

Sexuality erased, questioned, and explored: The experiences of South Africans with physical disabilities.

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ABSTRACT

The sexuality of people with disabilities has historically been a site of oppression and discrimination. The sexuality of people with disabilities remains relatively under-researched and poorly understood. As a result, many myths and misconceptions about the sexuality of people with disabilities may prevail. This paper reports on findings from a qualitative study exploring the experiences of 13 people with physical disabilities in South Africa. A thematic analysis was conducted to explore how the sexuality of participants are constructed by others, as revealed by reported interactions with non-disabled people. Results show that often the sexuality of people with disabilities is erased by others, or they are questioned, often in prejudiced ways, and less frequently they are explored in intimate relationships.

INTRODUCTION

Sex and sexuality are more than just biological matters; our understanding of sex and sexuality and what they mean are socially constructed (Weeks, 2010). The sexual lives of people with disabilities have, for many years, been a site of oppression and stigmatization (Shakespeare, 2000), and have even been regarded as dangerous. Disability has commonly been understood to be hereditary, and so reproduction amongst people with disabilities has historically been seen as undesirable, or people with disabilities understood to be unfit parents. Sexuality and reproduction has, in the past, been controlled by means of involuntary sterilization programmes (Sheldon, 2014). Though there are issues about disability and sexuality in general, the current article focusses more narrowly on issues of sexuality for people with physical disability.

There is a growing emphasis on recognising the sexual and reproductive health of people with disabilities in global public health (WHO, 2011). Sexual health is understood in broad terms to mean not just the absence of sexually transmitted disease or the presence of problems with reproduction, but to include personal and interpersonal sexual wellbeing (WHO, 2006). Research on physical disability and sexuality has, for the most part, tended to focus on sexual dysfunction, with other aspects of the sexual lives of people with disabilities more broadly remaining an under-researched area (Carew et al., 2016).

In the context of South Africa, where the research reported on in this paper was based, few published studies have focussed on the sexuality of people with physical disabilities. The few studies which do exist have indicated that young people with

physical disabilities receive limited education and care on matters of sexual and reproductive health (e.g. Eide et al., 2011; Wazakili et al., 2009). As a result, people with physical disabilities in South Africa may have inadequate levels of knowledge, acquired skills, and sense of agency to engage in safe sex practices and healthy sexual relationships (Rohleder et al., 2012; Wazikili et al., 2006). Furthermore, sexual violence and exploitation, particularly for women with disabilities, is a significant issue (Groce & Trasi, 2004; Hanass-Hancock, 2009; Kvam & Braathen, 2008).

For people with physical disabilities, many myths and misconceptions about their sexuality and sexual lives prevail. A prominent misconception is that people with physical disabilities are nonsexual or have reduced interest in, and capacity for, sex and sexual relationships (Esmail, Darry, Walter, & Knupp, 2010; Milligan & Neufeldt, 2001). In addition to constructions about the sexual capacity of people with physical disabilities, they may also be viewed by non-disabled people as sexually undesirable or unsuitable relationship partners, because they may be regarded as being too frequently sick and needing care, as too dependent, and as awkward to interact with (Marini, Chan, Feist & Flores-Torres, 2011; Marini, Wang, Etzbach & Del Castillo, 2012). Thus, when it comes to sex and sexuality, people with physical disabilities are positioned as 'other'.

Simon and Gagnon's (2007) theory of sexual scripts emphasises how interpersonal and socio-cultural scenarios and interactions shape a person's sexual meaning and sexual lives. Social constructions of disability and sexuality may become internalised whereby people with physical disabilities may feel sexually excluded and sexually

othered, and may experience low sexual self-esteem (McCabe & Taleporos, 2003). While sexual script theory does not provide a complete account of individual sexuality and sexual sense of self (Sakaluk et al., 2014), it nevertheless provides a useful framework for considering how sexuality and sexual sense of self is also a social process. The social model of disability (Oliver, 1990) emphasises the disabling role that the social environment has on persons with impairments, by creating barriers to participation. Sexual scripts as ascribed to people with disabilities can similarly highlight the process of disablement that occurs with regards to the sexuality and sexual health of people with disabilities, through assumptions that prejudice and exclusion by non-disabled peoples, and may become incorporated into a sense of self.

