

ACCESS DENIED: EXPLORING PEOPLE WITH DISABILITIES' EXPERIENCES

ACCESSING AN EROTIC LIFE

Research Practicum Report (Journal Article Submission Option)

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By Michelle Apps

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Introduction and Summary of Journal Article Submission

This journal article submission, titled ‘Access Denied: Exploring People with Disabilities’ Lived Experiences Accessing an Erotic Life’, has been prepared for submission to the Canadian Journal of Disability Studies. The journal article submission begins with the research question, which is “from a narrative based perspective, what are the lived experiences of people with disabilities accessing and facilitating an erotic life?” Sub-questions included: How do they feel about it, and how do they think it could be facilitated? In this introduction I also discuss what an erotic life means within the terms of the study, and give a brief historical context of sexuality and disability.

Supporting the United Nations Convention on the Rights of Persons with Disabilities (2006), and borrowing from the World Health Organizations’ working definition of sexuality (2004), this article then provides a literature review discussing and challenging society’s narrow definitions of sex, and revealing that disability and sexuality research is an understudied and taboo topic within both academic and non-academic discourses. I then discuss the methodology behind the study, discussing narrative research, my sampling methods, the sample itself, and the process of my own empowerment through knowledge translation. Following the methodology is a discussion section in which I explore my own ableist assumptions, and introduce the main themes and sub-themes within them. I then discuss in detail each of the main themes. These themes were: access; facilitation; perceptions acting as attitudinal barriers; the role of interlocking oppressions; and notions of control, before concluding the article. Attached are two appendices, one outlining the interview questions, the other depicting a visual representation of the themes and sub-themes, and their relation to one another.

The findings of the study show that there are a multitude of social, societal and personal barriers for people with disabilities in accessing an erotic life, an area fraught with emotions, but also an area with much work to be done in order to increase access and facilitation for people with disabilities.

Abstract

This paper investigates the lived experiences of people with physical and intellectual disabilities' in accessing an erotic life (defined as any sexually charged touch, with the desire to create intimacy). The research is chiefly concerned with how people with disabilities feel about having an erotic life, which is an overlooked area, and how they think that should be facilitated. The study was conducted through a narrative inquiry (Riessman, 2008), in which the participants told stories about their lives within the context of accessing and facilitating an erotic life. A thematic analysis revealed the main themes of access, perceptions acting as attitudinal barriers, facilitation, the role of interlocking oppressions, and notions of control.

Keywords: Access, Facilitation, Erotic Life, Narrative Inquiry, Persons with a Disability

“Inclusion does not just mean building a ramp” (Tilley, 1998, p. 91).

Introduction

While the rights and recognition of people with disabilities has recently advanced to include them as people deserving the same opportunities as their non-disabled peers, they have yet to completely appear as sexual citizens within a human rights context (Kangaude, 2010). This is not only underscored by the fact that there is an undeniable connection between a group’s sexual status and their broader social and political status (Wilkerson, 2002), but also that it is inhumane to deny people with disabilities sexual pleasure (Owens, 2015).

Disability and sexuality are at the crossroads of a taboo and under-studied area of academic and mainstream discourses (Siebers, 2012; Stevens, 2010). In part, this study aims to answer Shuttleworth’s (2012) call for sexuality and disability studies that take seriously what people with disabilities “actually do and say” (p. 56), and to investigate people with disabilities’ sense of their sexuality, and their everyday sexual interactions, which still remains under researched (Shuttleworth, 2012).

Grounded in a human rights framework, supporting the United Nations Convention on the Rights of People with Disabilities (2006), and utilizing the World Health Organization’s (2004) working definition of sexuality, this qualitative narrative study explored the lived experiences of people with disabilities’ in accessing and facilitating an erotic life. The main questions guiding the research are how do people with disabilities feel about accessing an erotic life, and how do they feel that it could be best facilitated?

Sexuality and an Erotic Life

For the purpose of this study, the term ‘erotic life’ is defined as any sexually charged touch, including hugging, kissing, cuddling and other alternative ways of sexually expressing oneself (Siebers, 2012; Shakespeare, 2000).

Given that this study is concerned with non-normative – meaning not conforming to a prescribed standard or norm (Oxford English Dictionary, n.d.) - perspectives of sexuality, I believed

that it was important to first discuss the conflicting definitions of what sexuality is. The World Health Organization's (2004) working definition of sexuality states that:

Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities, and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.

Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, religious and spiritual factors (Defining Sexual Health, p.5).

While this working definition appears to be all encompassing, there are some pieces that it leaves out, especially within the context of this study. For example, Wilkerson (2002) notes that sexuality is also a means of connection, and the acceptance of one's body and of self, which is important to keep in mind as these are many of the things one looks for when seeking out an erotic life. Sexuality as a means of connection and acceptance of one's body and self came up many times in the study, and is something often denied to people with disabilities.

