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ORIGINAL PAPER

An Exploration into People with Disabilities' Access to Sex, Sexuality, and Sex Education in South Africa

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Abstract

Introduction The needs of people living with disabilities regarding sex and sexual health remain largely neglected. Knowledge and resources about disabled sexuality have emerged mainly from the global north and have centered on heteronormative ideas about sex, gender, and sexuality.

Methods An affirmative, sex positive, queer, and intersectional exploration was undertaken of the experiences and needs a group of adults with disabilities living in Gauteng, South Africa in relation to accessing information about sex, sexuality, and sexual health. Interviews were conducted with people of diverse disabilities, language groups, and cultural backgrounds. Interviews were analyzed using thematic analysis.

Results The participants revealed that sexual encounters, relationships, and dating were infused with negative experiences related to lack of understanding about sex, internalized ableism, exploitation, and physical, sexual, and emotional abuse resulting from societal stigma and ignorance regarding disability. Participants offered suggestions for how their needs could be addressed.

Conclusion Our study concludes that the denial of sexual rights is a central element of the broader forms of social exclusion that people with disabilities. In South Africa, many of these forms of exclusion have been compounded by the legacy of apartheid, and the persistence of racial inequality, taboos about sex, and stigmas associated with disability.

Keywords Disability · Sex · Sexuality · Sexual health · Sexual education · South Africa

Introduction

The sex and sexual health needs of people living with disabilities remain largely neglected, not only in South Africa, but globally. Knowledge and resources that do exist about 'disabled sexuality' have emerged mainly from contexts in the global north, and have also

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centered around heteronormative ideas about sex, gender, and sexuality. We employ the term ‘disabled sexuality’ following the work of Paul Chappell [1]. In his use of the term ‘disabled sexuality’, Chappell referred to the sexual *identities* and sexual *experiences* of people with disabilities as well as to sexuality, sexual expression, and desirability more broadly in the context of disability (p. 112). In addition, Chappell noted that within ableist societies, it is widely assumed that people with disabilities are either asexual or hypersexual, with the subjugation of disabled sexuality being embedded within broader social relations, institutions, and sectors. This notion is compounded by the fact that the dominant notions of disabled sexuality have been framed by the medical paradigm that constructs people with disabilities as victims of their impairment [2].

According to Chappell [3], medicalized narratives of disabled sexuality that focus on (dys)functional reproductive organs, “has not only drawn attention away from the sexual agency of people with disabilities, but also from the socio-cultural meanings of disability and desirability” (p. 113). These narratives have also been deeply heteronormative, which further deny that people with disabilities have sexual desire, and that these forms of desire are diverse. Such medicalized, heteronormative notions of disabled sexuality have also contributed to the pathologizing of many lesbian, gay, bisexual, transgender, and intersex individuals as ‘mad or ‘insane’ within western scientific paradigms [3]. It is from this perspective that we approach the topic of ‘disabled sexuality’ to challenge prevailing ideas and assumptions that contribute to the denial of human dignity, and rights for people with disabilities.

In this article, we share findings that emerged from research that we undertook to attend to the gaps in knowledge and advocacy regarding the experiences of people with disabilities’ access to sex, sexual health services, and sex education. As we discuss later in this article, addressing the sexual rights of people with disabilities requires an acknowledgement that sexual and gender identity, as well as the opportunity to engage in sexual relationships, is fraught with forms of social exclusion, and sexual violence [4]. The need for comprehensive sex education, regardless of (dis)ability, emerges as an intervention needed to contribute towards the creation of an inclusive and non-violent society for all.

In addressing the concerns described above, we have been guided by the affirmative, sex positive, and queer approach to sexuality articulated by Paul Chappell [3] who, prior to his passing, was the coordinator of this project. He proposed that queer theory can challenge and extend current debates surrounding disabled sexual identities in South Africa, and that disabled sexualities have the potential to queer dominant constructs of sexuality. The information that currently exists about disabled sexuality is largely focused on the reproductive as well as solutions to erectile dysfunction and centers around penetrative and heterosexual sexual desires and experiences [5]. Normative notions of what constitutes sexual pleasure and how to achieve it have disabled socio-sexual imaginaries—who and what is considered desirable have been dominated by ableist, heterosexual and male-centered constructions of sexuality, limiting imaginaries of sex, sexuality, and gender [1].

Sex, Sexuality and Disability in South Africa

Our perspective is taken from the context of South Africa within the Global South. South Africa has a history of legalized attempts at regulating sex and sexuality, including, for example, the infamous Immorality Act [6] and its later amendments which prohibited the sexual relations, or more specifically, “carnal intercourse” and “indecent acts” between people of different races (p10). Furthermore, the illegality of such acts was based on legally sanctioned presumptions where, “Any person who seems in appearance obviously to be a white person or a coloured[1] person, as the case may be, shall for the purpose of this Act be deemed to be such unless the contrary is proved” (p12). The act also prohibited sexual relations with persons with mental disability, although the language was cruder at the time and referred to “idiots” and “imbeciles” (p.10). This aforementioned act was the forerunner to the Sexual Offences and Related Matters Act 32 of 2007 [7] which provided for people with disabilities but only seems to refer to persons with mental disability which it defines as “a person affected by any mental disability, including any disorder or disability of the mind, to the extent that he or she, at the time of the alleged commission of the offence in question, was (a) unable to appreciate the nature and reasonably foreseeable consequences of a sexual act; (b) able to appreciate the nature and reasonably foreseeable consequences of such an act, but unable to act in accordance with that appreciation; (c) unable to resist the commission of any such act; or (d) unable to communicate his or her unwillingness to participate in any such act” [7].