This article draws on data from a research project exploring attitudes and lived experience of sexuality among people with physical disabilities in South Africa. As part of the project, a survey of the perceptions of non-disabled respondents toward the sexuality of people with physical disabilities indicated generally negative attitudes, with people with physical disabilities regarded as having less sexual and reproductive health needs and rights and seen as less desirable and suitable as sexual partners (** et al., 2017; ** et al., 2018[*citations not named for review purposes*]). With this background, in this paper we explore qualitative accounts of people with physical disabilities themselves as to the sorts of interactions and responses from others regarding their sexuality. This informs the possible constructions about their sexuality that people with physical disabilities may receive in everyday life; how their sexuality is perceived and responded to by others.

METHODS

This article reports on the analysis of qualitative interview data from 13 participants with physical disabilities. Participants were recruited through an email advertisement about the study disseminated by a southern African disability organisation to its networks. . Participants were also recruited through snowball sampling. Participants included 7 men and 6 women, from different ethnic and social backgrounds¹, different ages and with congenital or acquired physical disabilities (see Table 1). All had visible physical disabilities; all but two participants made use of a wheelchair. Participants all identified as heterosexual, and so their experiences represent primarily a heteronormative one. None of the participants identified as asexual.

INSERT TABLE 1 HERE

Participants took part in individual interviews, which used photovoice (Wang & Burris, 1997) as a technique for eliciting personal stories and narratives, around which the interview progressed. Photovoice is a participatory research method, where participants are trained as co-researchers and photographers, and invited to take photographs of things that represent or are symbolic of their experiences and then talk about their experiences as represented by the photographs. Participants were each given digital cameras and invited to take photographs of things that represented their sexuality and relationship experiences. Participants were invited to use other media (e.g. drawing) if they so wished. The interview was focused on narratives associated with the photographs related to experiences of sexuality and

¹ In South Africa, the population continues to be identified according to categories of race, created during Apartheid. Although we acknowledge that 'race' is a construction and is contested, we use racial categories here as they are typically used in South Africa, and provide a broad indication of social differences and inequalities.

relationships. Photovoice was used as a participatory research method to facilitate participants being able to set their own agenda for the interviews and helped provide a sense of ownership over the stories to be told. In this paper we do not present the photographs as data, focusing rather on the interview transcript data. A selection of photographs and accompanying narratives are available to view on a project website (*link to website removed for review purposes*). Each interview ran for between 1 and 2 hours and took place at participants homes or place of work. Interviews were undertaken by authors 1, 2 and 3, with participants invited to give their preference to be interviewed by a male or female researcher. All participants gave informed consent to take part and for their photographs to be used for research and dissemination purposes. Pseudonyms have been used to ensure anonymity². Ethical approval for the project was gained from the lead institutions in the United Kingdom and South Africa.

Transcripts of the interviews were analysed using thematic analysis (Braun and Clarke, 2006), with the aid of NVivo software. Our thematic analysis was conducted from a critical realist epistemology, recognising that sexuality is social constructed, but determined by experience of disability and associated social oppression. Thematic analysis was utilized in order to identify common themes across the data set, providing an overview of the experiences of the participants as a group. Initial coding and identification of themes was conducted by authors 1 and 3, and then checked, discussed and refined as a research team. In identifying themes for this article we were concerned primarily with different ways in which the sexuality of

² On the project website, some participants specifically wished for their own names to be used. In this paper we have chosen pseudonyms for all participants

participants were constructed by others. Findings regarding the sexual lives and difficulties experienced by participants are reported on elsewhere, including presentation of some of the photographs (*** et al., 2018). We focus here on how participants' sexuality are constructed and responded to by others, revealed by social interactions with others as reported on by the participants.