Given the many differing definitions of sexuality that exist, it is not within the scope of the study to critically examine all of them. With that in mind, heuristically and for the purpose of this study, I have elected to utilize the WHO's (2004) working definition of sexuality, with the inclusion that sexuality is a means of connection and acceptance of one's body and self (Wilkerson, 2002), regardless of dis/ability.

Before I delve into the specifics around the study, I will provide an overview of the recent history surrounding society's construction of disability in order to provide some context to this study. The history surrounding the construction of disability is steeped in ableism, which can be defined as the discrimination or the oppression of an individual or group based on their disability (Merriam-Webster, n.d.; Withers, 2012).

Historical Context

There is a long and sordid history when it comes to governing people with disabilities' sexuality, which is why, in part, there are still many negative and inaccurate perceptions surrounding their sexuality. The historical practice of eugenics which is a theory that people with disabilities were carriers of genetic traits meant to be bred out of society, has served as the foundation to modern Western society's understanding and definition of people with disabilities' sexuality (Kangaude, 2010; Withers, 2012). With the forced sterilization of thousands of people with disabilities in both Canada and the United States up until the 1970's (Withers, 2012), it is no wonder that negative assumptions, policies and practices about people with disabilities' rights to access sex and their sexuality continue to be fostered today. Indeed, Withers (2012) notes that many eugenic policies such as prenatal screening programs are still in operation today, although these programs are carried out less aggressively, and under different names and guises.

Undoubtedly as a result of this history, there is a well-documented societal myth of asexuality projected upon people with disabilities (Hollomotz, 2010; Kangaude, 2010; Mulligan & Newfeldt, 2001). Not only do inaccurate portrayals of people with disabilities in popular culture perpetrate this myth of asexuality, but the silence that surrounds the subject may also help to perpetuate the myth that people with disabilities are asexual (Shildrick, 2007). Kangaude (2010) asserts that the projection of the myth of asexuality has been constructed through various modern social and legal policies; and occurs in part because people with disabilities' sexuality exists outside of the privileged spaces of heteronormativity. Heteronormativity prescribes to a worldview that promotes heterosexuality as the normal or favoured sexual orientation (Oxford English Dictionary, n.d.).

Given this historical context, and the undoubtedly narrow views and definitions of sexuality in general, but especially within the context of disability, normative assumptions about sex and disability stubbornly persist. The relevant literature and many people with disabilities are challenging these problematic assumptions.

Literature Review

Wanting to expand this study's definition of sex and an erotic life, I looked towards Shakespeare's (2000b) work, which urges us to reconsider society's current able-bodied and normative definitions of sex – both as people with and without disabilities. Along a similar vein to Siebers' (2012) discussion around normative sexuality, Shakespeare (2000) asks what is “normal” sex, and why should it revolve around penetration? Separating ourselves from the traditional ideas and norms surrounding what many people define as sex, Siebers (2012) goes so far as to argue that the idea of a sex life is ableist, in that people with disabilities may be stigmatized out of having sex, and that their sexual activities do not always follow able-bodied peoples normative assumptions about what a sex life is or ought to be.

Instead of prescribing to traditional ideas and norms surrounding sex, Shakespeare (2000) argues that the constraints of disability should generate different options instead of shutting down possibilities. On a similar note, Siebers (2012) suggests that contemplating sex and sexuality within the context of a disability expands what society typically defines as sexual behaviour. Further to that, he argues that thinking about sex and disability exposes unidentified beliefs about the ability to have sex and how the construct of ability regulates or determines the value and worth of certain sexual practices and ideas over others (Siebers, 2012).

Moving away from the understandings of sexuality as strictly erotic experiences, Shakespeare (2000) notes that most people aren't necessarily or always seeking out sex specifically, but instead they are looking for intimacy, touch, affirmation and connection with others. “That is” he says, “relationships rather than sex are what counts” (p. 164). He suggests that researchers explore issues around physical contact and the scarcity of such intimacy in many people with disabilities' lives. While this aspect of sexuality was not necessarily included in this study's definition of an erotic life, themes of non-sexual intimacy, like relationships, and their importance to participants' lives certainly did emerge during the interviews that were conducted during this study, and will be explored further in this

paper. Shakespeare (2000) asks if we are trying to achieve access for an erotic life for people with disabilities from the mainstream notion of sexuality; or, are we trying to object and challenge the ways in which sex and sexuality are narrowly defined in our contemporary society? It is clear through this literature review that there needs to be a major shift in thinking around what constitutes as sex. This is a theme that emerged again and again throughout the study interviews with research participants.

The UN Convention on the Rights of Persons with Disabilities

Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (2006) (herein after referred to as the Convention) provides a definition of the rights for persons with disabilities. It states that all States Parties shall and “...must be able to enjoy, on the same basis of others, the same rights as others” (United Nations, 2006, Article 25). However, according to DeThan (2015) several states involved in the drafting process for the Convention objected to the inclusion of a requirement that “persons with disabilities are not denied the equal opportunity to experience their sexuality, have sexual and other relationships, and experience parenthood” (p. 194), and as a result, there was no explicit reference to the right to sexuality in the Disability Convention.

