de-gendering portrayals of different embodiment. Almost all of these foreclose on the possibilities of the portrayed subject (the people with physical disabilities) being conceived of as a normal sexual subject (instead, they are portrayed as asexual, hypersexual, or presexual). However, this must be premised by the recognition that, mostly, there is a dearth of images of different than average embodiment in our visual landscape. That representation which does occur, often draws on visual tropes which are problematic.

For instance, Freakshow-type aesthetics depend on accentuating and displaying bodily difference. Freakshows – mass exhibitions of anatomically unusual bodies – Garland-Thomson [11] writes, relies on a "cultural logic [which] construct[s] certain corporeal variations as deviant" (p. 2). Clinical or medicalised depictions of disability frame it as pathology, seeking out bodily difference for the sake of categorising and condemning it. Inspiration porn[1] images employ people with physical disabilities as exemplary of different virtues, particularly determination.

When people with physical disabilities are objectified in the manner of the Freakshow, it becomes near impossible to see them as sexual subjects. If we were to sexualise them, we might feel uncomfortable. As viewers of disability spectacle, we know that there is something intrusive about our looking. But if our looking is sanctioned as curiosity, we may be able to rationalise it. If we were to acknowledge the human subject behind the objectifying image, we would have to divorce this pretence, and in so doing confront our complicity in another's subjugation. Subjugation in the context of sexualised looking takes on the tone of perversion, and we do not want to feel perverted, so we efface the sexuality of people with physical disabilities-as-spectacle.

In the case of clinical objectification and subjugation, we learn to pathologise difference: to conflate physical impairment with illness and contamination, and physical with moral difference. Under the clinical gaze, the humanity of the examined subject is compromised, and their social and sexual desirability tarnished. As Garland-Thomson [3] notes, the visual representation of different bodies in medical journals and textbooks invites a de-sexualising way of thinking about people with physical disabilities. The objectified, pathologised, sick person with a physical disability is not a suitable sexual subject.

With images which implore us to pity people with physical disabilities, we assume (another) position of power – this time as the fortunate 'normal' person pitying the unfortunate other. We may feel admiration, but we are also grateful for our distance from difference. Feminist critics such as Simone de Beauvoir [12] [13] have taught us why pity

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[1] Inspiration porn is the term coined to describe the representation of people with disabilities in charitable campaigns.

prohibits mutuality: it is the obverse of hatred and aggression, and confers a sort of sadistic might on the viewer, albeit under the guise of sympathy. In representing people with physical disabilities as pitiful, the viewer's eyes invited to look down on the disabled body. Again, there is no room for sexualised or romantic looking: pity prohibits sexualisation.

Finally, and relatedly, the relative absence of people with physical disabilities in popular culture, except as ciphers of the type we have been discussing, serves to exclude them from sexual society. We cannot conceive of – in nuanced, personalizing ways – that which we do not see. By withholding people with physical disabilities from our daily visual life, we are not challenged to think inclusively about sex and sexuality. Equally, averting our eyes from the novel sight of physical difference forecloses on mutuality.

Both visual and social representations act in synchrony (and cyclically) to pathologise or negate the sexuality of people with physical disabilities. As many authors have noted [8 14-17], the sexuality of people with disabilities is particularly poorly understood and attended to, despite the fact that society as a whole is increasingly sexualised in the public sphere [18-22]. The social desexualisation of people with physical disabilities, Payne et al. [20] write, "further makes invisible an already marginalised and pathologised population" (p. 1031)[2].

Drawing on self-representation by people with physical disabilities to develop a positive visual grammar to portray diverse embodiments, seems a fruitful avenue for research and activist praxis. This might give rise to alternative social representations. The promise of photovoice for inverting problematic past representational dynamics is twofold. Firstly, it promises to alter the problematic dynamic which may manifest between a majority

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[2] An exception to this general desexualisation of disabled people in the popular imaginary, is its opposite: the fetishization of disability and bodily difference. Think, for instance, of Lady Gaga in her music video for the song "Paparazzi", or Michael Stokes' photographic series "Always Loyal". In both instances, a very specific type of bodily difference – the merging of body and prosthetic – is eroticized. Whilst such image undoubtedly speak back to desexualising imagery of disabled people, they do so within a very specific and potentially problematic grammar (see 23. Hickey-Moody A. CARBON FIBRE MASCULINITY: disability and surfaces of homosociality. *Angelaki* 2015;20(1):139-53.).

photographer, and a minority subject, and in so doing alter the nature of representations of minoritised subjects. Secondly, visuals concerning something as steeped in representational trouble as the sexuality of people with physical disabilities, should best be done by (or at the behest of) those in the know – people with physical disabilities themselves – if thinking around that topic are to begin to represent the interests of those portrayed[3].

Activist images: Photovoice as emancipatory research method

Until the 1950s, photography generally played a role in the social sciences only when researchers took photographs as mnemonics for later scholarly reflection [24-26]. However, since then, and particularly in light of the work of Hubbard [27] and Wang and Burris [28], researchers have transferred the activity of photography to participants. The result is that contemporary photography in research involves a means to generate an “emic” (insider) perspective on a research question, as participants are requested to collect photographs as data [24]. In participatory action research, particularly, participant photographs have proven useful to facilitate cooperation and understanding in research teams with members of varied expertise [29 30].

Among the many forms of participatory photographic research, photovoice is perhaps the most clearly operationalised [28]. Moreover, photovoice is touted, by scholars from various fields [30], to be an *emancipatory* participatory research method which has the potential to put minoritised subjects in charge of their own representation in the visual realm, mobilise communities, and pave the way for policy change, cleaving open a space for counter-narratives through representation [1 31-38].

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[3] In the case of people with physical disabilities who may have difficulty using a camera, the assistance of another may be employed in photovoice work, an individual who then captures images upon instruction from the participant.

Photovoice projects require that participants use photography to express – or aid in the expression of – their sentiments around a given topic. Where other forms of qualitative work are dialogue-driven, photovoice pairs participants' narrative accounts of the phenomenon with their photographic depictions of it [39]. These products – participants' images and accompanying narratives – not only constitute the data for the project in question, but can also be used as social objects for political action: activist images. That is, in addition to their value as social objects, photographs as an artistic medium allow for increased visibility in the public sector [1 28 40].

Photovoice has become increasingly popular in qualitative research with people with physical disabilities [38 41-44]. This is perhaps unsurprising given that photovoice has its roots in participatory action research, which is also a favoured way of working in disability studies [45-49]. The reasons for the use of photovoice in past projects with people with physical disabilities are varied, but centre on the utility of the images generated for activism, and their proposed capacity to combat stigma [40]. However, in the photovoice project upon which we reflect here, the reasons were somewhat different.

As noted, our project concerned physical disability and sexuality. Briefly, we set out to explore the experiences of sexuality amongst a group of 14 adults with physical disabilities in South Africa, between 2015 and 2016. Participant photographers were asked to contribute images (mainly photographs, although some respondents contributed drawings) which expressed some facet of their experiences of sexuality as a person with a physical disability. The topic arose out of the investigators' interest in the so-called myth of asexuality amongst people with physical disabilities: the popular belief in and imperative for asexuality amongst people with physical disabilities (for a detailed review, please see [22 50]). Photovoice was deemed an appropriate tool for two reasons: Firstly, because the topic at hand was sensitive, images serve as a neutral segue into participants' narratives concerning sexuality; secondly, due to the cumbersome representational baggage sketched above, to which people with physical disabilities inevitably find themselves tethered.

The representation of people with physical disabilities in the visual realm has seldom been affirming of their personhood, let alone their sexuality. Thus, one of the implicit projects of the investigators was to explore how self-representation could be used as a vehicle to re-present the sexuality of people with physical disabilities. If problematic images of people with physical disabilities taken by non-disabled others beget negative attitudes towards them and their sexuality, then self-generated, self-determined images could beget positive attitudes [51].

Representing the over-determined self: Problems and possible solutions

If one thinks through the project of photovoice work in relation to the visual representation of minoritised subjects, especially people with disabilities, three central problematics arise: the development of a visual grammar by which to represent the hitherto misrepresented; the inevitability of drawing on (often troublesome) representational tropes in order to frame the self, and the consequences of this for photovoice images and activism; and photovoice as inaccessible practice. Below, we draw on case study images to think through these two challenges, and interrogate possible ways of responding to them – to think about photovoice with representation in mind.

A new aesthetic

Plato wrote that all art is an imitation of an imitation. Certainly, whenever one represents something – say on canvas or film – one must necessarily look to, and draw on, past representations of that thing. As children, we learn to draw trees not by looking at trees, but by looking at how trees have been drawn in the past. This poses a problem for creating images of people with physical disabilities: how to develop a new way of 'drawing' a person with a disability when almost all past images of them are somehow troublesome or perpetuate problematic beliefs?

Caption:

"I can't hide my flaws and imperfections like other people can. Mine is there for the world to see. In the process of rediscovering my sexuality, I have learned to use what I have to seduce and entice. The silent battles I have fought of self-acceptance and validation has left me with the realisation that I no longer have to hide the naked beautiful truth of who I am...a woman in every essence of the word" (Kate)

For instance, disabled women work against two strong visual tropes. The first infantilizes them, conflating some given lack of 'normative ability' with passiveness and dependence (see, for instance, pity porn images [52]). The second, reflected in devoteeism and amputee porn, views them as sexual fetish objects (although not everyone agrees with this reading of devoteeism, see [53]). Now, given that the present project was concerned with desexualisation more than hypersexualisation (as this was what participant-photographers highlighted as being the more prevalent attitude which they encountered from non-disabled others), Kate (pseudonym) seems to have taken her photos with this grand narrative in mind (as evidenced by the narrative which accompanies the picture).

Her images (including the one above) actively speak back to the desexualisation of disabled women. However, in the process of re-inscribing sexuality into a body which society might desexualise, Kate employs aesthetics which invite a certain type of (acquisitive) male gaze. Performing sexuality, as she does in this image, evokes a different genre of visual, one which is not without its drawbacks. In trying to find a visual grammar through which to positively encode the femininity and sexuality of the disabled female body, Kate has drawn on tropes which might be viewed as sexist.

If we see her choice as lying at one end of a continuum of possibilities when confronted with representing the overdetermined subject, then the choice of the majority of our participant-photographers (as exemplified in the image below) at the other: the absence of the disabled subject.

Caption:

"I actually wanted a picture of a seesaw. One can't really enjoy the full benefits of the seesaw unless there's another person on the other side. So you might be in a park full of people with very high spirits and all of that [and] you might go and sit on the seesaw, but it's almost entirely useless until someone sees you as worthy of joining you." (Ian)

Many of our participant-photographers drew heavily on metaphor, and the images of the built environment, to represent their experiences of sexuality as people with physical disabilities. Ian's picture, for instance, exemplifies an erasure of sexuality – there is nothing sexual about the picture. None of the participants discussed why they removed the self from the pictures, and why their images were often devoid of sexual imagery as one might popularly conceive of such. One manner of reading this reliance on signs (a picture of a bench) which are divorced from the signified (sexual relationships as a disabled man), is nervousness around representing the disabled body. In an attempt not to re-perpetuate problematic looking dynamics around the disabled body, these respondents chose not to represent it at all.