RESULTS

Results of the analysis are presented in three broad themes: Sexuality erased (being perceived by others as nonsexual); sexuality being questioned by others; and sexuality explored in relationships.

“You put us in the desert” – sexuality erased

All participants spoke about how others often tend to assume that they, as people with physical disabilities are nonsexual. In many cases these assumptions seem to be expressed as a certainty, with others acting in ways that erase any suggestion of sexuality within the individual with disability. For those growing up with a disability, this assumption was prevalent within the family where it was assumed that the child with disability would not have sexual relationships, marry, or have children as an adult. For example, Nedah and Mary both refer to these messages they received while growing up:

“For the family it’s like, I’ll never get married [...] for them it was just a friend. No idea about the wishes or dreams of this young woman to one day get married, because it’s impossible.” (Nedah)

“because I was in a very conservative environment as a child...I wouldn’t say super-protected...I mean, my brothers made sure I experienced most things, except sexuality. So we had a lot of fun and adventure. But it just wasn’t for me. People would talk about...they would address...I’ve got two brothers and no sisters...and they would address...you know, it would be, your children one day, and then when they spoke to me it would be about my career one day. So there was that difference.” (Mary)

Both Nedah and Mary describe family interactions and discussions where their sexuality is not even questioned or explored; they are assumed never to be married or be in a sexual relationship. They were both born with a disability, so this may be the family members’ wish to protect the child from what they perceive to be future rejection. As Mary notes, different questions are asked of her, whereas she hears the sexuality of her brothers being affirmed. From what Mary says, her family were seemingly positive about her disability and supportive of her career (though she does not report on whether they held stereotypes about the type of work she could do), yet marriage and sex seemed like a frontier too far.

Mary also spoke about being constructed as nonsexual and sexually undesirable by others as a young adult. She recalled her observation at being treated different when she was involved as a co-leader in a church youth camp. She went on to say:

“I was very active and very in with them. And yet, the church allowed the youth pastor, who was unmarried, and me as the only youth leaders on the camp, whereas all the other girls, if they went alone with him they were not

allowed to go alone. There had to be more than one girl or more adults and so on. But it was okay for [him] and myself to be the only adults leading a camp, because of this - that nothing can happen and nothing will happen. And I must say, I struggle with that still, looking back, I struggle with...and would like an opportunity one day to just...and I'm probably still too angry about that...but just that assumption, because Mary is okay, she can go alone. But if any of the other girl leaders go, then it has to be more of them!"

(Mary)

Here Mary points to how she is constructed as nonsexual and thus there being no need to be concerned about potential sexual inappropriateness. Nothing is explicitly stated, but the difference in how other, non-disabled females are treated gave her an implicit message as to her perceived nonsexuality.

The male participants too spoke about being perceived as nonsexual by family and others:

"people don't expect me to be in a relationship or be able to do anything because I'm in a wheelchair." (John)

"When I told my mum for the first time that I had a girlfriend, she asked me, 'what do you want to do with a girlfriend?'. And if I had to tell her all the things that I want to do with my girlfriend!" (Tazz)

Tazz's mother's dismissal of his sexuality is evident in his humorous retort about the (presumably sexual) "things" he would want "to do" with his girlfriend.

However, there may be some gendered differences on how the sexuality of women and men with physical disabilities is constructed. For the women, like Nedah and Mary, the constructions of their sexuality seem to revolve primarily around their being undesirable and nonsexual in the eyes of others – they will never be a sexual partner for someone, and they will never be mothers and wives. In contrast, for men, the construction of nonsexuality seemed to revolve primarily around performance, specifically the assumption of impotence; assumptions around the *doing* of sex. Siphon explained it in terms of being perceived as having a "waist problem":

"with the help of medicine I can be sexually active; with the help of medicine I can get babies. But other people, because they don't know, but only because they don't know, they think that, 'ah, he can't have sex'. That's the first question in our society, they don't know what happens to a person who is using a wheelchair. They'll just assume that you have a waist problem and you can't be sexually active." (Siphon)