Despite South Africa entering a state of democracy in 1994, our country has the unfortunate title of being one of the most unequal countries in the world, and also one of the most violent and dangerous societies for women and sexual minorities to live in, with the country reported to have the highest per capita rate of femicide, intimate partner violence, and rape in the world [8], yet, South Africa has also been praised internationally for having one of the most progressive constitutions in the world—one that enshrines the equal rights of all people with regard to race, gender, sexual orientation, ability, or religion [9]. The struggle to advance social justice in this society has remained a feature of the social and political landscape beyond the nation’s liberation from apartheid and the dawn of democracy. The literature shows that for persons living with a disability, low socioeconomic status, and being a woman increases the chances that one will experience sexual violence [10]. In the South African context, the history of colonialism and apartheid has entrenched racialized inequality, with most of the Black African population residing in communities with inadequate infrastructure, housing, and health care services. For people living with disabilities in these communities, the experiences of disablist oppression are compounded by the persistence of systemic inequality that has severely disadvantaged the black population.

In South Africa, as in most parts of the world, people with disabilities are disproportionately represented amongst the population that is poor and unemployed [11, 12]. While women and girls across the society experience high levels of violence, those with disabilities face even greater risk. For instance, the Human Immuno-Deficiency Virus (HIV) and Acquired Immuno-Deficiency Syndrome (AIDS) prevalence is an issue that disproportionately affects people with disability, who also tend to be the poorest within their communities [13], yet disability continues to be marginalized within HIV and AIDS prevention and awareness campaigns. Lack of information and poor access to health care have been identified as the primary factors that have contributed to increased risk of HIV and AIDS infection amongst the disabled population [14]. Lack of sex education, and social taboos against talking about sex have also been factors that have contributed towards the risk of the population contracting HIV and AIDS and other sexually transmitted infections. Taboos that also exist about disabled sexuality, either that people with disabilities are hypersexual or

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[1] In the South African context, the term ‘Coloured’ was defined by the apartheid government as ‘a person who is not a white person or a native’, and the term continues to be used in the post-apartheid period to refer to groups of mixed-race origin.

non-sexual, deepen the censorship of sex in relation to issues of disability, both from the outside and the inside of the disability community. Addressing the needs of people with disabilities in this context requires an intersectional approach that acknowledges raced, sexed, and gendered forms of oppression. In this political environment, the sexual rights of people with disabilities have been largely ignored beyond limited acknowledgement of the kinds of sexual violence that this part of the population experiences.

Discourse and advocacy that addresses sexual violence has not adequately accounted for the ways in which these forms of violence impact the lives of people with disabilities, especially those who identify as lesbian, gay, bisexual, transexual, intersex, queer, or belong to other gender and sexual identity minority groups (LGBTIQ+) [15]. At the same time, while the link between poverty and disability has been well established in research, less attention has been paid to the ways in which gender, sexuality, and race also mediate the lived experiences of people with disabilities. In a context such as South Africa, the neglect of race is particularly problematic, given the ways in which race has profoundly shaped poverty outcomes for all people, and especially people with disability. As elucidated by Chappell, inattention to these intersections have resulted in a lack of knowledge about the forms of gender discrimination that women, transgender and gender nonconforming people with disabilities experience professionally and personally [3]. There is also limited knowledge about the experiences of discrimination amongst women who are mothers or caregivers to a child with a disability.

Sex and Sexuality Education for People with Disabilities

The need for sex and sexuality education for people with physical, sensory, and intellectual disabilities has been noted consistently throughout international literature. Studies have shown that people with disabilities have fewer opportunities to learn about sexuality than their able-bodied peers, a relatively low level of knowledge about sexuality, and less experience with dating, intimacy, and sexual interaction [16, 17]. As research has shown, the lack of sex education offered to people with disabilities contributes to already existing vulnerabilities to sexual abuse [16], transmission of sexually transmitted infections, and high rates of unplanned pregnancy.

In the absence of adequate sex education in schools that accommodate learners with disabilities, the need to address sexual health, sex, and relationships becomes the responsibility of parents who are often unequipped to deliver this information [18–20]. Here, parental overprotection has been cited as a key barrier that prevents young people with disabilities from accessing information about sex, sexuality, and sexual health. As discussed by Ballan, parental anxieties about their children’s ability to appropriately express their sexual impulses and fears of sexual abuse often results in overprotection, which ultimately deprives children with disabilities of their sexual rights and freedom [21]. To alleviate their fears and anxieties, Ballan argues, “parents may suppress their children’s sexuality, and thus fail to equip them with the knowledge to deal appropriately with the sexual experiences they will encounter” (p. 14) [21].