This representational tactic, however, has its own host of implications, the main being that – in a project concerned with disability and sexuality – the disabled body itself is absent from many of the images. This is exemplified in the image above, where Ian employs a disability-void image to represent his experiences of relationship inequality. However, the presence of a person with a physical disability in an image is not the only means by which disability can be visually represented. Several of the participant-photographers chose to keep themselves out of their images, instead focussing on motifs and metaphors, places and spaces. This could be due to a reluctance to self-display – bordering on concealment – due to the vulnerability which such an act entails – a vulnerability which is amplified in the context of disability, due to history of problematic representation.

However, it could also be due to the participant-photographers' conceptions of their own sexuality which are relational, dependent on accommodations and access, and reflected in their daily realities. Where dominant systems of visual and social representations objectify and medicalise disability, many photographer-participant-photographers produced images which altogether lack the carnivalesque aesthetics of this cannon. While this does not make for photography which stands alone in obvious conversation with the cannon, it reveals certain facets of sexuality in the context of physical disability which the stereotypical or limiting representations of the past elide. So, while we could read this photovoice aesthetic as thwarting the development of a visual grammar to portray the disabled body, it may also represent a new grammar, one devoid of the problematics of the past.

The meaning of a picture

The second issue inherent in visually representing minoritised subjects in the context of a photovoice project stems from the limits of control over the meaning of an image. In a nut shell:

a. Once created, an image is not hostage to its intended meaning. Any meaning can be read from it; it is a social object in its own right.
b. As noted, it is difficult not to represent people with physical disabilities without potentially drawing on some ways of representing which might be problematic, even if the creator-subject does not intend the meanings which these ways of representing evoke.
c. Once 'out in the world', it is possible that an image will be interpellated with a host of meanings which subjugate the creator-subject

To briefly expand on the above – once a social object is in the world, its meaning is determined by its viewer. As Roland Barthes [54] wrote about "the death of the author", so in photovoice we might find ourselves confronted with a death of another kind – the death, as it were, of the photographer. What Barthes [54] meant, as intended here, is that readers and viewers have agency, and they use that agency to read and make meaning from the social objects they encounter. This meaning may be at odds with that intended by the creator. Central to photovoice is the idea that narrative should accompany image, and participant-photographers provide captions which are distributed with their images. These captions convey what they as photographers intended the image to 'say' and 'do'. As evident from the above discussion, these meanings might be at odds with what the image seems to 'do' or represent. However, it is very difficult to guarantee that once the images are distributed across various platforms as tools for activism, that this meaning will remain alongside them.

Consider, as discussed above, that it is extremely difficult to represent the self in a manner which does not harbour the ghosts of past representational tropes. When within a project, a photographer who does draw on a problematic representational trope may still be able to mitigate any damage which such a portrayal might do, with the use of a caption which carries their intended meaning (as in the case of, say, Kate, above, where her narrative works against fetishist interpretations of her photograph).

The intended meaning might very well be at odds with the trope employed. This might be particularly the case for people with physical disabilities because social and visual representations as social products play a substantial role in the structuring of identities and self-representations [41]. As it is a common belief that people with disabilities make sense of their experiences in light of the existing meanings and practices prevalent in a predominantly nondisabled society, the narrative and visual coding of social objects created by people with physical disabilities might very well reflect meanings attached to them by the majority.

Thus, when representing the self during the course of a photovoice project, it is entirely possible that a person with a physical disability might draw on a trope which is problematic. The image, when displayed after the completion of the project, might go on to evoke negative reactions, or perpetuate troublesome viewing dynamics between non-disabled and disabled subjects, despite this not being the photographer-subjects' intention.

As Higgins [55] writes, one of the major ethical problematics of photovoice-type work is that participant-photographers may actively participate in the appropriation of their images, "reproducing the oppressive relations of power that it aims to work against, albeit differently" (p. 672). For instance, returning to the image of Kate above, the disabled subject is caught between two problematical tropes. The first is that of the asexual disabled female body; the second is that of the disabled female body as fetish object. Working against what Heiss (2011, 2) argues is the "media's frequent situate[ion] of the "normal" female body as the … absence of fat, wrinkles, physical disabilities, and deformities", Kate represents herself in a manner which could not only invoke a particularly acquisitive male gaze, but also evoke fetishizing looking characteristic of devotee porn. So, while the image was intended (as stated in the accompanying narrative) to be an affirmation of her sexuality, it could be read in a manner which perpetuates a troublesome way of relating to the disabled female body.

Writing about the representation of people with physical disabilities in Indian cinema, Dawn [4] recommends that “the film-maker [must] be deliberately mindful of the structures and conventions that permits film to communicate effectively to the mass audience, be conscious of how this language works, how the screen communicates to people and effects their emotions” (p. 517). In a similar manner, participant-photographers in photovoice projects might best be educated regarding the emotional power of images, and its promises and pitfalls. However, to do this, without limiting or constraining participant-photographers’ capacity to convey their sentiments in a congruent way, is a fine line to tread.

Does the risk of producing an image which might be misread by some, outweigh the promise of self-representation as a liberatory end in itself? Past work by Mji, Schneider, Vergunst, and Author [56] has shown that the sheer fact of seeing the self represented, may hold benefits regardless of the purpose, or later readings, of the image. Thus, it might be necessary to tolerate the possibilities of later misreadings of a given visual, if the production of that visual is of benefit to the participant, *and their communities*. The emphasis here is a difficult one to untangle: do the benefits of an individual representing themselves in a way which feels liberatory in the moment take precedence over the possibility that the image could lead to the subjugation of members of the community with which they identify?

Due to the importance of exploration (developing a new visual grammar) in photovoice work of this kind, it may be necessary to not overly mediate the production of images – constraining participant-photographers to be responsible for the way in which their communities are portrayed (this simply reinforces the notion that members of a given social group must ‘represent’ that group, which deindividualises members). Equally, however, it may not be a bad thing for participant-photographers to be cognizant of past visual traditions, and their implications. This is not to say that their choice of images should be shaped by future audiences, but rather that they should be put in a position to make informed decisions regarding the types of visuals which they produce. Although this may well stifle some of the spontaneity of image-taking, we would argue that researchers have the responsibility not to place participant-photographers in a position where they unknowingly produce images of themselves which are undoubtedly problematic or could have negative consequences for them or their communities [1 57].

Photographs are just as capable of carrying discernable messages as the narratives which accompany them, and this is both a strength and a weakness of photovoice as methodology. However, if the weaknesses/risks outlined above are borne in mind, it is possible that self-representation can offer a process through which people with physical disabilities may challenge problematic assumptions about their sexual selves: images-challenging-ideology. Below, we outline the manner in which photovoice may cleave open a space for a truly emancipatory politics of self-representation through photography, one which offers a process through which other minoritised populations in the Global South may challenge problematic assumptions about their selves by presenting their self in the manner in which they would like to be seen. We argue that images of subjects generated by those subjects could constitute a challenge not only to dominant aesthetics, but also to the discursive regimes and ideologies which underlie them.

Photovoice as inaccessible practice

The final issue which photovoice work brings into question is one of accessibility. This has to do with both representation and participation in representation. Photovoice is clearly most suited to use with people who have good enough vision and motor skills to hold a camera and take the photo which they desire. As such, people with visual impairments or more severe functional limitations may not be able to actively participate in the photographic process.

Regarding the latter population, people with severe physical disabilities may be able to instruct an assistant to take photographs at their instruction, and so perhaps less is lost here than as concerns people with visual impairments. This project, as specifically concerned with physical disability, was satisfied with the former solution. However, it is worth considering the limitations of work around representing subjects (such as people with visual disabilities) who perhaps do not relate to visual and representational frameworks themselves, despite the fact that they might still be subject to problematic representations by others.

Finally, amongst people with intellectual disabilities, may not be able to take photographs about what is meaningful in relation to the research question in interpretable ways. This limits the value to photovoice as activist practice for populations who do not relate to visual representations in the manner in which majority society might. Equally, only some disabilities can be easily represented – a wheel chair, yes, schizophrenia, perhaps not. Focusing on the visual, then, may inadvertently reify and reinforce hierarchies of disability: that which we can revision (physical disability, for instance) may become more readily accepted than that which we cannot (say, schizophrenia).

Creation as resistance:

Photovoice as participatory communication for the minoritized subject

Adopting a participatory action approach in disability research does more than foreground the importance of accessibility and the effective inclusion of people with physical disabilities in research *about* people with physical disabilities. It also promises to make an important methodological contribution to disability and sexuality research in the global South. The contribution of photovoice is unique in this regard. If the visual representation of people with physical disabilities is often problematic, mirroring negative social representations concerning their sexuality, then novel visual representation might equally play a role in challenging such social representations.

Creating an archive from below: Re-visioning disability imagery

In response to this burdensome representational and ideological baggage, Shildrick [58-60] has argued that there is a need to urgently foreground the aesthetic and intellectual value of disability. Shildrick [58-61], Erevelles [62] notes, "proposes a radical (re)conceptualization of the disabled subject as sexual subject" (p. 50). That is, critical reflections on disability should not merely oppose the devaluing of disability but actively value it as an identity (a perspective which has been echoed by McRuer [63]). Photovoice not only holds the potential for this radical reconceptualization to be a radical re-representation tool, but also that it is done at the behest of people with physical disabilities themselves. The necessity of doing needs- and rights-based work of a very fundamental kind in settings in which the resources with which to intervene are scarce (such as inquiry into issues of access) is clear. However, this does not negate the relevance of creative, participatory work around 'softer' issues of, say, representation. Self-representation, or taking charge of the dominant other's gaze is an act of resistance, but also an act of self-definition which inscribes into disabled bodies new, generative meanings. As a methodology, then, photovoice seems extremely well-suited to use in application to disability and sexuality.

This suitableness is perhaps amplified in global Southern contexts, as illuminated by a reflection of postcolonial critique. Like disability theory postcolonial critique is concerned with examining the relations of domination between and within groups. However, where disability studies is concerned with the able/disabled dichotomy, postcolonial critique attends to relations amongst countries, 'races', or cultures. Both disability and postcolonialism are central discourses in the social construction of personhood [64]. Both have been used to determine which bodies are deemed worthy of citizenship and rights.

As with disability, the visual representation of persons deemed racially Other – people of colour – has a fraught history. Stereotypical, flattened, problematic renderings of racial 'alterity' have overlain societal anxiety regarding miscegenation and contamination. When it comes to conceiving of the sexuality of the racial Other, a similar process is noted – their is all that white sexuality is not, and the racial and sexual Other is feared or fetishized. In social representations myths and fears about the deviant or hypersexuality of PWD, are very similar to anxieties about people of colour [65 66].

Given the history of national and international race relations, any image of a person of colour persons carriers with it a host or interpellated meanings. Whilst these meanings today include sexuality, that sexuality often skirts the edges of the 'normal' (socially desirable, sanctioned), and, if a genuine portrayal is offered, it is hard-pressed not fall into stereotypical patterns of representing race (see, for instance, discussions surrounding black persons in pornography; [67-69].