Impotence may be a difficulty, as Siphon suggests in his reference to needing to use medication (possibly referring to Viagra), but what is most important here is the sense of being written off as not being able to have sex, without question. Similarly, Edward talks about the assumptions, and mocking, he receives from women:

“Most of the ladies like to tease me and they say, ‘come, I want to marry you’. And then they say, ‘if I marry you, how are you going to satisfy me sex-wise?’. I said, ‘that’s the problem with you people, when you look at people with spinal cord injuries, physically-challenged people, you still have that mindset of saying that they can’t have sex, they can’t do this or they can’t do that. That is your big mistake. We can have sex. We can live a normal life like everyone. So that thing must come out of your mind.’” (Edward)

What the male participants, like Edward, Siphon and Tazz allude to above is the heteronormative assumption of sex as equating to penis-vagina intercourse; where the men with disabilities are constructed by others as nonsexual; not being able to perform, as they have a “waist problem”. Edward also talked about how he is assumed to be nonsexual and undesirable to women, by his male non-disabled peers:

“You know, when talking to the guys, honestly, we talk nonsense. We as guys, we talk nonsense because we are open. We talk. And then the jokes...we joke about something first. I remember there was a day when we were sitting outside. We’ve got a bar, so we were sitting outside our bar here. And then a lot of ladies came there and we were looking, wow, and then we started saying that this place is going to grow now that there are ladies there. We were just talking. And then I was looking and I said, ‘hey, girls’. They [his peers] said to me, ‘hey, don’t even look, you can’t do anything, man. Don’t waste these ladies’. I said, ‘guys, don’t make that mistake of judging. Don’t

judge me because of my situation'. They said, 'no, man, don't waste their time, let us try our luck here'." (Edward)

It is interesting that Edward here talks of his experience in the form of dialogue, emphasising the ways in which he is actively socially constructed as nonsexual and undesirable by others. He presents his counter-argument, attempting to resist and challenge these assumptions, but in these accounts, they seem futile, with the male friends merely repeating "don't waste their time". Later in his interview he reflects on this exclusion, as he describes being 'put in the desert':

"You are talking negative about us. But people who've got certain sicknesses, they have a normal sexual life, and you still have people who are not even sick and they can't have sex. But now you're creating a certain group for us, then you guys have your normal life, and then we're living in this place...in this desert. You know, you put us in the desert"

This social othering is made more salient in his grouping "us", with "you" (which includes the interviewer, a nondisabled man).

"Do you still have sex?" - Sexuality questioned

While many of the constructions from others create an erasure of their sexuality, other nondisabled people express curiosity about the sexual lives of physically disabled people. Again, the assumption is one of impotence and nonsexuality, but there is some recognition of the person as sexual, and so they are asked about it. It

was the male participants that gave an indication of this, where again their sexuality is thought about in terms of functionality and performance:

“most of the people I speak of, they always have got this question in their mind: ‘do you still have sex?’ So it usually comes up in their conversation. I usually tell people everything they need to know about it.” (Tazz)

“There has been, even today still, why him or why her? What is the pleasure that you get from each other? But, what is the solution and, if there is any pleasure, how do you do it and what is it like to be in that situation? yes, I get those type of questions.” (Fazil)

Another male participant, Sipho, who has a girlfriend, commented on how others ask him about the girlfriend’s faithfulness to him, because they assume that he is unable to satisfy her sexually:

“when we go out here, if you can ask them to comment, you will hear for yourself. They are staring. You will see them, if we are walking in the mall, people stare. And you will see flashlights, and you don’t want to look around to see who is taking pictures or what. I don’t know what do they think. I don’t know what is going on in their minds. But people comment. They say to me, ‘are you sure about her? Is she not cheating?’ Because they believe that I can’t be sexually active. They don’t know. They ask you. Now because of that assumption they have that question, ‘is she not cheating? Is she satisfied with her sexual life?’ And some even say, ‘hey, you must be struggling when

it comes to a sexual life. You must have struggled to get such a faithful person in your life'. Those are the comments that are coming out, more especially from friends, people who can talk to me about that." (Sipho)