The Current State of Disability and Sexuality Research

Until recently, sex and disability research has been entrenched in the medical model; a model of disability focuses on people with disabilities’ sexuality, as well as their impairment(s), as problems to be ‘fixed’ or rehabilitated at the individual level (Shuttleworth, 2010). Globally, the medical model still holds an authoritative influence in the understanding of disability today (Kangaude, 2010). Coming from a social relational perspective and drawing on the capabilities model, Kulick and Rydstrom (2015) note that academic scholarship has only just begun to take notice of disability and sex outside of rehabilitation and medical contexts. McRuer and Mollow (2012) also note that society must start by considering the concept of access, which is a central political and theoretical tenet in disability studies and within the disability rights movement. The term is most often used in the context of access to public spaces like office buildings, banks, restaurants, or theatres. When studying sex and disability,

McRuer and Mollow (2012) apply the concept of access to the private sphere (e.g. homes).

Shakespeare (2000) notes that the disability rights movement has been chiefly concerned with access in the public sphere.

In summary, Shuttleworth (2012) recognizes that there is a dearth of literature on the topic of sex and disability; and even less literature that explores the lived experiences of people with disabilities. He also states that researchers continually neglect to research issues raising ethical dilemmas, such as facilitated sex, (the use of a sex worker to therapeutically deliver sexual services) and do not include other marginalized groups such as people who are gay, lesbian, bisexual, or transgendered. In addition, Shuttleworth (2010) states that sex and disability, as an academic discourse, has been distinctly lacking in the discussion of sexual access, and that sexuality studies have not fully accepted the sexual access issues of marginalized groups – such as people with disabilities – as a scholarly concern. McRuer and Mollow (2012) also point this out, stating the ‘major texts’ in the field of sexuality studies rarely mention disability, while the ‘major texts’ in disability studies do not discuss sex in great detail either. Mulligan and Neufeldt (2001) also call for more research to be done in the area of sexuality and disability, due to the lack of literature, especially “exploratory, qualitative investigations targeted to eliciting the experiences of people with disabilities...to enhance our understanding of both the personal and social barriers that face people with disabilities in the domain of sexuality” (p. 103). In fact, a multitude of barriers in accessing and erotic life, both personal and social, were identified by research participants within this study.

Building upon the foundation set by these notable scholars, this qualitative narrative study aims to add to the small but growing body of literature of disability and sexuality studies.

Methodology

This research project utilized a narrative approach in which the researcher is interested in the lives of the research participants, and asks participants to tell stories about their lives (Riessman, 2008). The information gathered from these stories is then retold or 'restored' (Creswell, 2014) into a chronological narrative. The end result is a collaborative combination of perspectives from the research participant's life combined with those of the researcher (Clandinen & Connelly, 2000). I chose a narrative approach for this study because the subject matter of disability is fraught with emotions and full of stories (Horrocks & Callahan, 2007; Moen, 2006). I thought that using a narrative approach was the most respectful means in which to honour peoples' stories, and the most appropriate way in which to properly communicate those stories. Storytelling is a natural way of relaying one's experience, or creating order out of an experience (Horrocks & Callahan, 2007; Moen, 2006). As individuals, we produce these stories or narratives to make order out of and structure our life experiences (Moen, 2006). I believed that a narrative inquiry was the most natural way of eliciting participants' experiences about the subject matter at hand.

In this project, the interview questions related specifically to the lived experiences of how the research participants accessed an erotic life; how they thought that an erotic life could be facilitated for people with disabilities; their experiences with any barriers they faced (social, personal, societal) when accessing or facilitating an erotic life; their experiences with receiving or not receiving sexual education; and the attitudes of friends, family and caregivers regarding participants accessing and facilitating an erotic life (See Appendix A for a complete list of interview questions).

Several participants that I interviewed had questions around what the study would translate into, specifically, if or how it would result in helping them in some way to access an erotic life for themselves. This raised some ethical dilemmas for me: on one hand, the purpose of my research was to hear and story participants' lived experiences about accessing and facilitating an erotic life and not to directly connect or help participants to meet potential partners as some participants were asking for. However, at the same time, I was asking them to discuss in detail very personal and potentially painful

aspects of their lives and how they felt about it. While participants had been made aware of the potential risks and benefits of participating in this type of research, I somehow felt as if I owed them all something more. However, as I quickly realized, if I wanted to do this kind of research, I had to live with the reality that due to the nature of questions I was asking participants, these types of queries were bound to arise.