Mapping the interstice between visual representations of two types of visual 'difference', racial Otherness and disability, then, reveals a number of areas of commonality. As such, an exercise in shooting back at representations sexual otherness amongst people with physical disabilities in a postcolonial global Southern setting, is an intersectional enterprise, and has the potential to explode stereotypes of both race and embodiment. it is also a project which echoes calls by postcolonial and Southern theorists for an archive from below[70 71].

Marcus [72] draws our attention to the “the activist imaginary”, the means by which media, including photographs and film, can be used by minority groups to “pursue traditional goals of broad-based social change through a politics of identity and representation” (p. 6). It is possible that the types of representation – and the types of identities – revealed by creators with disabilities during the course of photovoice work, may indeed be vastly different from those imposed onto them by dominant meaning systems. This holds, we would suggest, for participant-photographers who accidentally draw on problematic representational tropes, encountering the two challenges outlined above. Given that photovoice accompanies each image with a participant-generated narrative, might allow for these problematic visuals to begin to evoke new meanings (for instance, if images such as Kate’s are repeatedly displayed alongside narratives such as hers which speak an affirming meaning into the sexualised disabled female body, then eventually images of that body may come to evoke more liberatory meanings).

This is important. Spectators’ responses to disability are often determined by ready-made or pre-determined response options – for every disability trope, there is a limited way of viewing disability. If new ways of representing disability *or* viewing disability are explored, the greater the possible range of readings and meanings disability imagery may have [73]. New ways of viewing disability, encouraged either by new aesthetics or by new meanings accompanying old aesthetics, may provide a space for consensus-building negotiations about disability, the body, and representation [73].

Through self-representation, our participant-photographers attempted to challenge our conceptions of what disability and sexuality in the global South might look like. Where dominant systems of visual and social representations objectify and medicalise disability, playing up impairment to suit one of other grand metaphorical narrative, our respondents produced images which altogether lack the carnivalesque aesthetics of this canon. Instead, they used their photographs to highlight the relational nature of sexuality and intimacy, and employed the built environment and issues of physical access to shed light on the importance of accommodation, power dynamics, and social representations in determining their sexual self-esteem, and development.

Yet, there is ambivalence here – the absence of the disabled body from the images, and the sexualised gaze anticipated by the disabled woman trying to achieve sexual selfhood – in these images: is absence concealment? Is the desire for the gaze problematic? Perhaps. However, if the very making of the image is a political action, and a departure from past enforced inaction, then such work constitutes a first step, regardless of how uncertain, or how rocky the terrain.

Putting custody of the camera with these co-researcher-photographers enabled them to act as thought leaders, drawing on the immediacy of the visual image to stimulate discussion, and a revisioning of the intersection between geopolitics, sexuality, and bodily difference [28]. Pribram, [74] reading Foucault, suggests that representation is a site for cultural struggles over meaning formation. In the process of photovoice, we see that meaning production occurs around the visual image; social structures, ideologies, and contested identities are played out within the frame. It is possible that the harm of an unintended meaning being read from an image is outweighed by the value of the production of that image in an end in its own right.

Perhaps one of the greatest contributions of photovoice for working with people with physical disabilities is the potential for such work to create an archive from below – an archive of disability self-representation. Such cultural products, and their creation and public display, can foster audience's engagement with a credible and authentic cultural counter-narrative [75].

Finally, as already noted, if we harbour beliefs of a negative nature, or emotions of a negative valence about a thing, we are unlikely to represent it visually in a positive manner.

This works on the intrapersonal level too, and we are as unlikely to visually represent ourselves in a positive light if we feel badly about who we are. Working within the bounds of projects aimed at re-imagining how the self can be portrayed, using different visual grammars, could allow for a positive re-definition of the self. These images invert the usual dynamics of looking characteristic of the cannon of representations of different bodies. The enforced passivity of viewing offers a reversal of the usual habits of looking at people with physical disabilities. The photographer-subject is empowered and accorded status because of their power as creator [28 76]. In the case of photovoice, that power can be used to take pictures which do not conform to a societal stereotype or social expectations for the subject or their visual representation. However, before such a re-imagining of disability aesthetics can take place, greater attention must be paid to issues of visual representation: we must think photovoice with representation in mind.

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CHAPTER FOUR

Limitations and Discussion

4.1 Limitations

The limitations of this study as a whole are discussed in each publication. However, it is worth revisiting each of them here.

4.1.1 Survey

Firstly, regarding the survey data, the sample includes a greater proportion of White respondents, and is better educated than the general population in South Africa. Caution must then be applied in generalising the findings reported in the first three publications. As noted in Publication 1, *The sexual and reproductive rights and benefit derived from sexual and reproductive health services of people with physical disabilities in South Africa: beliefs of non-disabled people*, I acknowledged from the outset that such non-probability survey research would not result in representativeness, and so my goal was to achieve as much diversity as possible. However, despite our attempts to sample from different sectors of the South African population, including individuals without access to computers, and people from different language groups and provinces, our sample still suffers from over-representation of the countries' minority (well-educated Whites).

Secondly, given the non-probabilistic nature of the sample, selection bias is a possible concern. That is, that the pen-and-paper respondents (who were selected at convenience by data collectors) could be biased towards people known to the data collectors, or frequenting areas frequented by the data collectors. However, during training of the data collectors, emphasis was placed on approaching as random a selection of people as possible from busy areas in their communities, rather than from their social networks. It is also worth noting that there is conflation between method of data collection, and language, SES, and race. That is, the pen-and-paper versions of the survey were administered to a different population (low SES, Xhosa-speaking, Black South Africans only), to the online survey (open to higher SES individuals who spoke largely English and Afrikaans, and came from a variety of racial groups).

The next limitation concerns the use of a vignette story-completion task alone to elicit survey respondents' thinking, and feeling about, dating people with physical disabilities. Vignettes are one of a number of ways of eliciting information of this kind. My understanding and interpretation of the data gathered from these items is premised on the idea that participants, in their completion of the vignette, would insert some of their own opinions, thoughts, and feelings about the situation at hand. It is entirely possible that some respondents did not do this, and completed the vignette in an idiosyncratic manner. However, due to the substantial size of this sample, I believe that this randomness will have "come out in the wash", as it were, and that the themes in answering revealed were too pervasive to have been due to caprice.

Regarding the survey, self-report measures are sensitive to social desirability concerns, though the majority of the responses should be less encumbered by this bias than non-web based survey research. Online and anonymous survey methods and the use of indirect measures have been proposed to reduce social desirability responding (Fricker & Schonlau, 2002; Krysan, 1998; Simmons & Bobo, 2015). As such, I employed these insofar as possible in an attempt to circumvent social desirability in the present study. Finally, regarding the data gathered in the manuscript concerning stereotypes, there could have been a priming effect, as the free-response items were situated near the end of the survey, which began with a number of questions about disability and sexuality. However, as reported in

Publication 3, the fact that stereotypes concerning sexuality were not very prevalent in the data set, priming does not seem to have had an effect.

4.1.2 Photovoice

As concerns the photovoice segment of this study, there are two primary limitations; the first concerns the interview data generated during the photovoice work, and the second concerns the nature of photovoice itself. Regarding the first, I drew on a volunteer sample for the photovoice project, and, as such, it is possible that those people who volunteered to participate had already devoted thinking space to matters of sexuality, or had been unduly impacted in the realm of sexuality, and were thus more interested than most in the topic of the study. Still, and as noted, in Publication 4, *Intimacy, intercourse and adjustments: Experiences of sexual life of a group of people with physical disabilities in South Africa*, the fact that so many of the topics which arose in the interviews mirrored those of past work, seems to suggest that these issues are not unique to a few individuals, but somewhat universal.

The interviews for this segment of the study were carried out by three different people (the author; Dr Poul Rohleder, my co-supervisor; and Dr Stine Hellum Braathen, a co-investigator on the study). Thus, the interactions which gave rise to the interview data were different. Interviewer effects are well-documented in qualitative research (Hatchett & Schuman, 1975; O’Muircheartaigh & Campanelli, 1998; Opdenakker, 2006), and so I cannot overlook the fact that these might have been different depending on who conducted the interview, and our respective positions in relation to the participants. We are all experienced interviewers, and so tried to minimise these effects. Participants were also invited to select the gender of the interviewer with whom they spoke and would feel most comfortable.

Another limitation of the present work is that the participants all identified as heterosexual and cisgender. The results of this work thus reflect a heteronormative exploration of sexuality. This is less than ideal, given the importance of explorations of intersections of gender identity and sexual orientation, and disability and sexuality, today. However, given that I drew on a volunteer sample in this study, I was not in a position to control these variables.

Finally, it is possible that photovoice may itself be an inaccessible method for conducting participatory research with people with physical disabilities. Photovoice is clearly most suited to use with people who have good enough vision, and sufficient motor skills to direct a camera and snap whatever shot they desire. People with visual impairments or more severe functional limitations, such as quadriplegia, may not be able to actively participate in the photographic process. In the present study, those individuals who had such limitations were encouraged to employ an assistant of their choosing to assist them. The participant was to choose and curate the shot which they desired, and their assistant was to take the image at their behest. So, for these individuals, less is lost here than for people with visual impairments. In this project, concerned as I am with physical disability only, I have been satisfied with the assistant solution (although it might well be worthwhile to explore, in future work, the differences in experiences of photovoice as process, for those holding, versus those only directing, the camera). Still, it is worth considering the limitations of work around representing subjects (like people with visual impairments) who do not relate to visual and representational frameworks themselves, despite the fact that they might still be subject to problematic representations by others. This is an avenue worthy of enquiry.

4.2 Reflections

Now, for a discussion of the work presented here. I began this dissertation by drawing attention to two interrelated gaps in the study of physical disability and sexuality, which are particularly acute in the Global South generally, and South Africa specifically. These lay between theorisations of sexuality and disability (mainly hailing from the Global North) and the state of knowledge concerning: (a) the thinking and feeling about and representations of non-disabled people of the sexuality of people with physical disabilities, and (b) the experiences of sexuality (including sexual and reproductive health, relationships and sexual activity) of people with physical disabilities, in the Global South. I proposed that a simple, lay-of-the-land survey of non-disabled people's attitudes towards the sexuality of people with physical disabilities would be suitable to address the first question, and that qualitative inquiry would be enlightening with regard to the experiences of sexuality of people with physical disabilities, in the South African context. Particularly, as pertains to the latter, I proposed that – given the pervasiveness of negative visual imagery of people with physical disabilities – self-representation, in the form of photovoice work, would be a generative mode of inquiry.

Based on the survey data, I drew three broad conclusions. Firstly, in Publication 1, I presented findings which show that non-disabled people showed a greater endorsement of the sexual and reproductive rights of the population without disability than those of people with physical disabilities. Non-disabled people were also more likely to rate the benefit derived from sexual and reproductive health care of the population without disability as greater than people with physical disabilities.

Secondly, in Publication 2, I presented findings to the effect that non-disabled people hold negative views of dating people with physical disabilities. Non-disabled South Africans attitudes about a dating scenario involving a person with a physical disability were dependent on the nature and severity of the disability, but were characterised by pity for people with physical disabilities. Non-disabled people’s responses were marked by fears about the stigma which they would face were they to date a person with a physical disability, and fears of that person’s dependency. However, and notably, in this latter publication, I also found evidence of inclusive attitudes, characterised by responses that did not focus on the disability status of the dating target, or where non-disabled respondents expressed an openness to dating a person with a physical disability. Such responses suggest that there are some positive attitudes towards dating people with physical disabilities in South Africa.