Only some of the male participants spoke about being asked about whether they were able to have sex or not. One male participant and his wife were asked as a couple, in public, by a stranger:

"when she was pregnant. The one person to get up at [a shop] asked, 'how do you guys have sex?' Completely inappropriate! [...] and I've got two options and I could say: 'well, don't be so rude, piss off and die'. Or: 'I swing from the chandeliers'! (John)

Two participants spoke about others wanting to test whether they were sexual or not. One other person portrayed their ability to have sex as a matter to be tested and found out. It was not so much that others were asking whether they still had sex, but more that they were curious about whether they were still able to be sexuality active. One male participant spoke about being approached by a woman unknown to him, while on holiday:

"We were sitting at the Eiffel Tower, me and a friend of mine from South Africa. There were two girls opposite and they were really good-looking women. We were having a few beers, and the one woman kept on looking at me. And eventually I looked over and said to her, 'why are you looking at me the whole time?' She smiled. And I said, 'is something going on in your

head? Why are you smiling at me?' She said, 'No, I want to know something'. I said to her, 'what do you want to know?' She said, 'someone told me that guys in wheelchairs are excellent lovers'. And I said to her, 'well, I suppose you're going to have to find out'. And she did!" (Timothy)

For Timothy, this seems to have been a positive experience; the interaction is portrayed as a kind of flirtation, and his remark at the end ("and she did!") has a sense of proud virility to it. For women, on the other hand, this sort of questioning may have some more sinister implications. Pride spoke about this, in the context of being used and hurt by men:

"along the way some of the guys would just say, no, I'm not interested in this one, I just want to test if she is sexually active or if she can do that." (Pride)

In all these accounts, others are represented as bringing the sexuality of the person with disability into question – can they have sex or not, and how? The sorts of accounts spoken of here seem to include everyday interactions with strangers where they may face prejudiced attitudes and assumptions about their sexuality.

"it's all those touching points": Sexuality explored

The majority of participants spoke of a journey they had gone through from at first feeling nonsexual themselves or feeling like sex was not a prospect for them, to exploring their sexuality and sexual mutuality with another. A typical comment about the initial experiences would be:

“I just knew that I was not going to be sexually active. I thought I wouldn’t be able to wear trousers, let alone the shoes or washing myself. So the very basic things, I thought I was not going to be able to do them. So a sexual life was the last thing to think about.” (Sipho)

One female participant spoke of only having had negative experiences with men, where she has felt used, and so is hesitant to have sexual relationships. One young man had not had a sexual relationship by the time of the interview, but expressed concern about whether it would be a prospect for him or not:

“I might for instance be eager to explore and find out more what sex has to offer. So just my own thoughts about how it makes me feel, or how it can unleash any form of potential or to explore further possibilities with my partner. Unless that partner is almost on a similar page as me, I’m not going to be able to fully capture that.” (Bubele)

One female participant spoke of how at first (after having acquired a disability) sex was not enjoyable for her, because she had no feeling:

“I remember one day...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. It was something like that. 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! And as much as I wanted to enjoy...because it was just sex then, it wasn’t,

well, let's try something new, you're different. It was just sex, which was...because we didn't even know, and because I was also very...I would say much more disabled than I am now. So sex was terrible." (Kate)

Kate's reference to being a "piece of meat" is a powerful metaphor here. Kate is referring to having a lack of feeling and sensation; "a dead piece of body". But it also evokes the positioning of many women as sexual objects. This is reflected in the themes above where women with disabilities are no longer sexual objects; their sexuality erased by others, or are sexual objects whose sexuality is to be tested.