By engaging in this research, participants were given a voice and avenue in which to discuss their thoughts and ideas about this subject matter – something that they are not often afforded. The benefits participants experienced, however, were not a one way street - through this study, I had several opportunities to engage in a number of knowledge translation activities at local and national levels. I soon found my work transforming into knowledge translation. While these knowledge translation activities were most certainly welcomed, these were opportunities that I had not dreamed possible. Through this project, the research participants helped me to broaden and expand my knowledge base in ways that I never could have predicted; thus the process of empowerment that occurred during this project also empowered me, as a researcher and as an individual without disabilities.

After receiving research ethics approval, six participants were recruited via purposive and snowball sampling – three were recruited through my involvement with a local organization providing service to people with intellectual disabilities, and three were recruited through word of mouth in the community and on the university campus. Each participant took part in two interviews, each lasting from thirty to sixty minutes. In this qualitative study, I was concerned with hearing a small number of stories, as per guidelines for narrative inquiry (Cresswell, 2014), hence the small sample size. All interviews were audio recorded and transcribed verbatim. One female and five males were interviewed, with an age range of 26 to 49. Three participants self- identified as having an intellectual disability, and three participants identified as having a physical disability.

Initial research participant recruitment was difficult because a number of potential participants did not want to discuss something of such a personal nature. Understandably, many people did not want

to discuss such sensitive subject matter with a stranger. Several were unable to commit the time to participate, and others were concerned about what the study would translate into, not wanting to put in the time and effort to disclose such sensitive data, only to have their thoughts, experiences, and feelings end up as simply words on a page. Given the narrative nature of the study a number of personal stories were told during data collection. To help reflect this aspect of the research, many quotes from participants have been included to help further demonstrate and humanize their experiences (Stake, 2010). All participants elected to use a pseudonym to ensure anonymity.

I engaged in what Polkinghorne (1995) calls an analysis of narratives, in which I classified different themes found in the data into categories, while paying close attention to the relationships between and among the categories. This method also helped me to uncover the multiple commonalities that were found across the data (Polkinghorne, 1995). Through this analysis of narratives I was able to make meaning from the stories that were told (Polkinghorne, 1995). Using an inductive approach, in which I used particular examples to reach general conclusions, I let the concepts and themes emerge from the data. An inductive approach underscores or emphasizes relational understanding, suggesting that accessing an erotic life can be understood from the meanings inherent in everyday interactions, events, and situations (Hayes, Heit, & Swendsen, 2010; R. Johner, personal communication, June 30, 2016).

Discussion

Although the sample size was small, there was great variety found within the participants' experiences. Three participants self-identified as having a physical disability, and three identified as having an intellectual disability. Interviews with people with intellectual disabilities elicited different responses than interviews with people with physical disabilities did, due to varying differences in communication abilities (Schalock R., Verdugo M., Jenaro C., Wang M., Wehmeyer M. et al., 2005). For example, conversations with people with physical disabilities lasted longer than those with

intellectual disabilities, and went much deeper into the subject matter as it related to each question asked, therefore translating into more thoughtful answers and ensuing discussions with the researcher.

However, conversations with participants having an intellectual disability were generally shorter, eliciting simpler responses, sometimes even with prompting. With two participants, it was unclear if the participants fully grasped the concepts of the questions asked, based on their answers. This was in part due to the complexity of my questions, and also my inability to clearly translate or explain them into plain language (Withers, 2012). When interviewing another participant, however, her support worker was present, and was able to assist me in rephrasing and rewording the questions in ways that the participant could understand, therefore eliciting responses with more meaning behind them.

This observation about differences in responses is more of a comment and observation on my own inability to construct the interviews in a more accessible way. It was not intended to criticize participants or to highlight differences but did demonstrate my ableist lens or viewpoint as someone without an intellectual disability (Miller, Parker, & Gillinson, 2004; Withers, 2012). This ableism is important for me as a researcher to highlight. Withers (2012) notes that access, in one form or another, is always an issue within models of disability, and that a part of being more accessible includes the intentional and accessible use of language. I highlight this ableism and the importance of accessible because I believe it demonstrates how easy it was for me, even as someone who is conversant with the literature concerning disability and access is still able to so easily and unknowingly disable a conversation.

Using a thematic analysis, 5 themes were found in the interview data. These themes were access; perceptions acting as attitudinal barriers; facilitation; the role of interlocking oppressions; and notions of control. For the purposes of clarity, the themes and sub-themes have been organized with headings and sub headings in this paper. However, I want to stress the fact that many of the themes that emerged overlapped with one another. Therefore you will notice that parts of one theme will appear or

emerge under another theme, and vice-versa. Refer to Appendix B for a visual representation of these themes. Under the first theme of access are the sub-themes of (in)accessibility of public and private spaces, access to sexual education, and sexual access. Within the second theme of perceptions acting as attitudinal barriers are the sub-themes of changing perceptions and media representations. This theme is linked with access. The third theme of facilitation has no sub-themes within it, however it was found to be strongly linked with the fourth theme of the role of interlocking oppressions, which was strongly linked to access. The fifth and final main theme, notions of control has a sub-theme of forced and chosen celibacy, is also linked with access.