Finally, in Publication 3, I found that non-disabled people stereotype people with physical disabilities in fairly consistent ways, seeing them as either withdrawn and shy, supercrips, or happy, funny, and kind. These stereotypes can be read in both psychological and sociological terms, but – regardless of origin or function – seem to be extremely similar between genders of people with physical disabilities. Such findings suggest that stereotypes of people with physical disabilities are not overwhelmingly de-sexualising, but are undifferentiated by gender. This seems to evince a de-gendering of people with physical disabilities by non-disabled people. Disability as an identity category supersedes gender, it would appear, as it was the primary marker by which non-disabled people characterised people with physical disabilities, regardless of the latter’s gender.

Taken together, these publications provide evidence that non-disabled people’s perception that people with physical disabilities are less sexual than they are, may be underlain not only by a belief that people with physical disabilities are less sexual than non-disabled people (Publication 1), but also by non-disabled people’s active desexualisation of people with physical disabilities in interactions (Publication 2), and negation of the gender of people with physical disabilities (Publication 3).

The data presented in Publication 2 were particularly illustrative of some of the attitudinal barriers which people with physical disabilities may face in their social, romantic and sexual lives. Non-disabled people were prone to feel pity for people with physical disabilities, an emotional reaction which stymies equitable romantic relating. Non-disabled people actively desexualised people with physical disabilities, either assuming them to be unsuitable sexual partners (unable to engage in sexual activity), or seemingly automatically categorising them as suitable for platonic relationships only. Non-disabled people felt more uncomfortable with social proximity (in the form of dating) when the disability in question of their prospective partner was more visible or "severe" (engendered greater functional limitations). When supplemented by the findings from Publication 3, *Withdrawn, strong, kind, but de-gendered: Non-disabled South Africans' stereotypes concerning persons with physical disabilities*, which evinced a de-gendering of people with physical disabilities by non-disabled people, the attitudinal context in which sexuality is experienced by people with physical disabilities, seems particularly stark. This starkness is characterised by an enforcement of normalcy (Davis, 1995), where physical difference excludes one from conceptions of normative sexuality, and there is discomfort with the sexuality of people with different-than-average embodiments. This is then reflected and perpetuated by societal stocks of stereotypes and representations of people with physical disabilities as lacking gender and sexuality.

It is against this backdrop – of non-disabled people's thinking and feeling about, and representations of, the sexuality of people with physical disabilities – that people with physical disabilities come to develop, experience, and know their sexual selves. This is not to say that all people with physical disabilities, or even those in my sample, partner with non-disabled people; they do not. But, in a society marked by the views and sentiments of a majority who do not share their embodiment, and, indeed, seem to hold it in ill regard, it is hard to image that people with physical disabilities' sexual development would be unaffected by the disablist norm. As noted in the introductory review of the literature with which this dissertation began, the negative societal thinking and feeling about, and representations of, the sexuality of people with physical disabilities have pernicious sequelae. They can result in the people with physical disabilities experiencing barriers in their sexual and personal relationships, and difficulty accessing services and information about matters of sexuality (O'Dea et al., 2012; Shuttleworth et al., 2012). As such, the first publication reporting findings from the second facet of this project – the exploration of the experiences of sexuality of people with physical disabilities – attends to this experience: how is sexuality negotiated in the context of physical disability, and do the attitudes of non-disabled people come into play?

In Publication 4, I provided some tentative explorations of these questions. Amongst a sample of 13 adults with physical disabilities, I found that expressed concern over their "fitness" or suitability as sexual beings. Participants with congenital disabilities described how the attitudes of non-disabled people had impacted on their expectations for their own sexual lives, and future relationships. Participants with acquired disabilities described having to re-negotiate their sexual functioning in light of their altered embodiment, which they framed in contrast to their expectations for their sexual functioning as non-disabled people. Participants' concerns with their sexual fitness – their suitability as sexual subjects – originated in their ideas about how non-disabled people might view their different-than-average embodiment, or how they viewed their embodiment as measured against internalised non-disabled norms.

Taken against the backdrop of the findings presented in the first three publications, these ideas do not seem as irrational as one might hope them to be: my findings suggest that non-disabled people *do* view people with physical disabilities as less sexual than themselves, *do* view them as less sexual, and at times even harbour actively negative evaluations of physical disability. In past research in disability studies, particularly in the Global South, much of this context has, until this point, largely been deduced from accounts of people with physical disabilities, and theorised. This dissertation makes a contribution to the literature by examining and evidencing the often problematic context of societal thinking and feeling about, and representations of, disability and sexuality, *amongst non-disabled people*.

However, in Publication 4, I also presented findings which shed light on the generative, positive experiences of sexuality which take place in the context of physical disability. Many of these were framed in terms of initiation or re-initiation into what some would term normality: for instance, engaging in one's first sexual experience as a person with a congenital physical disability, or one's first sexual experience post-disability for people with acquired disabilities, was seen as a moment of "becoming normal (again)". However, there were glimmers of responses, or respondents' ways of thinking about, feeling, and representing their sexuality, which actively resisted the desexualising beliefs and ascriptions of non-disabled others. In these recollections, respondents' discussed experiences of pride in their sexuality, and noted how sexuality as a person with a physical disability could be enjoyed in ways that non-disabled sexuality might not be.

My curiosity about these framings of sexuality and physical disability informed the incorporation of photovoice work in the present study: if language limits the degree to which something can be framed differently from the norm, might visuals allow for novelty? Simply put, would people with physical disabilities be able to capture on camera interpretations of their sexuality which words limit or disallow? As noted, however, this publication did not discuss the photographic data in detail.

As such, in Publication 5 (a book chapter which is currently in press for Palgrave Macmillan's *Diverse voices of disabled sexuality in the Global South*), I addressed the images more deliberately. Given the findings presented in my publication concerning stereotypes of physical disability, this chapter tied together two loose ends. Firstly, it showed how stereotypes and social representations of physical disability and sexuality find corollaries in dominant visual representations of physical disability (which, although discussed in the first of my literature reviews, is presented more incisively in this chapter). Secondly, it pondered the role which self-representation could play in challenging these stereotypes and representations; how might the visual challenge the ideological (and, does it?).

Based on the exercise undertaken to construct this chapter (Publication 5), I made two observations. Firstly, people with physical disabilities did explore ideas about their sexuality in their images which constituted a challenge to the dominant aesthetics and the concomitant power imbalances characteristic of past representations of disabled subjects. This occurred largely through a focus on issues of access in relation to sexuality, and the general omission of disability imagery and signs of difference.

Secondly, it appeared that the value of self-representation as a process of encountering one’s self led participants (co-researchers) to create their own representational frameworks for representing sexuality and disability. These largely eschewed the visual representations of dominant meaning-making systems (ways of portraying), and could, potentially, allow for different mental representations (ways of thinking).

As hinted at in segments of the narratives presented in Publication 4, some of the meanings attached to sexuality in the context of physical disability in this chapter’s images were different from dominant portrayals of sexuality. However, this difference had less to do with revealing novel constructions of sexuality and ways of being sexual, than it had to do with foregrounding facets of sexuality not usually foregrounded. Issues of access took centre stage, challenging the idea that representations of sexuality should be sexual. However, this also reflects the fact that concerns about access – particularly social access – are a pervasive and looming burden which our participants bore in their internal worlds. Still, I hold that the images do constitute a challenge to dominant sexuality and disability aesthetics, and – potentially – to cultural ideologies concerning sexuality and disability. Primarily, this is because some of the images challenge the idea that the problematic canon of visual representations of people with physical disabilities in the past, mean that the sexuality of people with physical disabilities is always held hostage to alterity: the meanings spoken into the images by participants proffer new interpretations of imagery which in the past would either misrepresent or elide disability issues. They constitute an ideological challenge to dominant cultural ideologies concerning sexuality, and not only a visual challenge to sexuality aesthetics.

However, in the course of the photovoice project, and work with the participants, I began to think about the limits on control over the meaning of an image, and the challenges inherent in creating new visual grammars by which to represent something as imbued with social meaning as disability. So, whilst I endorse the view that photovoice may be an emancipatory, participatory research method, I also began to consider the possible role of images created as a result of photovoice projects in reflecting and perpetuating problematic beliefs about their creator-subjects.

In the final publication, Publication 6, I argued that – once in the world – the meaning of images is often hostage to interpretations which reify untruths about the subject. In the case of people with physical disabilities, this specifically entails the re-enfreakment or concealment of physical disability and sexuality, by images which were intended by their creators to do precisely the opposite. In this publication, I draw three conclusions. Firstly, there may be a need to tolerate the possibility that problematic meanings will be imposed on disability imagery, if that imagery is to become more prevalent, and new meanings eventually be associated with it. As Rice et al. (2015) note,

> when we revision disability, we do not create “new” representations that are completely distinct from, or in opposition to, the “old” ones. Nor do we attempt to elide old meanings altogether. Instead, we make our meanings in conversation with existing representations, through talking back, expanding on them, infusing them with lived experience, and reclaiming ourselves from them. (p. 516)

As such, in light of the fact that prior meanings attached to an image will not be expunged purely because new meanings are aired, it may be necessary to take representational contexts and histories into account if the meaning of an image is to be negotiated. Twenty out of twenty-five non-disabled people viewing a sexualised picture of a woman in a wheelchair outside the context of its photovoice narrative, may indeed see it as fetishistic. The other five, however, may come to view sexuality as inclusive of a sexy woman in a wheelchair.

What I am suggesting here, is a broadening of the intertextual frame for reading disability images. As noted by Swartz and Bantjes (in press), intertextuality as concept offers a useful way to understand the representational relationship between images (in this case, of disability generated by people with disabilities, and of images of disability which are problematic). Rose (2016) defines intertextuality as the “ways that the meaning of any one discursive image or text depend not only on that one text or image, but also on the meanings carried by other images and texts” (p. 188). What I am proposing is that, by encouraging images of people with physical disabilities to be produced and read in tandem with meanings intended by people with physical disabilities (as in photovoice), the viewer may develop new frameworks for reading disability. These frameworks can be drawn on in intertextual readings of physical disability at the viewers’ next encounter with physical impairment.

As I wrote in this Publication 6, “In the process of photovoice, we see that meaning production occurs around the visual image; social structures, ideologies, and contested identities are played out within the frame. It is possible that the harm of an unintended meaning being read from an image is outweighed by the value of the production of that image in an end in its own right”.

Secondly, and relatedly, one of the greatest contributions of photovoice for working with people with physical disabilities is the potential for the images generated to create an archive from below. This canon of disability self-representation may foster audience’s engagement with a credible and authentic cultural counter-narrative. Finally, people with physical disabilities, as shown in Publications 1 through 4, encounter their sexual selves through a filter of disablist meanings and values attached to sexuality and physical disability. This project, aimed as it is at re-imagining how the self can be thought and felt about, and internally represented, might mean that individuals using different visual grammars to represent themselves could begin to view their sexuality in a more positive light.