The participants who spoke of having experienced enjoyable sexual relationships as people with disabilities, spoke about it as a process of exploration. One process was talking with the partner about sex, what to try and how to make it work, in a manner that is enjoyable for both. For example, Siphon commented on how him and his partner would discuss practicalities:

"It was difficult because I wouldn't know that now my penis is inside her. So I told her that I needed a very patient person and a person who will understand that I can't feel. So she must let me know – she must help me to be sexually active. So it was not that difficult for her because she kept on telling me, no, it's okay, we'll do this, and we've done it. Ja, for me, it was not easy, but she made it to be not that difficult. Yes, she didn't worry much about positions and stuff, she's satisfied with the normal sexual life." (Siphon)

Kate spoke about it as a process of learning for both herself and her male sexual partner at the time:

“Well, because I felt so very comfortable with [name], and right from the start I felt completely comfortable with him. I think that, number 1, that is a big bonus in any relationship and for me that was a big plus to it. So physically he would learn. I mean, we kind of explored because it was new to me and it was new to him as well. So 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...and not very much, but a little bit...to be able to explore.”

(Kate)

For Kate, the exploration of sexuality, particularly for those having to renegotiate their sexuality after having acquired a disability, involved exploring new erotic sensations, and exploring new ways of having mutual pleasure. For example, Fazil, a male with an acquired disability

“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, but then my partner fulfils my needs in a different tactic or a different sensitive part of my body, for example, from the neck down, etc, etc.” (Fazil)

Similarly Timothy said:

“And also, to be sensitive to what you feel. I’ve had one or two girls that really understood me, that would say, ‘okay, Timothy, what do you enjoy?’ And 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!” (Timothy)

Mary, who was born with a disability also referred to a process of sexual exploration with a partner, and the importance of the connection between them:

“I sometimes even thought parts of me are beautiful, and that it actually doesn’t matter, the physical looks and so on, but what someone else feels or what one feels is the most important. And also, that it isn’t just about the physical, but it’s all those touching points. You know, because we were friends on so many different levels, that the sexual or physical was just usually a culmination. I mean, basically we had a series of honeymoons as I imagined it” (Mary)

Discussion

The results of our analysis presented in this paper outline three broad constructions about the sexuality of people with disabilities: that of being nonsexual, their ability to be sexual being questioned, and their sexuality acknowledged and mutuality explored. An underlying assumption in this construction is of sex as equating to penis-vaginal intercourse, where the ‘ability’ to have sex in these terms (“can you still have sex”?) is questioned and assumed impossible. The construction of nonsexuality is reported on as being primarily the view of other, non-disabled people, including

family members and friends. This has broad, and even dangerous implications. As one participant suggests, there is an assumption by others that disabled women are not at risk of being victims of sexual inappropriateness. Yet, other research shows that they are (Astbury & Walji, 2014; Chirawu, Hanass-Hancock, Aderemi, de Reus, & Henken, 2014). As such, and as suggested in other research, disabled women are more likely to be victims precisely because they are not educated to be aware of the dangers of sexual assault, and their claims of violation are not taken seriously when they do report them (Astbury & Walji, 2014).

If read in terms of Simon and Gagnon's (2007) influential theory, nonsexuality is generally not a script that our participants subscribed to themselves. The participants saw themselves as sexual beings, and the idea of asexuality that was imposed on them felt alien and excluding. This mirrors findings from past qualitative inquiry into the sexual lives of people with physical disabilities in the Global North (Guldin, 2000; Ostrander, 2009), suggesting that some of these experiences translate across contexts and cultures, and thus bearing some universal characteristics.