In South Africa too, people with disabilities lack access to sex education [22–24]. Several scholars have addressed the contextual factors that contribute to the denial of sex education for young people with disabilities. For instance, Rohleder and Swartz report that there is a tension between a human rights discourse and a discourse of restriction of sexual behaviors within sex education for young people with disability [25]. The risk of contracting HIV and AIDS, they argue, contributes to the construction of sex as dangerous, echoing past constructions of disabled sexuality as problematic. Research has also shown the extent to which teachers lack adequate training and resources to enable them to provide sex education to learners with disabilities [25]. Furthermore, this work is made more difficult by the anxieties that issues of sex and sexuality raise, as discussed by Rohleder [22]. While these studies have found that educators recognize the importance of teaching about sexuality as part of the life orientation curriculum, they also reveal some of the barriers experienced by educators in delivering this content. As de Reus et al. report, these barriers are sociocultural (educators mentioned communication and language barriers, differing cultural expectations and values, and teacher's perceptions about sex and sexuality) and systemic (educators expressed a lack of support from parents, departments of education, fellow educators and the community) in nature [24]. Educators who participated in their study indicated that training and adapted tools for teaching learners with disability about HIV and sexuality would address these challenges. Educators also indicated the need for training that would enable them to offer appropriate communication strategies, and the tools to deal with the issue of sexual abuse [22].

Purpose of the Study

As several international scholars have argued, sexual freedom and rights have been largely neglected within disability scholarship and activism, particularly in the Global South. In the exploration of the matters relating to sexual freedom, rights, and practices of people with disabilities, it is necessary to also recognize the context in which these are lived to acknowledge the rights and voices of people with disabilities in policies and research.

South Africa's diverse population, our history of legalized oppression and the regulation of sex and sexuality, and our limited understanding of the ways in which intersections of race, class, gender, and sexual orientation shape the experiences of people with disabilities. As a research team, we recognized the need to explore the sexual needs and experiences of adults with disabilities in an urban setting, to strengthen our understanding of the experiences of people with disabilities regarding access to information, sex and reproductive health, as well as to obtain their perspectives on the ways in which sex-education and access to information can be improved. In so doing, we seek to contribute to existing knowledge about the needs and experiences of people with disabilities and to contribute to access and advocacy in these areas.

Method

The findings reported in this article form part of a larger collaborative and interdisciplinary initiative of academics at the University of the Witwatersrand, Johannesburg. The project team comprised fourteen scholars ranging in age from 26 to 58 years. The team included both disabled and non-disabled scholars with backgrounds in disability studies, rehabilitation, sociology, gender and sexuality studies, and critical diversity studies. The team was also diverse in terms of our racial and cultural positionalities, nationalities, gender identities, and sexual orientations. Our diverse backgrounds and areas of expertise were important in our ability to address and understand the multifaceted issues and dynamics that shape disabled sexuality in South Africa. The project team came together to pursue this project after a series of jointly convened events that addressed the topic of sexuality

Table 1 Participant demographics

Gender	Male	n = 12
	Female	n = 11
	Transgender	n = 4
Sexuality	Straight	n = 21
	Gay	n = 4
	Lesbian	n = 1
	Bisexual	n = 1
Race	Black	n = 23
	Coloured	n = 2
	White	n = 1
	Indian	n = 1
Impairment	Physical	n = 9
	Cognitive	n = 6
	Communicative	n = 5 (n = 1 speech and language and n = 4 hearing impaired)
	Multiple (combination of physical, cognitive, and communicative)	n = 7

and disability. Over a period of three years, the team worked together on all stages of the research, from conceptualization and implementation to analysis and dissemination.

Ethics Statement

The conceptualization of the project, data collection, analysis, and dissemination of results were guided by the Declaration of Helsinki [26] as well as by considering local and international recommendations for conducting research with vulnerable populations [e.g., 27, 28]. Only individuals who were able to provide consent for their participation were considered for the study, and consent was obtained for both participation and use of quotations in the write up of findings. Whether or not an individual was able to give consent was determined in the process of contacting potential participants through our existing networks. We invited participants with the permission and assistance of group home managers, protective workshops, social workers, and civil society organizations who assisted in the circulation of our invitation to participate in the study. The invitation was circulated in PDF and Word formatting to accommodate those using assistive reading devices. Ethical clearance was obtained from the non-medical Human Research Ethics Committee (Protocol Number H17/09/38) at the University of the Witwatersrand, Johannesburg.

Participants

A total of 27 participants with various sensory, physical, cognitive and/or communication impairments participated in the study (See Table 1 below). Participants resided in urban, suburban, and peri-urban areas, with some living with their families, and others residing in group homes for people with special needs. The youngest participant in the study was twenty-one years old, and the eldest was fifty-six years of age. All participants were asked to provide demographic details according to how they identified regarding gender, sexuality, race and nature of impairment. Twenty-three participants identified as ‘black’, one identified as ‘white’, two identified as ‘coloured’, and one identified as ‘Indian’. In this project, we have worked with these apartheid era racial categories in a critical manner, recognizing that while racial categories are not biological or fixed realities, race and racialized inequality continue to shape the life opportunities of individuals.

In terms of gender identity, twelve participants identified as ‘male’, eleven identified as ‘female’, and four identified as ‘transgender’. All but six of the participants identified as ‘heterosexual’. Some of our participants were currently married or in relationships, while others had limited experience with dating and being in a romantic or physical relationship. Most participants presented with physical impairments, followed by multiple impairments, cognitive impairments, and sensory impairments.

Methods of Data Collection

A series of semi-structured in-depth interviews were conducted over a period of one year by members of the project committee in English, isiZulu, seSotho, and/or South African Sign Language (SASL). Participants were asked to reflect on their experiences in relation to sex, sexuality, relationships, and sexual health. All participants consented to the audio recording of the interviews. During the process of data collection all participants were asked to select pseudonyms which they felt reflected their identities. These pseudonyms are used in the write up of findings below.