4.2.1 The important question of so what

In conversation with one another, these pieces conjure a picture of sexuality and physical disability as conceived of and experienced in South Africa. I have the “lay-of-the-land” findings; that non-disabled people’s thinking and feeling about physical disability and sexuality are problematic, and their representations of physical disability are stereotypical, limited and limiting. This could cause social barriers to sexual life for people with physical disabilities. Possible solutions I offer could include conscientisation of non-disabled people about sexuality in the context of physical disability, and creating opportunities for contact between disabled and non-disabled people (I discuss this more in the conclusion).

However, as I note in Publication 2, *Dating persons with physical disabilities: the perceptions of South Africans without disabilities*, “it is clear that a much more complex politics of intimacy and desire is at stake here, not only contact” (p. 12). Evidence for this comes from dating attitudes which evidenced contempt or disgust for people with physical disabilities (“[The woman with disability] might respond with disgust due to his disability and tell John it’s her reason not to pursue anything with him.”), or expressed the sentiment that physical disability evoked a visceral or affective reaction which squelched attraction (“[The person without disability] might have a problem with disability; perhaps the prospect of being intimate with [the person with physical disabilities] given his physical condition makes her feel uncomfortable.”).

Unless these more complex issues are borne in mind, then there will continue to be the disjuncture between conceptions of physical disability and sexuality which this dissertation found amongst non-disabled people, and the experiences of people with physical disabilities, respectively. At this point, I look outward: what do these pieces and the project as a whole, say in conversation with the broader literature concerning sexuality and physical disability?

This work dovetails with recent theorisations of intimate citizenship by Ignagni, Shromans, Liddiard, and Runswick-Cole (2016). As a concept, “intimate citizenship” concerns our rights and responsibilities to make personal and private decisions about with whom and how we are intimate, when we are intimate, and why (Plummer, 2001). As revealed in this project, as in past work, this citizenship, for people with physical disabilities, is actively impinged upon by the thoughts, feelings and actions of non-disabled people (and internalisations of disablist attitudes). Although the work of Ignagni et al. (2016) concerns intellectual disability, their treatise holds for physical disability: “Intimate citizenship is fragile in the lives of labelled people” (p. 132). If people with physical disabilities continue to be excluded from dominant conceptions of sexuality, and seen as less sexual and less deserving of sexual rights than non-disabled people, their intimate citizenship will continue to be precarious. This matters, firstly, because intimate, equitable relationships play a dominant role in securing the social support and capital which support activity and success in numerous other facets of existence (Ignagni et al, 2016). Intimate, equitable relationships are also a source of support against disablism in other spheres of life, including vulnerability to violence and discrimination which we know are pervasive in the lives of people with physical disabilities in Africa (Astbury & Walji, 2014; Chirawu et al., 2014).

As such, the attitudinal barriers encountered in this project may have very real social and economic costs for people with physical disabilities. These issues of recognition and exclusion are issues of citizenship and justice. To achieve intimate citizenship, and inclusion in mainstream conceptions of sexual selfhood, must be the focus of activism efforts. The form that this intimate citizenship might take and how it might look is suggested by the photographic data presented in the latter part of this dissertation: recognition as sexual agents, inclusion in sexual relationships, and a desire to live in a different-than-average embodiment without the fear of second class sexual citizenship.

These images go some way, as Rice et al. (2015) propose, to right the wrong of misrepresentation which parallels and perpetuates the exclusion of people with physical disabilities from sexual life. “If justice [is] to be achieved for all disabled people, we must focus on how disability is represented and thus who we imagine disabled people to be and what we could imagine ‘full inclusion’ to become” (Rice et al., 2015, p. 515).

These authors, as well as others, like Goodley et al. (2014) and Goodley and Runswick-Cole (2016), hold that developing this vision of fuller inclusion of disability must involve a revisioning of the idea of the human (built as it is on humanism), and of interrogating the value of disability as a biopedagogy. The full articulation of these ideas is beyond the scope of this discussion and the dissertation which it attempts to complete. However, simply put, the idea is that posthumanist disability studies would employ disability and the generative potential of difference to unsettle traditional notions of the human, and the citizen. Biopedagogies, or the biomedical ways of thinking about disability which tend to equate it with pathology, would be replaced with “becoming pedagogies”; this would encourage creative endeavours, and an exploration of the abilities and possibilities afforded by different embodiments.

The images presented in the latter part of this dissertation, then, are exemplary of becoming pedagogies – explorations of the way in which embodiment is experienced in the context of physical disability, which do not necessarily take lack as their starting and end points.

But, more simply, these images and the subtle or direct challenge which they pose to dominant conceptions of sexuality, represent an end in themselves for the photographers who took them. It is also important not to elide, in enthusiasm for ideas about the ideas of Goodley and Runswick-Cole (2014), and Rice et al. (2015), the lived experience of exclusion and difficulty of which some of the images “spoke”. Here we see how in South Africa, marked as it is by pragmatic needs of access and acceptance, representation serves a dual purpose. The photographs produced in this project inform theorisations of difference, and open up “talking space”. But they also simply point out the quotidian difficulties faced by people with physical disabilities in contexts of infrastructural lack and problematic attitudes (revealed in the survey).

The tempering influence of writers such as Vehmas and Watson (2016) and Shakespeare (2013) must be borne in mind: disability may have transgressive potential as an instance of embodiment which challenges our ideas about enforced normalcy. However, it is also a lived experience for people. In “Exploring normativity in disability studies”, Vehmas and Watson (2016) write that both the social model and postconventional disability studies have negated normativity in their accounts of disability, at times conflating it with the enforcement of normalcy, or antithetical to inclusivity and difference. In my encounters with people with physical disabilities in the present project, many of the participants had normative desires: for inclusion in the “normal” sexual realm, for partners, children, and recognition as sexual agents. Not to be seen as transgressive and different, but rather the opposite. I do not take this to be a matter of “passing” or not fully embracing their disability identity, but, rather, an expression of a relatively universal desire for certain things. This does not negate the theoretical and political value of their cultural products for re-visioning sexuality. But it does remind me, as custodian of these accounts and images, not to impose further difference on them – even if it is an interesting theoretical exercise to think about becoming pedagogies.

This dissertation, and the data which it presents and reflects on, does two things, which dovetail with the pragmatics of Vehmas, Watson, and Shakespeare of thought, and the enthusiasms of theoretical writers such as Goodley and Rice. I have provided evidence for a problem – negative attitudes and problematic ways of thinking and feeling about, and representing, people with physical disabilities. This problem is a practical one, and must be dealt with. In a country like South Africa, addressing this attitudinal milieu is a matter of access, physical, social, and intimate. But, in this work, I have also explored how a creative, arts-based approach to doing participatory research can be used to explore the experiences of people with physical disabilities, and generate the impetus (and materials) for activism.

Despite the necessity and obligation of doing exploratory research around issues of pragmatic need, like perceptions of access rights of people with physical disabilities, there is also room in a context such as South Africa to do meaningful and generative creative work.

CHAPTER FIVE

Conclusion and Future Directions

The present work is all but complete, and the discussion section (see Chapter Three) draws broad conclusions within the dissertation – the etic conclusions, as it were. This final chapter, then, will deal with the broader implications of the work for the field of disability studies, psychology, cultural studies, and for intervention. I structure this in terms of recommendations for future work (research or practice or activism) stemming from each publication, and, then, make some final comments regarding disability studies in South Africa, and what this dissertation contributes.

In Publication 1, *The sexual and reproductive rights and benefit derived from sexual and reproductive health services of people with physical disabilities in South Africa: beliefs of non-disabled people*, I conclude that, if people with physical disabilities are desexualised, their need and capacity for sexuality diminished in the eyes of the public, and their suitability/ability for reproduction called into question, it is little surprise that they may encounter neglect in service provision. This is true – if society as a whole assumes that you are less sexual than non-disabled people, you are likely to receive substandard care, or face barriers to care, in sexual and reproductive health services. However, what remains to be seen, is whether the conceptions of sexual rights and access of service providers in the health system in South Africa mirror those of the general population. Although knowing that general population-level conceptions of the sexual rights and access, and sexuality of people with physical disabilities are problematic, it would be extremely useful to have this information from service providers specifically.

As past work (Esmail et al., 2010) has shown that harsh and desexualising service provider attitudes have negative consequences for people with physical disabilities, this information would be useful. It would provide concrete evidence that interventions aimed at improving knowledge and raising awareness, and even changing attitudes about, the sexuality of people with physical disabilities, is needed amongst health care service providers in South Africa.

The primary implication of Publication 2, *Dating persons with physical disabilities: the perceptions of South Africans without disabilities*, is that detailed exploration and analysis of the beliefs and attitudes of people without disability, regarding the sexuality of people with physical disabilities, is necessary. That is, while the qualitative survey data from the present study go some way in showing the kinds of thinking and feeling about, and representations of disability, which underlie non-disabled people's disinclination to date people with physical disabilities (the *why*), more information is needed. Focus groups or individual interviews, for instance, might be more suitable in generating in depth accounts of the *why*. This information could then be used to tailor awareness-raising and attitude change tools. From this study, it is clear that such tools need, for instance, to deal with the perception that people with physical disabilities are unable to have sex. However, if further inquiry were to reveal why this perception is so pervasive, despite its inaccuracy, then the manner in which this perception is altered could be tailored to the kind of thinking underlying it.

Respondents proposed that part of their reticence to date people with physical disabilities was due to limited experience in being with people with physical disabilities. In global Southern contexts, and in Africa in particular, opportunities for contact between people with physical disabilities and non-disabled people may indeed be more limited than in high-income, northern countries (Goodley & Swartz, 2016). This is at least in part due to the relative cost of specialised transport, and the lack of infrastructural accessibility. People with physical disabilities are often unable to access the kinds of spaces and opportunities which would then create opportunities for contact between them and non-disabled people. There are many barriers to the kinds of contact which would foster and support relationships and intimacy (Goodley & Swartz, 2016). Thus, as noted in Publication 2, *Dating persons with physical disabilities: the perceptions of South Africans without disabilities*, some of the work that must be done may involve creating more opportunities for contact between people with physical disabilities and people without disability on an equal basis every day, in higher education institutions, places of employment and public spaces.

However, as noted, the work which must be done to change attitudes towards dating people with physical disabilities, and promote intimate citizenship for people with physical disabilities, seems to have more to do with changing conceptions of the sexuality of people with physical disabilities – and sexuality in general – than it has to do with contact (although contact will be important). Indeed, if conceptions of sexuality itself are not broadened, contact in and of itself will unlikely be a sufficient condition for attitude change regarding the sexuality of people with physical disabilities: unless the way in which people with physical disabilities are perceived when encountered changes, then encounters themselves are unlikely to change.

In Publication 3, *Withdrawn, strong, kind, but de-gendered: Non-disabled South Africans' stereotypes concerning persons with physical disabilities*, I found that non-disabled people seem to hold stereotypes of disability which are undifferentiated by gender. However, I did find evidence of stereotypes regarding physical disability and femininity which could place Women with Physical Disabilities at risk of negative attitudes, and even, as Hanass-Hancock (2009) proposed in her work which revealed similar stereotypes, sexual violence. Part of the work which will need to be done to address this, will involve sustained activism around the sexual and reproductive rights and needs of women with physical disabilities.