Theme 1: Access

The (in) accessibility of public and private spaces was identified in the literature, along with themes of sexual access (Shuttleworth, 2007), and access to sexual education. Public spaces can include restaurants, banks, bars, clubs, movie theatres, and so on; any space that is (or in this case, should be) accessible to the general public. The term private spaces refer to spaces that one would consider private, such as one's home or a washroom.

Sub-theme: (In)Accessibility of Public and Private Spaces

Many public spaces in which one usually goes to access an erotic life were often found to be inaccessible to research participants. Shakespeare (2000) also points this out as a barrier – reporting that many people with disabilities don't have the opportunity to attend university, to engage in work, or have access to other public spaces, therefore making it difficult to meet potential partners, unlike their non-disabled peers. To demonstrate this, one participant, John, said after a lengthy discussion over the lack of accessible bars and clubs in town: *“If I'm not able to get where the action is, I'm not gonna get the action!”* He also talked about the lack of accessible spaces to even go and socialize in: *“I can't get into any bars on the strip...And that's where it happens...Where do I go to socialize?...You know, I'm restricted to the internet...which is bulls—t.”*

Demonstrating the effects of inaccessible private spaces, John also reported living in his parents' home, after extensive renovations had been made over the years so that he could navigate his wheelchair around the house. When asked if people in his life, such as friends or family were unsupportive of his attempts to access an erotic life, he said *"the problem...socially, is the dearth of wheelchair accessible housing in this city for single people...the lack of a decent bachelor pad sucks"* He clearly identified his living situation as barrier for him to access an erotic life. He went on to say:

"I'm certainly not going to shower with anybody...as much as I'd love to...it's not gonna work. And of course, mine is. [Referring to the accessibility of his home and shower] But who wants to hear, 'Let's go to Mom's place and f—k?"

While John did identify as being gainfully employed and being able to meet people through and socialize with at work, his living situation was less than ideal in terms of accessing and facilitating an erotic life, as was his ability to access public spaces in which to socialize and meet potential partners.

Sub-theme: Access to Sexual Education

Another finding highlighted throughout the study was how little sexual education some participants had received growing up, especially those with intellectual disabilities. As Mallet and Runswick-Cole (2014) point out, in the lives of people with disabilities, taking sexuality seriously involves more than a satisfying sex life; it also requires access to sex education. Once again this brings in themes of access, in this case, access to sexual education for people with disabilities.

One participant, Jeanette, had not been given sexual education growing up, thus rendering her in a very vulnerable position in her adolescence. She shared several stories in which she was sexually coerced or taken advantage of when she was younger. Because she had not been given adequate sexual education, she was subjected to many experiences where she was sexually assaulted, not realizing that she had the choice to say no to what was happening to her body.

Because of these experiences, she chose celibacy, saying *"I don't feel comfortable having a boyfriend; I'd rather be single because of those bad relationships. And I don't wanna have another bad*

one, that's why I choose not to have another relationship.” This demonstrates the deleterious effects of not providing sexual education to people with disabilities, especially those with intellectual disabilities, who may have different ways of understanding and seeing the world from those without intellectual disabilities. Therefore many possibly do not fully understand their rights and the concept of consent without it being explained to them.

Jeanette’s story is not uncommon. It has been widely noted that people with disabilities, especially those with intellectual disabilities, receive inadequate, if any, sexual education (Adams, 2015; Hollomotz, 2009; Mallett & Runswick-Cole, 2014) and are often prohibited from engaging in any type of safe or consensual sexual activity (Adams, 2015). This often happens under the guise of protection; however, these intentions usually backfire, resulting in instances like Jeanette’s – not being taught concepts like consent can result in disastrous consequences. In fact, not providing sexual health and educational programming violates the UN Convention (2006), which states that all States Parties shall “Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, *including in the area of sexual and reproductive health*” [emphasis added] (Treaty Series 2515, 2006).

Sub-theme: Sexual Access

I would be amiss to assume that the concept of access does not go beyond physical and educational barriers. Shuttleworth (2007) discusses the concept of sexual access, which is premised around the understanding that the stigma surrounding sexuality restricts people with disabilities in their efforts towards accessing an erotic life. This concept can be used as a tool for focusing discussions around sexuality and the sexual rights of people with disabilities (Shuttleworth, 2007). Within the context of this study, nearly all participants’ sexual access was restricted in some way due to various factors including inaccurate perceptions of their sexuality from other people. Through the concept of sexual access, it has been identified that we need to work toward cultivating a culture of sexual access for people with disabilities. The concept of sexual access was identified by several participants as the

largest barrier they faced when attempting to access or facilitate an erotic life for themselves. This parlays into how perceptions of others act as attitudinal barriers for people with disabilities accessing an erotic life.