The participants often had their 'ability' to be sexual questioned by others, sometimes by strangers. While some of the participants spoke of certain inabilities or difficulties which they experience sexually, the idea that people with physical disabilities are completely unable to be sexual was not perceived as true for any of them. Some participants who had acquired a disability feared that they would be unable to be sexual in the future. As previously nondisabled people, this was a script which they held, and which they had needed to renegotiate for themselves. They had to do this in the context of nondisabled others making these assumptions about

them. Where their sexuality was acknowledged by nondisabled others it was typically spoken about in the context of mutual exploration with a partner. Here, participants also spoke of some embodied difficulties or inabilities and their own exploration of feeling erotic and being sexual in new, different ways. Once again, past research has documented the need to transition for people with acquired disabilities and their partners, to new conceptions of intimacy and sexual activity following one partner's injury (Esmail, Esmail & Munro, 2001; Loaring, Larkin, Shaw & Flowers, 2015). The role of the body and possible physical limitations (as described by some of the participants like Kate, Fazil and Timothy) highlights the importance of considering disability not solely as a social construction, as in the social model of disability. Critics of the social model argue that disability is also an embodied experience, and the biopsychosocial model, understanding disability as an interaction between impairments and social exclusion, is a helpful approach to take (Shakespeare, 2017).

There are limitations to this study that need to be considered. The conclusions drawn here are drawn from work with a small, self-selected, heterosexual sample, and referred to interactions as reported on by the participants, rather than an investigation of actual interactions. Furthermore, the data refers to the participants' perceptions as to how they are perceived by others. Other work from within this project explored the constructions held by non-disabled people themselves, and found that nondisabled people did perceive people with physical disabilities to be less sexual than people without disabilities, were disinclined to date people with physical disabilities, and help problematic stereotypes about the sexuality of people with physical disabilities (** et al., 2017; ** et al., 2018). Thus what the participants

report on as common sorts of interactions, reflect what has been found in research looking at non-disabled people's constructions of the sexuality of persons with disabilities. What comes across clearly in the data presented in this article is how the messages and responses from others are powerfully exclusionary and rest on misconceptions and assumptions. The sexuality of people with disabilities may be ignored and questioned in a public, often prejudiced and inappropriate manner. It is often only in private or in the context of an intimate relationships that our participants could explore and acknowledge their own sexuality and have it acknowledged by others. But for many persons with disabilities, they are excluded from the possibility of relationships, where they may explore mutuality and sexuality.

Weeks (1998), in writing about sexual minority identities (gay, lesbian and bisexual), developed the concept of the 'sexual citizen', where 'citizenship' is the process of claiming inclusion and belonging by bringing the private life (sexuality) into public life, as a political issue. In the context of disability advocacy, Shakespeare (2000) extends this notion of 'sexual citizenship' to people with disability, demanding control, access and choice with regards to matters of body, relationships, feelings, sexuality, representation, and public spaces. In order to challenge exclusionary social constructions of disability and sexuality, the private needs to be brought into public.

Further efforts at advocacy around the sexual rights and agency of disabled people need to be made. However, it is clear, as has been noted before (Author et al., 2017), that what is at stake is a politics of intimacy and desire (p. 12), and not only awareness. Further efforts need to be made by scholars and activists to understand

how to improve not only awareness of the sexuality of disabled people, but also equitable relating between nondisabled and disabled people.

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Name	Gender	Age	Race	Disability Description	Relationship
Fazil	M	25	Coloured	Acquired in adolescence – paraplegic	married
Bubele	M	Not provided	Black	Acquired in childhood – paraplegic	single
Kate	F	45	Coloured	Acquired in adulthood – paraplegic	divorced
Nedah	F	50	Coloured	Cerebral Palsy	Married
Timothy	M	50	White	Acquired in adulthood – paraplegic	Single
Mary	F	56	White	Congenital	single
Sipho	M	28	Black	Acquired in adulthood – paraplegic	engaged
Edward	M	Not provided	Black	Acquired in adulthood – paraplegic	separated

Thembeke	F	48	Black	Acquired in adulthood – paraplegic	single
Pride	F	42	Black	Acquired in Childhood – semi-paraplegic	single
Rachel	F	60	Coloured	Acquired in childhood – paraplegic	divorced
Tazz	M	32	Coloured	Acquired in adulthood - quadriplegic	single
John	M	47	White	Acquired in adulthood - quadriplegic	married