Further, as Hanass-Hancock (2009) notes, if women with physical disabilities are characterised, as we found them to be, as unattractive, ineligible, asexual, having difficulties with reproduction, and being bad mothers, then “sexual abuse or exploitation [may] sometimes [be] interpreted as a blessing such as that the person with disability can ‘count herself lucky’ to have sexual intercourse” (p. 40). In line with this reading of the implications of stereotyping for sexual violence, improved schools-based sexual education and life skills programmes for young girls with physical disabilities, including components which aim to build sexual self-esteem, and self-esteem, could go some way to empowering these young women. However, as in the case of the other evidence of problematic societal attitudes, the burden of coping should not be placed on people with physical disabilities: the onus should not be on people with physical disabilities to manage a bad attitudinal climate, but, rather, the climate should be changed (more on this presently).

Next, in Publication 4, *Physical disability and sexual life: Experiences of people with physical disabilities in a photovoice study from South Africa*, I found that people with physical disabilities doubted whether they were “fit” or suitable sexual beings, a concern which seemed to find its origins in their ideas about how non-disabled people might view their embodiment. However, these respondents also reported being sexual, and actively participating in sexual life, as would any non-disabled person. Given the disjuncture between the fact that people with physical disabilities are regarded as less sexual than non-disabled people by non-disabled people, and the reality that people with physical disabilities are sexual and sexually active and want to be included in sexual society, something needs to change. Advocacy around the sexual and reproductive health rights of people with disabilities is imperative if this disjuncture between attitudes and ascriptions, and lived experience, is to be bridged. This is especially so given that the findings reported in this publication show that people with physical disabilities’ experiences of their sexual lives and sexual selves are actively impinged on by the desexualising attitudes of non-disabled others.

Stemming from the conclusions of all four of these publications, is a clear need for awareness-raising about the sexuality of people with physical disabilities. In line with this need, and as part of this dissertation, I was involved in the creation of a documentary. It drew on the experiences of four of the study participants to create a short film about disability and sexuality in South Africa. The film, which has been shown at several conferences (including the International Society of Critical Health Psychology Conference in Loughborough, 2017, and the Rural Research Day Conference in Worcester, 2017), and is now available online (https://disabilityandsexualityproject.com/videos/), aims to serve as a catalyst for conversations around several facets of sexuality amongst people with physical disabilities. The participants, who generously and candidly shared their experiences and their time for the making of the film, explode several of the most common misconceptions which people have about the sexuality of people with physical disabilities. I wrote the script with a view to tackling the problematic attitudes and misconceptions uncovered during the survey part of this study. I hope work regarding issues relevant to people with physical disabilities in South Africa will similarly use data to give their participants – if the latter so wish – the platform to speak back to disablist norms and mores.

Indeed, a major contribution of this work, in my view, is the degree to which participants' voices, experiences and perspectives could be borne through the photovoice work, and the counter-narratives and complexity which they conveyed. As discussed, the latter segment of the study – the photovoice work – had the goal of speaking ("shooting") back in mind. As reported in Publication 5, *Shooting back and (re)framing: Challenging dominant representations of the disabled body in the Global South*, my examination of photographic data, and reflections on interviews with our co-researchers regarding photography-as-process, showed that co-researchers photographs did indeed challenge past representations – social and visual – of disabled subjects. They omitted disability imagery, in the main, and were concerned, instead, with issues of access in relation to sexuality.

This alternative aesthetic which characterised participants' narratives of sexuality, as well as the value of the photovoice process for self-expression, led to my calling, in the final publication – Publication 6, *(Re)presenting the self: Reflections on a photovoice project with people with physical disabilities in South Africa* – for the creation of an archive from below. This, certainly, is one of the most important future directions for this sort of creative research with people with physical disabilities, particularly in the Global South.

As noted in this publication, photovoice holds the potential for self-definition and self-representation to challenge dominant aesthetics, and the discursive regimes which underlie them. Through the creation of a trove of new disability aesthetics, or the imbuing of new meanings into old aesthetics, and all that happens and is created in between, this archive may serve several purposes. Firstly, new ways of viewing disability, encouraged either by new aesthetics or by new meanings accompanying old aesthetics, may provide a space for consensus-building negotiations about disability, the body, and representation (Hadley, 2014).

Secondly, and relatedly, new aesthetics and new meanings, associated with physical disability and sexuality, may begin to challenge and undermine some of the negative attributions non-disabled people make about people with physical disabilities, their bodies, gender, and sexuality. The process of creating this archive, for people with physical disabilities, may lead to negative self-attributions regarding physical disability, bodies, gender and sexuality for people with physical disabilities. Future work in disability studies, particularly in relation to matters of sexuality, and other areas of social exclusion of people with physical disabilities related to their misrepresentation in the public imagining, could usefully employ image generative methodologies.

The present project did not explore, in depth, the degree to which, or whether, the participants' own sense of themselves as sexual beings changes over the course of the project or as a result of self-representation. It may be that such work is useful for activism and attitude change for non-disabled people, but does little for the participants themselves (although anecdotal reports from the participants in the present work suggest otherwise). Thus, a final direction for work in the future which I propose arising from this project, would entail the in-depth exploration of what photovoice means and does on an intrapersonal level, for people with physical disabilities.

What remains to be written, here, then, concerns the contribution of this work. I will keep it brief. In South Africa, we knew little about the attitudinal climate regarding the sexuality of people with physical disabilities. We thought that non-disabled people might desexualise people with physical disabilities, but we did not know to what extent, or why. I have shown that this is the case – non-disabled people do desexualise (and degender) people with physical disabilities. The degree to which this is the case remains unclear, but it appears to be pervasive. We did not know what underlay this negative thinking and feeling, and these negative representations: why do non-disabled people appear to be uncomfortable with the sexuality of people with physical disabilities, and why do non-disabled people assume that people with physical disabilities are asexual? I have shown that non-disabled people appear to be uncomfortable with different-than-average embodiment and what it might mean for sexual activity, and are uncomfortable with the unfamiliarity of physical disability, fearing dependence on the part of people with physical disabilities as partners. The assumption of asexuality amongst people with physical disabilities, on the part of non-disabled people, my data suggest is predicated on an assumption that "abnormal" bodies cannot engage in "normal" sex or have "normal"' sexuality. I have also shown that problematic thinking and feeling about, and representations of, the sexuality of people with physical disabilities are not uniform, and some non-disabled people in South Africa hold inclusive attitudes.

Finally, I have shown that creative research methods can be used to great effect, even in low-resource settings in which rights-based, pragmatic research often needs to, and does, take precedence. The video and website generated as a result of this creative work, may serve as catalysts for awareness-raising and potentially even attitude change, amongst non-disabled South Africans.

I have written over a thousand words to each picture presented here, but I believe the participants' contributions speak louder than my commentary. I am indebted to them. I thank the reader for bearing with this account of a project which has shaped my research career, thinking, and way of being in the world. I hope the pictures ease the work of reading, and that my enthusiasm for the project, its findings, contributions, and the directions in which it leads our thinking, have been sufficiently conveyed in these pages.

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APPENDICES

Appendix A: Ethical Clearance

Appendix A.1

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Approved with Stipulations

New Application

06-Mar-2015
Swartz, Leslie LP

Proposal #: HS1163/2015

Title: The myth of asexuality? Disability stigma as a barrier to sexual relationships in South Africa.

Dear Professor Leslie Swartz,

Your **New Application** received on **05-Feb-2015**, was reviewed by the Research Ethics Committee: Human Research (Humanities) via Committee Review procedures on **26-Feb-2015**.

Please note the following information about your approved research proposal:

Proposal Approval Period: **26-Feb-2015 -25-Feb-2016**

Present Committee Members:
Van Deventer, Karel KJ
Hansen, Leonard LD
Theron, Carl CC
Beukes, Winston WA
Graham, Clarissa CJ
Lesch, Anthea AM
Horn, Lynette LM
De Klerk, Jeremias JJ
Hall, Susan SLC

The following stipulations are relevant to the approval of your project and must be adhered to:
Please make all changes on the ORIGINAL proposal/relevant documents using TRACK CHANGES. Furthermore, it is required that a letter be sent to the REC, responding to each of the REC's concerns and comments in NUMBERED FORMAT, indicating the page numbers/documents on which the changes were made.

The researcher may not proceed with the envisaged research until all the requests made by the REC have been adhered to or addressed.
If the research in any way deviates from the undertaking that were made in the original submission for ethical clearance to the REC, the researcher should undertake to notify the REC of these changes.

1. GENERAL COMMENTS
This is a very well presented research proposal by an experienced research team and does not require any changes. The informed consent documents are participant-friendly and easy to read.
The researcher is reminded to obtain ethics clearance for the second phase of the study, by submitting a request for proposal amendment to the REC.

2. FAIR SELECTION OF PARTICIPANTS
Initially participants will be invited to attend a planning workshop or focus group and SAFOD will facilitate this. SAFOD is participating as a collaborating party. After this workshop a sample of 8 men and 8 women will be recruited also via SAFOD networks. Some may have participated in the workshop.

Although it is acceptable that SAFOD networks are used to distribute information about the study to participants it is important that freedom of choice to participate remains guaranteed and that no undue influence to participate is exerted by SAFOD. Also, it is important that the implications of the pending Protection of Personal Information (PoPI) Act is kept in mind when using personal data such as names and contact details, held by an institution (in this case SAFOD) for research purposes. Please ensure that this legislation is complied with where applicable.

3. CONFIDENTIALITY

The main ethical issue with this project is its narrative nature and the fact that stories will be told and photographs will be used to tell the story. Although names will not be used, it is likely that the participants will be identifiable and may even want to be identified. This aspect is explained very clearly in the informed consent form(s). The REC accepts that the research team will exercise due diligence in ensuring that all participants are completely comfortable with what information is revealed and what remains confidential.

Please provide a letter of response to all the points raised IN ADDITION to HIGHLIGHTING or using the TRACK CHANGES function to indicate ALL the corrections/amendments of ALL DOCUMENTS clearly in order to allow rapid scrutiny and appraisal.

Please take note of the general Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

Please remember to use your **proposal number** (**HS1163/2015**) on any documents or correspondence with the REC concerning your research proposal.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Also note that a progress report should be submitted to the Committee before the approval period has expired if a continuation is required. The Committee will then consider the continuation of the project for a further year (if necessary).

This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki and the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health). Annually a number of projects may be selected randomly for an external audit.

National Health Research Ethics Committee (NHREC) registration number REC-050411-032.

We wish you the best as you conduct your research.

If you have any questions or need further help, please contact the REC office at 218089183.

Included Documents:
DESC Checklist form
Research Proposal
REC Application form
Informed consent form
Interview schedule

Sincerely,

Clarissa Graham
REC Coordinator
Research Ethics Committee: Human Research (Humanities)

Investigator Responsibilities

Protection of Human Research Participants

Some of the general responsibilities investigators have when conducting research involving human participants are listed below:

1.Conducting the Research. You are responsible for making sure that the research is conducted according to the REC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research. You must also ensure that the research is conducted within the standards of your field of research.

2.Participant Enrollment. You may not recruit or enroll participants prior to the REC approval date or after the expiration date of REC approval. All recruitment materials for any form of media must be approved by the REC prior to their use. If you need to recruit more participants than was noted in your REC approval letter, you must submit an amendment requesting an increase in the number of participants.