Only one participant, Mason, did not identify any barriers or negative perceptions and attitudes from his friends, family and caregivers regarding him accessing an erotic life. He identified as having a girlfriend, with whom he had been dating for three years. He reported their activities consisted of going on dates to the movies, local dances, floor hockey, and holding hands. He did not identify as wanting to explore his relationship with his girlfriend in any deeper way, and did not seem to have qualms with his dates always being supervised in some way, as he constantly required supervisory care. Their erotic activities consisted of hand holding and kissing.

Theme 2: Perceptions Acting as Attitudinal Barriers

Another key theme that emerged from the data was the role of perceptions acting as attitudinal barriers. The insurmountable attitudinal barriers that participants faced in regards to their sexuality were one of the most prominent themes to emerge from the data. Nearly all participants identified the attitudes and perceptions of others as their largest barrier to accessing an erotic life.

“I just want to let the populace know...when you see a disabled person...don't look on the surface. Dive deep, and find out that we are the same as everybody else. We have our minds, we have our feelings....we are not eunuchs” (Ben).

Societal views and perceptions of people with disabilities' sexuality emerged again and again as a theme within the research, particularly in regards to questions posed to participants about tackling the taboo nature of sex and disability, and changes that participants envisioned to eliminate the stigma that surrounds it. The limited perceptions of others towards sexuality and disability acted as attitudinal barriers for people with disabilities, and were found to directly affect participants' attempts to access an erotic life.

Whether it was blatant or covert, participants retold many personal narratives in which they were combating or coming up against negative perceptions about themselves in regards to their sexuality. One participant recounted an evening at a local bar:

“...one night, I went into a bar, I went up to this nice looking woman...but, when I asked her out on a date, she looked at me, laughed, pointed, ‘why would I go out with a fat retard like you?’ ...To my face...I haven’t gone out to a bar since” (Ben).

The above story exemplifies the struggles that people with disabilities face when attempting to access and facilitate an erotic life. It also shows how discrimination and perceptions of others translates into inaccurate and ableist stereotypes that are then projected onto people with disabilities, and how that can have long lasting consequences.

Sub-theme: Media representations.

It was identified by several participants that in order to combat negative perceptions of those with disabilities and sexuality, a change in ways of thinking about disability among non-disabled people was a necessity. General increased awareness of disability and sexuality topics through more positive and inclusive media representations were suggested by several participants as possible avenues to help ameliorate negative views of people with disabilities’ sexuality. Indeed, as Haller and Zhang (2014) point out, contemporary media presented through news, TV, film and advertising provides most of the cultural portrayals of disability in many countries. Sadly, the vast majority of those media representations of people with disabilities have proven to be rather problematic (Haller & Zhang, 2014). Given that most of these representations are through either the ‘supercrip’ narrative where one is expected to somehow “overcome” their disability, or through the cure-seeking medical model (Haller, 2010; Titchkosky, 2008; Withers, 2012). It is little wonder that the troubling messages within popular media were identified by participants as problematic and need to be changed in order to paint a more honest and accurate picture of people with disabilities’ sexuality and to lessen the stigma surrounding this topic.

Stevens (2010) notes how these media representations of people with disabilities notably within either the ‘supercrip’ narrative or in the deficit focused medical model has led to the internalization of many of these narratives and negative messages (e.g., inspirational, undesirable, asexual, dependent, and so on), and points to ways in which to “negotiate these constricting cultural narratives” (p. 60).

Sub-theme: Changing perceptions.

Changes within the education system were identified by several participants as ways in which to begin changing perceptions of people with disabilities’ sexuality. Several participants said that sexual education in schools should include components on disabled sexuality.

“...in the school system...they’re really after the inclusion of students with disabilities, learning disabilities, physical disabilities, stuff like that. So maybe they can start being incorporated in the sex ed portion...It seems like if there’s change to be made, or needed, the social change is expected to be done by the education system...because that’s where everybody starts” (David).

In regards to being asked what could be done to increase access and facilitation, John said: *“I think it’s about...somehow finding a way to alter the perception...of people with disabilities as asexual...There is that perception, I don’t think you’d be doing the study if there wasn’t that perception”* (John). Ben noted that *“If they [non-disabled people] understood what being disabled is...and how being intimate would be much more beneficial. Not physically, but emotionally...it’s a benefit”*. This sentiment also demonstrates how important not just an erotic life is, but also how being in an intimate relationship with another person can be beneficial (Yoo, Bartle-Haring, Day, & Gangamma, 2014).

As research participants confirmed, a change in societal perceptions about people with disabilities was needed, which is consistent with the United Nations Convention (2006) that states “...a change of perceptions is essential to improve the situation of persons with disabilities” calling on

ratifying countries to “combat stereotypes and prejudices and promote awareness of the capabilities of persons with disabilities” (Article 8, UN Convention, 2006).