An audio recording device was used for interviews conducted verbally and a video recording device was used to record interviews conducted in SASL. All interviews were transcribed, and interviews conducted in isiZulu, Sesotho and SASL were also translated into English for analysis.

Data Analysis

The process of data analysis involved both inductive and deductive coding as described by Braun and Clarke [29]. The initial process of identifying of first level ‘codes’ or themes that emerged in the data was guided by particular questions that we set out to interrogate in the research, such as ‘where do people with disabilities gain access to information about sex, sexuality, and sexual health’, and ‘what barriers or challenges do people with disability experience when attempting to access sex, sexuality, and sexual health information and services’. Project members worked in small groups, including the researchers who had conducted the interviews to determine the initial codes. These were subsequently presented and interrogated by the full research team, until agreement was reached. Following first level coding, we conducted second level coding to identify unanticipated themes and issues; for instance, the ways in which the experience of disability, and barriers of access to information and resources, shape sexed and gendered subjectivities. The project committee worked together to interpret the themes and the cross-cutting issues that were emerging in the data. This process enabled a constant cross-checking of our interpretations, which were also largely informed by our respective areas of expertise, personal backgrounds, (dis)abilities, and sexual identities.

Data analysis was guided by critical theoretical frameworks, namely critical disability studies, intersectionality theory, and queer theory. While the analysis process aimed to answer the research questions, it also allowed for other unanticipated themes and issues to emerge. While several important themes emerged throughout the process of analysis, for the purpose of this article we will be focusing the findings that emerged in relation to access to information about sex, sexuality, and sexual health, which was the central question guiding the research project. In addition to addressing challenges, this theme also includes ideas that participants had for how the situation could be improved. These two dimensions of the theme of 'access' therefore serve as an example where participants asserted agency, critical thinking, creativity, and practical suggestions that can destigmatize and liberate disabled sexuality in South Africa.

Results

For many of our participants, experiences of having sexual encounters, relationships, and dating were infused with negative experiences related to lack of understanding about sex, internalized ableism, economic exploitation, and physical, sexual, and emotional forms of abuse. In analyzing the experiences of sexual violence and exploitation shared by many participants, it became clear that these forms of interpersonal violence were directly related to systemic forms of exclusion and oppression resulting from stigma and perceptions of disability. Many of the suggestions provided reflect a desire to be included in the realm of desire through positive representations of people with disability people across the society. The experiences shared by participants reflect the extent to which ableist sexual imaginaries shape society, and how these normative ideas contribute to the oppression of people who are not able-bodied in ways that have not been adequately addressed in literature or in activism.

Access to Information About Sex, Sexuality, and Sexual Health

In this section, we will share what emerged regarding the places where participants accessed information about sex, sexuality and sexual health, and the experiences of doing so. In speaking to these experiences, participants also shared their ideas for how access to information, and their experiences of accessing this information, can be improved.

Access to Information Via Family Members and Peers

Overall, participants consistently expressed a need for information about sex, sexuality, relationships, love, family planning, and sexual health. Family, partners, and friends were mentioned by several participants as sources of information about these issues. For example, Bernard stated,

> Well, honestly that would come from my friends that I was growing up with, from the TV and obviously you know life orientation we had at school. We did also delve into that a little bit about what sex is. What precautions one should take when having sex and you know all those types of things. The risks associated and the different types of diseases sexually transmitted diseases as they are now called and basically that was just what I got from the basic curriculum and what I then learnt from my friends. And then obviously as I grew older, I then experimented, and did sexually

> and you know learn things through personal experience and things that I was taught from partners. You just kind of evolve like that.

Tshegofatso indicated that she had not received any form of sex education from her parents or during her time at school, where she said “I learnt about sex while in a relationship. I used to date this guy and it was he who taught me about sexuality and relationships.” Given the increased vulnerability of persons with disabilities to sexual violence, it is worrying to note that people such as Tshegofatso only receive sexual education through the process of being involved in a sexual relationship as this could compromise their abilities to protect and defend themselves should they be threatened.

A few participants stated that family members educated them about sex, but the only information that was shared was being told to abstain from sex to not contract sexually transmitted diseases or fall pregnant. It was also mentioned that family members relied on the church to share information about sex and sexual relationships, however, the information provided in these contexts indicates that these participants received a sex education that stigmatizes sex. As Katlego said, "at church they said we must read the book of Exodus, the Ten Commandments, it says sex before marriage is a sin.”

Access to Information Via the School Curriculum and Publicly Available Information

School, and the ‘Life Orientation’ curriculum were often cited as places where participants had learned about sex, sexuality, and sexual health. These findings are a positive reflection of the reach of the Life Orientation curriculum and the impact that it is making in the lives of young people with disabilities. As Bernard stated that while friends and television were places where they had learned about sex, the curriculum was another important source of information. Life Orientation had provided information about “what precautions one should take when having sex, the risks associated and the different types of diseases, STI as they now are now called.” He further reflected that “Life Orientation was a subject at school where they would teach us about life basically you know and about you know sex and condoms and contraceptives.” From these participants, it appears that the Life Orientation curriculum on sex education has been an important site for learning. Yet, at the same time, their comments indicate that the sex education component of the Life Orientation curriculum only addresses sexual health, neglecting issues such as consent, relationships, and sex.