3.Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the REC-approved consent documents, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least five (5) years.

4.Continuing Review. The REC must review and approve all REC-approved research proposals at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period.** Prior to the date on which the REC approval of the research expires, **it is your responsibility to submit the continuing review report in a timely fashion to ensure a lapse in REC approval does not occur.** If REC approval of your research lapses, you must stop new participant enrollment, and contact the REC office immediately.

5.Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, number of participants, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the REC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written REC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.

6.Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research related injuries, occurring at this institution or at other performance sites must be reported to Malene Fouch within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the RECs requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch Universtiy Research Ethics Committee Standard Operating Procedures. All reportable events should be submitted to the REC using the Serious Adverse Event Report Form.

7.Research Record Keeping. You must keep the following research related records, at a minimum, in a secure location for a minimum of five years: the REC approved research proposal and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the REC

8.Provision of Counselling or emergency support. When a dedicated counsellor or psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognised as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.

9.Final reports. When you have completed (no further participant enrollment, interactions, interventions or data analysis) or stopped work on your research, you must submit a Final Report to the REC.

10.On-Site Evaluations, Inspections, or Audits. If you are notified that your research will be reviewed or audited by the sponsor or any other external agency or any internal group, you must inform the REC immediately of the impending audit/evaluation.

EXTERNAL AND STRATEGIC DEVELOPMENT SERVICES
uel.ac.uk/qa
Quality Assurance and Enhancement

UEL University of East London

27 March 2015

Dear Poul

Project Title:	**The myth of asexuality? Disability stigma as a barrier to sexual relationships in South Africa**
Researcher(s):	**Dr Poul Rohleder**
Principal Investigator:	**Dr Poul Rohleder**
Reference Number:	**UREC_1415_61**

I am writing to confirm the outcome of your application to the University Research Ethics Committee (UREC), which was considered at the meeting on **Wednesday 18th March 2015**.

The decision made by members of the Committee is **Approved**. The Committee's response is based on the protocol described in the application form and supporting documentation. Your study has received ethical approval from the date of this letter. The Committee also recommend that you familiarise yourself with UEL policy on conducting overseas research.

Should any significant adverse events or considerable changes occur in connection with this research project that may consequently alter relevant ethical considerations, this must be reported immediately to UREC. Subsequent to such changes an Ethical Amendment Form should be completed and submitted to UREC.

Approved Research Site

I am pleased to confirm that the approval of the proposed research applies to the following research site.

Research Site	**Principal Investigator / Local Collaborator**
Locations in Western Cape, South Africa	Dr Poul Rohleder

Approved Documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	***Version***	***Date***
UREC application form	1.0	27 February 2015
Interview schedule	1.0	27 February 2015
Consent form	1.0	27 February 2015

Approval letter from SAFOD	1.0	27 February 2015
Participant information sheet	1.0	27 February 2015
Ethical approval letter from Stellenbosch University	1.0	09 March 2015

Approval is given on the understanding that the UEL Code of Good Practice in Research is adhered to.

Please note, it is your responsibility to retain this letter for your records.

With the Committee’s best wishes for the success of this project.

Yours sincerely,

Rosalind Eccles
University Research Ethics Committee (UREC)
UREC Servicing Officer
Email: researchethics@uel.ac.uk

Appendix B

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

Approved with Stipulations

Progress Report

23-Feb-2016
Swartz, Leslie LP

Proposal #: HS1163/2015
Title: The myth of asexuality? Disability stigma as a barrier to sexual relationships in South Africa.

Dear Prof Leslie Swartz,

Your **Progress Report** received on **03-Feb-2016**, was reviewed by members of the **Research Ethics Committee: Human Research (Humanities)** via Expedited review procedures on **22-Feb-2016**.

Please note the following information about your approved research proposal:

Proposal Approval Period: **23-Feb-2016 -22-Feb-2017**

The following stipulations are relevant to the approval of your project and must be adhered to:
The researcher may proceed with the envisaged research provided that the following stipulations, relevant to the approval of your project are adhered to or addressed. Some of these stipulations may require your response. Where a response is required, you must respond to the REC within six (6) months of the date of this letter. Your approval would expire automatically should your response not be received by the REC within 6 months of the date of this letter.

If a response is required, please respond to the points raised in a separate cover letter titled "Response to REC stipulations" AND if requested, HIGHLIGHT or use the TRACK CHANGES function to indicate corrections / amendments of ATTACHED DOCUMENTATION, to allow rapid scrutiny and appraisal.

Regarding recruitment of participants: [RESPONSE REQUIRED]
The researcher is required to obtain written institutional consent from organisations that will be used (e.g. as mentioned Woolworths, Old Mutual and Stellenbosch University) to access participants via advertisements on these institutions' platforms or premises regardless of the mode of recruitment (e-mail, posters, flyers, etc.).

Please provide a letter of response to all the points raised IN ADDITION to HIGHLIGHTING or using the TRACK CHANGES function to indicate ALL the corrections/amendments of ALL DOCUMENTS clearly in order to allow rapid scrutiny and appraisal.

Please take note of the general Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

Please remember to use your **proposal number** (**HS1163/2015**) on any documents or correspondence with the REC concerning your research proposal.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Also note that a progress report should be submitted to the Committee before the approval period has expired if a continuation is required. The Committee will then consider the continuation of the project for a further year (if necessary).

This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki and the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health). Annually a number of projects may be selected randomly for an external audit.

National Health Research Ethics Committee (NHREC) registration number REC-050411-032.

We wish you the best as you conduct your research.

If you have any questions or need further help, please contact the REC office at 218089183.

Sincerely,

Clarissa Graham
REC Coordinator
Research Ethics Committee: Human Research (Humanities)

Investigator Responsibilities

Protection of Human Research Participants

Some of the general responsibilities investigators have when conducting research involving human participants are listed below:

1.Conducting the Research. You are responsible for making sure that the research is conducted according to the REC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research. You must also ensure that the research is conducted within the standards of your field of research.

2.Participant Enrollment. You may not recruit or enroll participants prior to the REC approval date or after the expiration date of REC approval. All recruitment materials for any form of media must be approved by the REC prior to their use. If you need to recruit more participants than was noted in your REC approval letter, you must submit an amendment requesting an increase in the number of participants.

3.Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the REC-approved consent documents, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least five (5) years.

4.Continuing Review. The REC must review and approve all REC-approved research proposals at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period.** Prior to the date on which the REC approval of the research expires, **it is your responsibility to submit the continuing review report in a timely fashion to ensure a lapse in REC approval does not occur.** If REC approval of your research lapses, you must stop new participant enrollment, and contact the REC office immediately.

5.Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, number of participants, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the REC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written REC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.

6.Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research related injuries, occurring at this institution or at other performance sites must be reported to Malene Fouch within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the RECs requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch Universtiy Research Ethics Committee Standard Operating Procedures. All reportable events should be submitted to the REC using the Serious Adverse Event Report Form.

7.Research Record Keeping. You must keep the following research related records, at a minimum, in a secure location for a minimum of five years: the REC approved research proposal and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the REC

8.Provision of Counselling or emergency support. When a dedicated counsellor or psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognised as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.

9.Final reports. When you have completed (no further participant enrollment, interactions, interventions or data analysis) or stopped work on your research, you must submit a Final Report to the REC.

10.On-Site Evaluations, Inspections, or Audits. If you are notified that your research will be reviewed or audited by the sponsor or any other external agency or any internal group, you must inform the REC immediately of the impending audit/evaluation.

Appendix B: The Author's Contributions to the Publications

Publication 1: The sexual and reproductive rights and benefit derived from sexual and reproductive health services of people with physical disabilities in South Africa: beliefs of non-disabled people (Hunt, Carew, Braathen, Swartz, Chiwaula, & Rohleder, 2017)

In this publication, I led data gathering, with the assistance of an online survey, and three data collectors who administered pen-and-paper versions. I inputted pen-and-paper data into the master spreadsheet, and assisted Dr Mark Carew, the team's statistician, with the analyses. I wrote the first draft of the publication, which was then commented on by the rest of the team. I made all subsequent changes, including those recommended by reviewers during the publication process.

Publication 2: Dating persons with physical disabilities: the perceptions of South Africans without disabilities (Hunt, Swartz, Carew, Braathen, Chiwaula, & Rohleder, 2017)

In this publication, I led data gathering. I inputted pen-and-paper data into the master spreadsheet. With the assistance of two independent coders, I led the thematic analysis of the data. This process was monitored by both of my supervisors (Prof Swartz and Dr Rohleder), who commented on themes. I wrote the first draft of the publication, which was then commented on by the rest of the team. I made all subsequent changes, including those recommended by reviewers during the publication process. Each round of revisions was commented on by all other team members.

Publication 3: Withdrawn, strong, kind, but de-gendered: Non-disabled South Africans' stereotypes concerning persons with physical disabilities (Hunt, Swartz, Carew, Braathen, & Rohleder, in press)

I again led data gathering for the data which were used in this publication. I inputted pen-and-paper data into the master spreadsheet. Together with two independent coders, and assisted by Dr Mark Carew, I analysed the free response data. I wrote the first draft of the publication, which was then commented on by the rest of the team, with particular input from Prof Swartz and Dr Carew. I made all subsequent changes, including those recommended by reviewers during the publication process.

Publication 4: Physical disability and sexual life: Experiences of people with physical disabilities in a photovoice study from South Africa (Hunt, Braathen, Swartz, Carew, & Rohleder, 2017)

The data for the second trench of publications came from the photovoice segment of this study. The photographic data were thus generated by people with physical disabilities, who were subsequently interviewed either by Dr Rohleder, or Dr Braathen, or me. The qualitative analysis of the interview data was conducted by Dr Rohleder and me. I wrote the first draft of the publication, which was then commented on by the rest of the team, with particular input from Dr Braathen. I made all subsequent changes, including those recommended by reviewers during the review process.

Publication 5: Shooting back and (re)framing: Challenging dominant representations of the disabled body in the Global South (Hunt, Swartz, Braathen, Carew, Chiwaula, & Rohleder, in press)

The data for this chapter came from the photovoice segment of this study. The photographic data were thus generated by people with physical disabilities. I then analysed the photographs, in tandem with the narratives which participants generated in relation to the images. I conceptualised the publication on the basis of theoretical insights which came to me during the course of thinking about representation, and much influenced by the writing of Rose-Marie Garland Thomson. I wrote the first draft of the publication, which was then commented on by the rest of the team. No changes were suggested during the review process.

Publication 6: (Re)presenting the self: Reflections on a photovoice project with people with physical disabilities in South Africa (Hunt, Swartz, Braathen, & Rohleder, in press)

The final publication represents the culmination of my thinking about the photovoice segment of the study, as well as the creation of Publication 5. I conceptualised the publication, and drafted it. The rest of the team then commented on the piece, which was then presented, in its altered form, at a writing workshop for a special issue of the journal *Medical Humanities,* in Johannesburg in September 2017. I then implemented changes recommended by workshop participants.

Appendix C: Online Survey

The following questions will be used to generate a unique code which you can use to identify your survey responses, should you need to.