Again, regarding perceptions, John and I discussed why it seems that non-disabled people are unwilling to explore an intimate relationship with someone with a disability:

“It’s about combining the medical profession with the mainstream media, like, for the surrogacy piece, with the mainstream media, to let people know, this is what this is...and it’s OK, and it’s worthwhile for someone who...might not otherwise think about exploring sex with someone with a disability.”

Theme 3: Facilitation

Through the interviews and ensuing data analysis, participants identified several areas that could facilitate an erotic life for people with disabilities. Sexual surrogacy which is the use of a specially trained sex worker in which to have erotic experiences with was identified as a necessity by some participants. Shuttleworth (2012) has also noted the importance and need for some people with disabilities’ to be able to access sex through this avenue. When asked about facilitation of an erotic life, John identified sexual surrogacy as being an important piece of the facilitation puzzle for him, saying, *“...even just for me to have the confidence to know that I’m worthy of seeing somebody naked... ’cause...at this point in my life I can look you in the eye and tell you that that’s almost gone...that confidence.”* Ben has used the services of sex workers in the past, saying *“I found one that was open-minded...she even gave me a discount.”* He reported this as being a positive way for him to express his sexuality and to facilitate an erotic life for himself. Indeed, Kulick and Rydstrom (2015) note that for people with disabilities, experiences with sex workers can also help them understand and realize that they are indeed capable of having sex.

Theme 4: The Role of Interlocking Oppressions

Rarely did one participant's disability exist in a vacuum. Many of the participants identified as having other oppressions in their lives that complicated accessing an erotic life for themselves. Certain social categories such as sex, gender, orientation, class, ethnicity, nationality, and disability intersect with one another to reinforce inequality and oppression (Krumer-Nevo & Komem, 2015; Withers, 2012). For example, Withers (2012) notes that most people with a disability "have a least two points of marginality...women, racialized, poor, queer or any such combination" (p. 11). The intersectionality of interlocking oppressions were found to be at play within participants' experiences.

One participant identified as being immunosuppressed due to medical issues, and therefore identified casual sex or one-night stands as being out of the question because he would not know what their sexual health status was "*...going to the bar, and picking somebody up for a night...I'm immune suppressed, and there's immunological issues there in terms of STDs...*" (John).

Additionally, John reported some struggles with his mental health, in part due to past trauma, which he identified as a barrier for him approaching potential partners. "*...approaching someone...knowing what I know, and being made to feel how I've been made to feel...on top of the fact that I have anxiety disorder...it's become very terrifying*" (John).

Another participant identified as being gay, reporting that being disabled was one complicating factor in accessing an erotic life, but adding in being gay, he said:

"...That throws a whole different...scope into the ball game...So basically everything else is diminished by another ninety-nine per cent...In a normal world, without disabilities, it's still tricky...So you throw a disability in there, you might as well just wipe everything off the board, and say fuck it." (David).

The intersectionality of interlocking oppressions are inextricably linked with the concepts of access and facilitation. Whether it is one's sexual orientation, or their physical or mental health, it was clear that participants' varying disabilities did not occur in a vacuum, they occurred in conjunction with

other variables that only furthered compounded their oppression (Krumer-Nevo & Komem, 2015; Withers, 2012).

Theme 5: Notions of Control

Historically and contemporarily, people with disabilities often have not had much control over what happens to their bodies, especially within the realm of sexuality (Malacrida, 2015; Withers, 2012). This theme addresses control: control over the ability to access an erotic life, control of how one chooses to facilitate that erotic life, and the role of chosen and forced celibacy, which can diminish one's sexual agency.

Wilkerson (2002) states that sexual agency is not simply the capacity to choose to engage in or refuse sexual acts, but it is something that is socially based and comprises a sense of oneself as a sexual being, which others recognize and respect one's identity. Many people with disabilities' have a sense of their sexual agency in their lives that has been greatly, if not completely, diminished through various experiences and messages. Wilkerson (2002) notes that sexual agency is fundamental to political agency, and as a result, the denial of sexual agency to a group becomes a significant factor in the oppression that the group experiences. This denial of sexual agency only further exemplifies not just the individual implications of the continued denial of people with disabilities' sexuality, but also the political implications as well.

Sub-theme: Forced and Chosen Celibacy

Several participants were found to be in a state of unwanted celibacy, due mostly to various attitudinal barriers. Mulligan and Neufeldt (2001) point this out, reporting that there are still large attitudinal barriers towards people with disability, sex, and their sexuality.

“I tell people I should be a monk...I'm 49. You know how many older men get in a relationship at that age? (Ben).

“I find it difficult to break that barrier. There's something about the people in this city...they're much more conservative...They're much more...the word is superficial...There's a certain body

type that women in this city like...and I very clearly don't fit it. It's been difficult coming to grips with that...but I'm slowly starting to....It's lonely...it's a lonely existence for somebody with a disability who craves sex.” (John).

“...this [gesturing to wheelchair] is the only permanent mountain that I have....and I'm Mohammed. I'm at the top of the mountain...and women do not want, or see the mountain and [say] 'I'm not even going to find out what that man is about'...They see the mountain and, 'Nope! No way!'" (Ben).