While some participants felt that they had adequate access to information on sexuality, such as Jean who said “I get a lot of information from your phone, Facebook, you reading magazines and novels, TV and all and even workshops that they sometimes have”, most other participants indicated their need for further education around sex, dating and relationships and a desire for specific information for people with specific needs. For instance, Neo said, “information about sex and relationships should be made available”. Similarly, Lyton commented that he would like to have access to “brochures or handbooks to show how to get a girlfriend or something,” and Mbali added “I need to know what to do when I get aroused, because I don’t have a person who is willing to help me.” Materials that provide specific advice for dating among persons with disabilities, relationships, and sex are scarce, not only in SA, but internationally. These comments indicate that currently, adequate information is not available. This was a consistent sentiment amongst participants, who provided further detail about the kinds of sex education that they wanted to be made available. The types of sex education desired by participants varied, reflecting a spectrum of needs.

Access to Information Via the Media

Many participants mentioned different forms of media as an important gateway to information about sex, relationships, dating, and sexual health. Google, the internet, newspapers, magazines, and social media were the most common sources where participants said they had accessed information about these issues. The cellphone application WhatsApp was also specifically mentioned by Lyton as a potential site for support and sharing, suggesting that "support groups or maybe a support group on WhatsApp or a blog for people with disabilities to share knowledge and experiences" would be helpful places where information could be accessed. However, for those who do not have access to cellphones and the data needed to find information online, other kinds of materials should be available.

Pornography websites also emerged as an important place where some participants had learned about sex and sexuality. As Mpho explained, "I got information on sexuality from pornography. People shouldn't view pornography as a bad thing, instead you learn from it." Elaborating on the taboos that exist about pornography, Mpho went on to explain that it is an important form of erotic education. Similarly, Bernard expressed that although he had a sense of shame about the fact that he had watched pornography, he continued to value and consume it:

> I got information from pornography. I always knew it was wrong to watch pornography growing up, but I did in fact watch it quite often so that I would know.

Offline forms of media such as pamphlets collected at libraries, non-governmental organizations, and clinics were also mentioned by participants as sources of information, indicating that print media is another powerful form of communication for differently-abled people These findings show the importance of media in providing access to information about sex, sexuality, sexual health, and relationships for people whose access to this kind of information is often foreclosed by a society that stigmatizes disabled sexuality. Moreover, the findings motivate for information to be available in languages and modalities that are accessible to people with disabilities. The various forms of media mentioned by participants all create opportunities for people who are often erased within conversations about sex and reproduction to access the desired information. These findings also express a need for the creation of more platforms, offline and online spaces for people with disabilities to have space for sexual expression and to access information.

The need for easily accessible mass media representation that portrays people with disabilities in relationships was also suggested by some participants as a way of making information available. Media and positive representation emerged as a need expressed by several participants. Kamogelo said, "They should include us in the newspapers and make television shows to pass on this information", while Lyton said he would like to see shows on television "showing how young people with disabilities can go out and the places they can hang around and chill". Similarly, Johanna added "Television would be much better because most of them cannot read and write, yes, they might see pictures and everything, but television is much better. It should include sexual information about how and what not to do, they must teach them about condoms and pregnancies, prevention and teach parents how to care and guide disabled children." This seems to talk to the desire to be considered equal while also looking for equality of representation on different platforms so that there is equal sexual rights and erotic justice.

Access to Information Via Healthcare Professionals and Social Workers

Professionals in the support and care sector were mentioned as individuals who are already providing information for people with disabilities about sex, sexual health, and sexuality. One participant who resides in a group home indicated that one of the professionals at the residence offered “groups” where issues of sex and sexual health are addressed. Sipho explained that occupational therapy was a place where he had learned about sex, saying "In rehab they will just tell us the position that can work for us.” Kamogelo added that he had actively sought information from professionals, saying “I went to a lot of specialists trying to figure out information about sexuality”. Additionally, Jack explained,

> The professionals should give the disabled enough condoms so they can use them because they end up with all these sicknesses and pregnancies and enough information for people and sexual information should be in the forefront.

Furthermore, Nomthandazo suggested that social workers were well positioned to support and encourage people with disabilities in general about how to live their fullest lives:

> there should be a place where social workers can be able to talk to people with disabilities in their communities and enlighten them that being disabled doesn’t mean it’s the end of the world and explain the ways in which they can tackle their problems.

These findings provide important indications of spaces and sites that would be ideal for awareness campaigns targeting individuals with special needs and those who provide them with medical, social, or psychological care, and therapy. Moreover, there is the need to address stigma around sexuality and around disability, as well as the confluence of sexuality and disability, especially in a context where, as the participants highlighted, they already experience exclusion.

A Need for Specific Information and Opportunities to Learn About and Engage in Safe Sexual Practices

Several participants requested more explicit information in terms of sexuality, sexual health, pregnancy, and child-rearing practices. This was evident where Mbali said “We have organizations that come and tell us about sex, but they don’t explain it deep enough. They just emphasize on the use of condoms when having an intercourse with a male and about the sickness like HIV”, and where Jean stated, “we need more focus on sexual health, not just about having sex as a disabled person”. Similarly, George said “I know about things like sex and how to make a baby, but I need more information on, like how to care for a child if I have one.”

The overall findings of the project indicated that access to information about sex, sexuality, and sexual health for people with disabilities is uneven across the society and is largely dependent upon one’s social surroundings and community. Furthermore, the prevalence of stigma about sex is compounded by stigma of disability. Moreover, the lack of available information about sex and sexual health creates a vacuum that becomes filled with other forms of information that may be inaccurate and potentially dangerous, as highlighted by Tshegofatso.