Please state only the first letter of your first name:

____

Please state only the first letter of your father's first name:

____

Please state only the first letter of your mother's first name:

____

Please state your day of birth as two digits:

For example, if you were born on the 3rd October 1987, please put 03; if you were born on the 12th January, please put 12:

____

The following questions will just ask a bit about your background and lifestyle. Please answer each question by circling the appropriate option or writing in the space provided.

How old are you (in years)?

____

Are you:

1. Male
2. Female

How would you describe yourself in terms of your population group?

Black African (1) Coloured (2) Indian or Asian (3)

White (4) Other (5)

Which language do you speak most often in your household?

Afrikaans (1)
English (2)
IsiNedebele (3)
IsiXhosa (4)
IsiZulu (5)
Sepedi (6)
Sesotho (7)
Setswana (8)
Siswati (9)
Tshivenda (10)
Xitsonga (11)
Other (12)

In which province do you usually live?

1) Western Cape
2) Eastern Cape
3) Northern Cape
4) Free State
5) Kwa-Zulu Natal
6) North West
7) Gauteng
8) Mpumalanga
9) Limpopo

What is your highest level of education obtained?

1) No schooling
2) Up to Grade 2/Sub B
3) Up to Grade 7/Std 5
4) Grade 10/Std 8
5) Grade 12/ Std 10/ Matric
6) Bachelor Degree/Higher Diploma
7) Honours Degree
8) Higher Degree/Diploma (Masters/PhD)

How would you describe your sexual orientation?

1) Asexual
2) Bisexual
3) Gay or lesbian
4) Heterosexual

Do you have difficulty seeing, even if wearing glasses?

1. No- no difficulty.
2. Yes- some difficulty.
3. Yes- a lot of difficulty.
4. Cannot do at all.

Do you have difficulty hearing, even if using a hearing aid?

1. No- no difficulty.
2. Yes- some difficulty.
3. Yes- a lot of difficulty.

4. Cannot do at all.

Do you have difficulty walking or climbing steps?

1. No- no difficulty.
2. Yes- some difficulty.
3. Yes- a lot of difficulty.
4. Cannot do at all.

Do you have difficulty remembering or concentrating?

1. No- no difficulty.
2. Yes- some difficulty.
3. Yes- a lot of difficulty.
4. Cannot do at all.

Do you have difficulty with self-care such as washing all over or dressing?

1. No- no difficulty.
2. Yes- some difficulty.
3. Yes- a lot of difficulty.
4. Cannot do at all.

Using your usual language, do you have difficulty communicating, for example understanding or being understood?

1. No- no difficulty.
2. Yes- some difficulty.
3. Yes- a lot of difficulty.
4. Cannot do at all.

Please respond to the following questions by circling the number between 1 and 7 that best matches your opinion.

Please indicate the extent to which you mix with people who have physical disabilities...

...in the area that you live in.

Not at all 1 2 3 4 5 6 7 A great deal

...when socialising.

Not at all 1 2 3 4 5 6 7 A great deal

…when engaging in leisure activities.

Not at all 1 2 3 4 5 6 7 A great deal

…within your friendship group or family?

Not at all 1 2 3 4 5 6 7 A great deal

Please indicate the extent to which your past interactions with people who have physical disabilities have been…

…positive?

Not at all 1 2 3 4 5 6 7 Very much so

…personal?

Not at all 1 2 3 4 5 6 7 Very much so

…enjoyable?

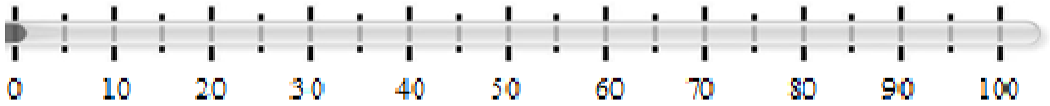
Not at all 1 2 3 4 5 6 7 Very much so

…worthwhile?

Not at all 1 2 3 4 5 6 7 Very much so

What percentage (%) of your contact with people who have physical disabilities, currently or in the past, has been romantic (e.g., dating, a relationship)? You can do this by marking on the line below the number between 0 and 100 that best represents your view.

% of romantic contact.



To what extent do you favour or oppose each of the ideas listed below?

We should do what we can to equalize conditions for different groups.

Strongly oppose 1 2 3 4 5 6 7 Strongly favour

We should work to give all groups an equal chance to succeed.

Strongly oppose 1 2 3 4 5 6 7 Strongly favour

Group equality should not be our primary goal.

Strongly oppose 1 2 3 4 5 6 7 Strongly favour
(recoded "GROUP EQUALITY SHOULD")

It is unjust to try to make groups equal.

Strongly oppose 1 2 3 4 5 6 7 Strongly favour

(RECODED "IT IS JUST")

Please read the following scenario carefully and then answer the below question by writing in the box provided:

A group of female friends sit and chat about their dates over the weekend – including some intimate details of their sexual encounters. One of them is a woman who has a physical disability. The group eggs one another on to share, naming and coaxing each person in turn to share something until all have shared except the woman who has a disability. What happens next?

Please read the following scenario carefully and then answer the below questions by writing in the box provided:

Jane, who is non-disabled, meets John, who has a physical disability, at a party. They have a nice chat together and seem to get along really well. At the end of the evening, John tells Jane that he really likes her, and invites her to go out on a date the following weekend.

How does Jane react to this? How might she respond to John?

Why might Jane react in this way? What are her thoughts and feelings about the situation?

Please list three traits that come to mind when thinking of *<u>men</u>* *who have physical disabilities* and three that come to mind when thinking of *<u>women</u>* *who have physical disabilities*.

Disabled men:

Disabled women:

To what extent would you feel comfortable…

…befriending a person who has a physical disability?

Very uncomfortable 1 2 3 4 5 6 7 Very comfortable

…going on a date with a person who has a physical disability?

Very uncomfortable 1 2 3 4 5 6 7 Very comfortable

…being in a relationship with a person who has a physical disability?

Very uncomfortable 1 2 3 4 5 6 7 Very comfortable

…if a person who has a physical disability married into your family?

Very uncomfortable 1 2 3 4 5 6 7 Very comfortable

I would NOT date a person who has a physical disability because…

…I think having to take care of them might be too much work.

Strongly disagree 1 2 3 4 5 6 7 Strongly agree

…I would feel awkward and not know what to say or how to treat them.

Strongly disagree 1 2 3 4 5 6 7 Strongly agree

…I would be afraid they would be sick or ill too often.

Strongly disagree 1 2 3 4 5 6 7 Strongly agree

…I do not think they would be able to satisfy me sexually.

Strongly disagree 1 2 3 4 5 6 7 Strongly agree

…I am just not attracted to people who have physical disabilities.

Strongly disagree 1 2 3 4 5 6 7 Strongly agree

…I think that people who have physical disabilities are not much fun.

Strongly disagree 1 2 3 4 5 6 7 Strongly agree

…I would be afraid of what my friends and family might think or say.

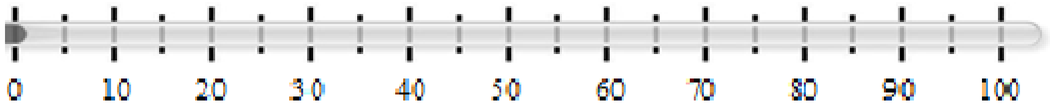
Strongly disagree 1 2 3 4 5 6 7 Strongly agree

…I do not think that they would be capable of being a good parent.

Strongly disagree 1 2 3 4 5 6 7 Strongly agree

Please indicate what % of <u>people with physical disabilities</u> the following statements apply to. You can do this by marking on the line below the number between 0 and 100 that best represents your view.

% of people with physical disabilities that are capable of expressing sexuality.



% of people with physical disabilities for whom expressing sexuality is a basic human need.

% of people who have physical disabilities that should be allowed to have children.

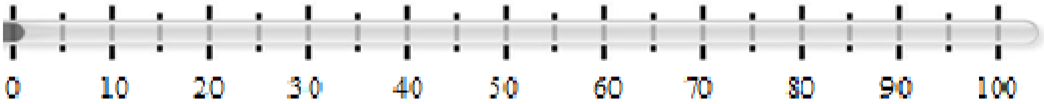
% of people with physical disabilities who benefit from sexual health care services (e.g., HIV testing) in your area.

% of people with physical disabilities who benefit from reproductive health care services (e.g., pregnancy screening) in your area.

% of people who benefit from sexual education services (e.g., classes providing information about HIV) in your area.

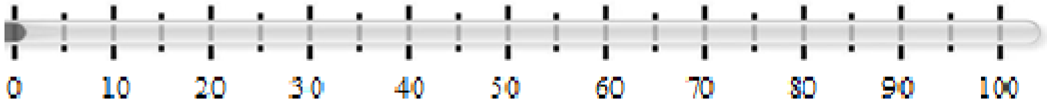
Please indicate below what % of <u>the general population</u> the following statements apply to. You can do this by marking on the line below the number between 0 and 100 that best represents your view.

% of the general population that is capable of expressing sexuality.



% of the general population for whom expressing sexuality is a basic human need.

% of the general population that should be allowed to have children.



% of the general population who benefit from sexual health care services (e.g., HIV testing) in your area.

% of the general population who benefit from reproductive health care services (e.g., pregnancy screening) in your area.

% of the general population who benefit from sexual education services (e.g., classes about HIV prevention) in your area.

Please indicate what % of <u>people with physical disabilities</u> the following statements apply to. You can do this by marking on the line below the number between 0 and 100 that best represents your view.

% of people with physical disabilities who identify as asexual.

% of people with physical disabilities who identify as bisexual.

% of people with physical disabilities who identify as gay or lesbian.

% of people with physical disabilities who identify as heterosexual.

Please indicate what % of <u>the general population</u> the following statements apply to. You can do this by marking on the line below the number between 0 and 100 that best represents your view.

% of the general population who identify as asexual.

% of the general population who identify as bisexual.

% of the general population who identify as gay or lesbian.

% of the general population who identify as heterosexual.

Please use the box below to write any additional thoughts you might have.

This is the end of the survey. Please call the researcher.

Appendix D: Interview Schedule

- Explain purpose of interview and what it would involve
- Participants will have been asked to select 5 photographs that they have taken to discuss
- Revisit consent
- Thanks for participation

1. Initial exploratory questions
    a. Occupation
    b. Disability
    c. Relationships
2. You were asked to take photographs over the past 3 months – what was that like? What did you learn in taking these photographs?
3. Choose a photograph that you took that you want to talk about. Tell me about this – what is this photograph about? What does it remind you of about yourself?

    [*Explore narrative in relation to sexuality, sexual and reproductive health as appropriate*]
4. Continue with other photographs
5. If not specifically discussed in relation to photographs, then include the following specific questions:
6. What feelings do you have about yourself as a sexual person?
7. What sorts of things or people influence your feeling in this way?
8. Have you had any sexual relationships? If so, what has your experience been like? If not, what are the reasons why not?

    [*ask probing questions about possible stigma or barriers to full intimacy, etc*]
9. What have your experiences been of using sexual and/or reproductive health care services?

    [*ask probing questions about access, staff attitudes, etc*]
10. What have been the most important relationships for you?
11. Anything more that you wish to add?