Mulligan and Neufeldt (2001) argue that an ecological perspective is needed to address larger issues surrounding disability and sexuality. Community based programming needs to focus on prevention, consultation and public awareness, rather than the existing services that simply focus only on the person with the disability. A similar theme was found among the participants' answers, again echoing statements made earlier about providing education about disabled sexuality in school based sexual education, and the inclusion of people with disabilities in mainstream media.

“The mainstream media has to be on board with it. It really does. Whether it's Hollywood, whether it's independent films here in this country...Until we're seen in a certain light...it'll never change” (John).

However, as one participant pointed out, there still needs to be a societal change in perceptions and understanding of people with disabilities:

“Until we're understood as people, as WHOLE people...who have every single desire every single other whole human being has...even with the inclusion of mainstream media...it's not going to change” (John).

David purposefully did not engage in any type of intimate relationships largely because of avoidance and protection such as: concerns around attracting “chair chasers” or ‘quad chasers’ (those who fetishize people in wheelchairs); being with him out of pity or wanting to appear as someone kind enough or brave enough to date someone with a disability; and due to the acquired nature of his

disability (motor vehicle accident), he identified potential partners as seeing him as flush with money from his car accident, and had concerns around attracting “gold diggers”, or people who would want be with him for his money. For him getting involved in intimate relationships was not worth the worry, concern and suspicions surrounding these possibilities, so he elected not to engage in accessing an erotic life.

“Because you do not know if it’s authentic, or if it’s curiosity, or if it’s sympathy, or if it’s a fetish...Chair chasers, quad chasers.” (David)

Peter, another participant with an intellectual disability, told me about a former group home that he lived in, saying that by living there, nearly all aspects of his life were controlled, including his sexuality. He said:

“I was trying to have this relationship with someone I knew really well. And they were like, ‘Oh, she can’t come over’, you know...and they were basically controlling me....they were more controlling there...you know, which really pissed me off...I couldn’t even have a girl over, like I couldn’t have a girlfriend...they wouldn’t even allow me to do that”

Jeanette identified as having no desire to access or facilitate an erotic life for herself as she had been subject to a number of unwanted sexual experiences in the past. As previously mentioned, she had not been given sexual education growing up. When she engaged in relationships later on, she did not understand the concept of consent because it had never been taught, therefore she engaged in unwanted sexual experiences and did not realize that she had a choice in the matter. *“If it was explained when I was younger...it would have helped...he...wanted to do it and I did not...”* Jeanette reported feeling comfortable and happy to not access an erotic life due to her past experiences of coercion and sexual abuse.

Conclusions

This small qualitative study consisting of 6 participants used narrative analysis to restory the narratives of (Creswell, 2014) people with disabilities’ lived experiences in accessing and facilitating

an erotic life. Based on this study, five major themes emerged, including issues surrounding access, the (in)accessibility of public and private spaces, access to sexual education, and the concept of sexual access. The theme of perceptions acting as attitudinal barriers was informed by a discussion of media representations and identifying that this needs to change those perceptions. Discussion around facilitation centred on the role of sexual surrogacy. The role of interlocking oppressions examined multiple factors in participants' lives that complicated their access to and facilitation of an erotic life. Notions of control addressed issues around the lack of control over one's sexuality and therefore their sexual agency in their life, and also discussed chosen and forced celibacy issues.

Some participants avoided any type of intimate relationship due to their perceptions that potential partners were inauthentic which served as a protective factor due to past sexual abuse and trauma. Other participants engaged in intimate but non-sexual relationships and did not identify any barriers. Two participants lived in self-imposed or unwanted celibacy due to preconceived notions from potential partners about their disability, and two participants lived in the context of chosen celibacy.

Through all of my analysis it was clear that there is still much work to be done in the area of access within disability and sexuality research both within academic and general discourses. Work needs to be done to improve access to and allow for the facilitation of an erotic life for people with disabilities. A massive change in how society views sex within the context of disability is clearly required that challenges heteronormative definitions of sex in a variety of contexts if people with disabilities are to really and truly gain full inclusion in society.

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Appendix A: Interview Questions

Interview I

1. Can you tell me about your experiences in accessing/having sex in your life? (This includes masturbation, mutual touch with another person, hugging, kissing, cuddling, etc.)
2. Have your efforts to access or have sex ever been blocked or stopped by anyone?
3. If so, why do you think that happened?
4. What do you think the attitudes of your friends, family, and caregivers are regarding you having a sex life?
5. How do you think having a sex life could be facilitated for people with disabilities?

Interview II

1. Is there anything we discussed in our last interview that you wanted to talk about? Any follow up thoughts?
2. Do you think you have ever been denied sex education because of your disability?
3. How do you think this topic could become less taboo?
4. What are some changes you would like to see about this subject/topic?