Our project had the overall finding that there is a lack of educational material, support, and services to support the healthy sexual development and realization of sexual rights across individuals with different kinds of disability. At the same time, we learned about the ways in which people with disability have attempted to access educational and support services, and our participants' suggestions for how relevant education and support for people with disabilities could be improved. Significantly, participants understood that their (in) ability to be seen as desiring and desirable is intimately linked to the experience of social exclusion, which is a further reflection of the implications of our findings in relation to the ongoing infringements that people with disability experience in relation to accessing sexual rights.

However, for other participants it appeared likely that peers and family members may not be well informed themselves, given widespread social taboos associated with sex, and talking about it, that were entrenched by apartheid, and which remain prevalent across the society. This was evident where another participant, Jack stated,

> To be honest, since I had the stroke, nobody has ever spoken to me about sex. The problem might be that we have not found anyone who has the knowledge to talk about it and maybe because people get shy and ashamed talking about sexuality.

Luthando shared similar sentiments where he said, "in this place there are no boxes of condoms and people do want to get together. They are human with feelings, but here we are not even allowed to practice safe sex."

A few participants mentioned the need for further information addressing issues of safety. Johanna stated "I have a problem with men; they take advantage of women, especially if you are disabled. This is because disabled people cannot say no, they will bribe them for sex. A next-door neighbor will impregnate a disabled person and will deny it when asked with cruel words like 'I can never impregnate a crazy person.' It is very painful." Denise said that she wanted information about "how to be safe and not to be raped". This comment not only alludes to the high risk of rape, but ultimately to its normalization. "Staying safe" in this context, for disabled and non-disabled women alike, refers to learning how to navigate a highly patriarchal society in which the sexual agency and rights of women are denied. While sexual violence and rape occur across the racially, ethnically, and religiously diverse country of South Africa, women in townships are especially at risk because of several factors that coalesce in the legacy of racial inequality left by colonialism and apartheid. While there are no simple lessons to be taught that can keep women safe, information can be provided that can help women to protect themselves and to identify high risk situations. Information about consent is also important in this context, as it is everywhere else.

The context of HIV and AIDS awareness and testing emerged as a site where further information is desired. While some participants indicated that they received information about sex from HIV and AIDS testing sites, this information was not adequately contextualized for people living with disabilities. Kamogelo related:

> We would get tested for HIV and it was not really a problem getting tested, but the problem is why are we getting tested? Who is it that we are sleeping with? They only spoke about HIV and everything else concerning it, but we cannot comment on it because we are not having sex.

While this participant infers that he, and other people with disabilities "are not having sex", what constitutes sex is not elaborated upon. Understanding that HIV transmission can result from non-penetrative sex, oral sex, and the transmission of bodily fluids is an important aspect of HIV and AIDS awareness and education. It is important that people with disabilities are included within HIV and AIDS awareness campaigns and that resources be made available that are accessible for people with a range of sensory, cognitive, and physical abilities.

Some participants indicated a need for information about how to have sex. Kamogelo, who is quoted above, summed this theme up succinctly, saying “There should be a book that educates people and not only parents, on the needs of the disabled. They should bring forward information on how to have sex as a disabled person.” Other participants expressed specific needs in this area. For instance, Sipho said he wanted to learn “how to make my pace last longer”. For people with physical impairments, knowledge about sex positions that they can use is an important piece of this conversation. As Sipho further explained, greater knowledge about “positions that we can use” is important “because we depend on…different techniques of having sex besides penetration.” Related to this, he expressed a need for understanding the functions of male sexual organs, indicating a need to be able to ask, “Sometimes the penis doesn’t want to work, then what can assist you? What causes that?”.

The Need for Connection and Ways to Improve Access to Information

The need for people with disabilities to connect with one another was shared by most of the participants, with Mpho, suggesting “You must organize to be able to meet up with boys and girls to talk to the youth and young ones about sexuality and relationships”. The need for such groups is significant, given the able-bodied normativities that permeate the Life Orientation curriculum on sex education as well as in mainstream media and general information about sexual health.

Creating online resources available on websites and social media platforms were suggested, reflecting the accessibility of the internet for many people with disabilities. Bernard shared a few ideas for virtual spaces that would be helpful:

> I would like there to be an open forum or a website where people like me are actually there to assist those who are unsure or who are seeking information. An open forum that will have even tutorials, videos of people sharing their personal experiences to show people that it is a safe space. Or we could do campaigns and roadshows to share information.

However, in recognition of the challenges that some people might face regarding access to technology Bernard went on to suggest several innovative ways to access people and to determine their needs:

> I can’t imagine everybody in South Africa has access to the internet so that may be a bit of a challenge also with that we would obviously then need to you know arrange perhaps… do surveys… find out who does and who doesn’t, in which areas mainly and I mean we can go out in a day, once a month you know to share this information with people and do campaigns and shows and roadshows you know.

The suggestion of in-person interaction was also supported by Jack who stated,

> A workshop is far better because people want something they can see and something that will teach them because some of us are uneducated another thing that would be helpful is the right usage of language, they should hold these workshops in the language of the people. The usage of English from educated people is causing difficulties for people to understand.

These findings highlight the need for active engagement with people with disabilities to determine their needs and the format in which sex education would be most beneficial. The findings further highlight that sex education should not only be targeted towards people with disabilities but also towards those who provide support and care for people with disabilities.

Intersectional Barriers Experienced by People with Disabilities

For people who are transgender and queer identifying, accessing support and care is made even more difficult by the intersection of ableism and heteronormativity and cisnormativity. As Sbu, a transgender woman who identifies as gay told, while the hearing community may be more accepting of her gender identity, she faces several difficulties in terms of being understood as a Deaf person. She explained, for instance, that “I go partying with hearing women and I go into their toilets. It is normal. They understand that I am gay and that is what I prefer to use but with Deaf women they get hysteric and chase me away. I get thrown out of balance but hearing gays and lesbians understand I strongly believe I should go into women’s toilets”. Yet, she explains that although she feels accepted as a transgender and gay woman amongst hearing people, she faces ridicule because of her disability, telling "It is difficult because an interpreter is not there, so you rely on writing as well as when you are looking for organizations, you are ridiculed or criticized. I want a Deaf organization”.

Jean, who identifies as female and lesbian, revealed that she didn’t feel that she could disclose her sexual identity to her mother, by saying, ‘I couldn’t, I just couldn’t tell her. She would disown me. First, she had to accept that I was disabled and now she must accept that I am gay.’ Denise also reflected on her past and the ways in which her past had influenced her sexual identity. Denise explained that she had been raped as a 9-year-old by her stepbrothers, and because of her disability and fear of abandonment, she did not feel safe to tell anyone about the rape. She added ‘ja, so since then, I can’t trust anyone to be close to me. I don’t think I am gay, but I just don’t want a relationship with anyone, especially a man.’

While there were only a few examples which highlight the multiple challenges that people with disabilities face and the ways in which gender and sexual identity intersect with disability, and in the case of Deaf people, with language too, the examples above draw attention to the complex and layered ways in which these intersections serve to marginalize people with disabilities.

Discussion and Conclusion

Although this study had a relatively small sample and was restricted to the experiences of adults with disabilities in an urban setting and excluded persons with moderate to severe communication and intellectual impairments, many of the findings resonate with those of people with disabilities in other parts of the world. The absence of disabled sexuality in sex education, sexual health information, and services, and within popular media more broadly, has created conditions of social exclusion, marginalization, and isolation for people with disabilities. The need for greater representation and inclusion of people with disabilities in sexuality education materials, sexual health information, and in mainstream media emerged as a cross-cutting theme that was emphasized by most participants in the study. At the same time, lack of adequate information, services, and spaces for people with disabilities related to sex, sexuality, and sexual health was a key challenge noted by many of the people we interviewed. In addition to creating a world in which their sexual desires and needs were erased, lack of attention to sexuality within education and care services for people with disabilities was noted by many of our participants as a key problem that needed to be addressed. Findings from this study indicate that positive representation of disability and disabled sexuality has the potential to not only address the needs of people with disabilities, but also to advance the stigmatization of disability and disabled sexuality in the society more broadly.

While our findings are largely consistent with those of comparable studies undertaken in other contexts, the context of post-apartheid South Africa, together with the high prevalence of HIV infection and AIDS and the country's high incidence of rape and violence, shaped the experiences of our participants, and the differences between them, in important ways. Factors such as nature of impairment, age at which impairment was acquired, gender, race, socio-economic status, age, and sexual orientation had implications for participant experiences of sex, relationships, and accessing sexual health information. While older and middle-class participants were able to seek out the assistance of specialists or were able to access pornography, those who were younger and from poorer communities had much more limited experiences and access. While race, racism, and systemic forms of racial inequality were not explicitly mentioned by participants, these dynamics remain embedded within the possibilities available to them in terms of sex and sexual health related care and services. Gender inequality and socio-cultural gender norms also had powerful baring on the experiences of participants in navigating relationships, sex, and sexual health.

While the findings that emerged provide valuable insight into the needs of people with disabilities when it comes to sexuality, there were several limitations inherent in the current project. The findings of this project raise important implications for people with disabilities, their families, friends, and caregivers, as well as service providers. In the immediate term, many participants expressed a desire for caregivers and parents to be better prepared to engage with people with disabilities about sex, sexuality, and sexual health. In response to this need, the authors of this article, in collaboration with the broader group of researchers involved in the disability and sexuality project, are developing a handbook on disabled sexuality.

Future research could focus on the sexual and reproductive health needs of people with disabilities, and the dynamics of the romantic and sexual relationships of people with disabilities including the formation and practice of those relationships. An important focus would involve exploring the intersection of gender and sexuality with hetero-normativity and hetero-ability.

Conflict of interest

There are no conflicts of interest related to this research.

Ethical Approval

H17/09/38 (Human Research Ethics Committee—Non Medical, University of the Witwatersrand Johannesburg.

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References

1. Chappell, P.: Troubling the socialisation of the sexual identities of youth with disabilities: lessons for sexuality and HIV pedagogy. In: Francis, D. (ed.) Sexuality, society and pedagogy, pp. 111–119. Sun-Media, Bloemfontein (2013)
2. Berghs, M., Atkin, K., Hatton, C., et al.: Rights to social determinants of flourishing? A paradigm for disability and public health research and policy. BMC Public Health **19**, 997 (2019). https://doi.org/10.1186/s12889-019-7334-8
3. Chappell, P.: Queering the social emergence of disabled sexual identities: Linking queer theory with disability studies in the South African context. Agenda **29**(1), 54–62 (2015)
4. Tomsa, R., Gutu, S., Cojocaru, D., Gutiérrez-Bermejo, B., Flores, N., Jenaro, C.: Prevalence of sexual abuse in adults with intellectual disability: systematic review and meta-analysis. Int. J. Environ. Res. Public Health **18**(4), 1980 (2021). https://doi.org/10.3390/ijerph18041980
5. Sharma, S.: Sexuality and relationship experiences of women with spinal cord injury: reflections from an indian context. Sex. Reprod. Health Matters **29**(2), 283–300 (2021)
6. Union of South Africa Gazette: Immorality Act No 23 of 1957. Government Printer. Cape Town, South Africa (1957)
7. Republic of South Africa Gazette: sexual offences and related matters act 32 of 2007. Government Printer. Cape Town, South Africa (2007)
8. Enaifoghe, A., Dlelana, M., Durokifa, A., Dlamini, N.: The prevalence of gender-based violence against women in South Africa: a call for action. Afr J Gender Soc Dev (2021). https://doi.org/10.31920/2634-3622/2021/v10n1a6
9. South African Constitution: http://www.justice.gov.za/legislation/constitution/saconstitution-web-eng.pdf (1996). Accessed 7 March 2019
10. Dlamini, N.: Gender-based violence: twin pandemic to COVID-19. Crit. Sociol. (2020). https://doi.org/10.1177/0896920520975465
11. Graham, L., Moodley, J., Selipsky, L.: The disability–poverty nexus and the case for a capabilities approach: evidence from Johannesburg South Africa. Disabili. Soc. **28**(3), 324–337 (2013)
12. UNAIDS: Disability and HIV. Geneva, Switzerland, Joint United NationsProgramme on HIV/AIDS. https://www.unaids.org/sites/default/files/media_asset/JC2905_disability-and-HIV_en.pdf (2017). Accessed on 20 July 2023
13. de Andrade, V., Baloyi, B.: Some of the things I understand but not all of it'. A group of deaf adolescents' sources of knowledge and concerns regarding the adequacy of their level of knowledge about human immunodeficiency virus/acquired immune deficiency syndrome. Vulnerable Child Youth Stud **6**(3), 255–262 (2011)
14. Olusanya, B.O., Neumann, K.J., Saunders, J.E.: The global burden of disabling hearing impairment: a call to action. Bull. World Health Organ. **92**, 367–373 (2014)
15. Phasha, T.N., Nyokangi, D.: School-based sexual violence among female learners with mild intellectual disability in South Africa. Violence Against Women **18**(3), 309–321 (2012)

16. Colarossi, L., Riquelme, M., Collier, K., Perez, S.: Dean, R: Youth and parent perspectives of sexual health education for people with intellectual disabilities. Disabil. Sex. **41**, 619–641 (2023). https://doi.org/10.1007/s11195-023-09805-y
17. Löfgren-Mårtenson, L.: 'I want to do it right!' A pilot study of Swedish sex education and young people with intellectual disabilities. Sex. Disabil. **30**(2), 209–225 (2012)
18. de Wit, W., van Oorsouw, W.M.W.J., Embregts, P.J.C.M.: Sexuality, education and support for people with intellectual disabilities: a systematic review of the attitudes of support staff and relatives. Sex. Disabil. **40**, 315–346 (2022). https://doi.org/10.1007/s11195-021-09724-w
19. East, L.J., Orchard, T.R.: Somebody else's job: experiences of sex education among health professionals, parents and adolescents with physical disabilities in Southwestern Ontario. Sex. Disabil. **32**, 335–350 (2014). https://doi.org/10.1007/s11195-013-9289-5
20. Pownall, J.D., Jahoda, A., Hastings, R.P.: Sexuality and sex education of adolescents with intellectual disability: mothers' attitudes, experiences, and support needs. Intellect. Dev. Disabil. **50**(2), 140–154 (2012)
21. Ballan, M.: Parents as sexuality educators for their children with developmental disabilities. Siccus Rep. **29**(3), 14 (2001)
22. Rohleder, P.: Educators' ambivalence and managing anxiety in providing sex education for people with learning disabilities. Psychodyn. Pract. **16**(2), 165–182 (2010)
23. Chirawu, P., Hanass-Hancock, J., Aderemi, T.J., de Reus, L., Henken, A.S.: Protect or enable? Teachers' beliefs and practices regarding provision of sexuality education to learners with disability in KwaZulu-Natal. South Africa. Sex. Disabil. **32**(3), 259–277 (2014)
24. de Reus, L., Hanass-Hancock, J., Henken, S., van Brakel, W.: Challenges in providing HIV and sexuality education to learners with disabilities in South Africa: the voice of educators. Sex Educ. **15**(4), 333–347 (2015)
25. Rohleder, P., Swartz, L.: Providing sex education to persons with learning disabilities in the era of HIV/AIDS: tensions between discourses of human rights and restriction. J. Health Psychol. **14**(4), 601–610 (2009)
26. World Medical Association: World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research involving Human Subjects. Ferney-Voltaire: World Medical Association (2008)
27. Mollard, E., Hatton-Bowers, H., Tippens, J.: Finding strength in vulnerability: ethical approaches when conducting research with vulnerable populations. J Midwifery Healthc **65**(6), 802–8027 (2020)
28. Penn, C., De Andrade, V.: Informed consent and deafness in South Africa: guidelines for clinicians and researchers. S. Afr. J. Bioeth. Law (2017). https://doi.org/10.7196/SAJBL.2017.v10i2.541
29. Braun, V., Clarke, V.: Using thematic analysis in psychology. Qual. Res. Psychol. **3**(2), 77–101 (2006)