

An Interview and PhotoVoice Exploration of Sexual Education Provision to Women with Physical Disability and Potential Experiences of Violence

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Abstract—This research explored sexual identity for women with physical disability, both congenital and acquired. It also explored whether exposure to violence or negative risk-taking had played a role in their intimate relationships. This phenomenological research used semi-structured interviews and photo elicitation with the researcher's insider knowledge adding experiential substance and understanding to the discussion. Findings confirm sexuality for women with physical disability is marginalised and de-gendered making it less of a priority for professionals and policy makers and emphasising the need to more effectively support women with disability in relation to their sexuality, sexual expression and violence.

Keywords—Lived-experience, PhotoVoice, sexuality, violence.

I. INTRODUCTION

THIS research has shown that women with disability usually experience double discrimination on the basis of their gender and the presence of disability, especially when it comes to the sexual lives and identities of women with physical disability [1, ch.1]. Parents, support staff and practitioners, such as occupational therapists, have a role to play in ensuring women with physical disability possess the information necessary for them to express and experience their sexual selves free of violence. Violence needs to be understood in its broadest sense and can be reflected in exclusion. Businesses, such as the fashion industry, need to be considerate and inclusive of people with disability as clothing can be oppressive or expressive of sexual identity.

Everyday experiences inform and motivate this research which sought to explore the everyday and sexual lives of women with physical disability as these are intrinsically connected [2]. Fig. 1 is an artistic representation of the social interrogations experienced by women with physical disability when engaging in the community, rendering them both visible and invisible [3]. An exploration of the interconnecting topics of disability and sexuality of women with disability was undertaken as these interconnecting topics create controversy and are surrounded by myth [4]. This research is informed by *insider* knowledge [5]. Therefore, adhering to the adage, 'Nothing about us, without us' was essential [6]. The research involved engaging with other women with disability, learning about their histories, cultural understandings and the bureaucratic constraints they had experienced to inform deeper

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understandings of this little explored phenomenon.

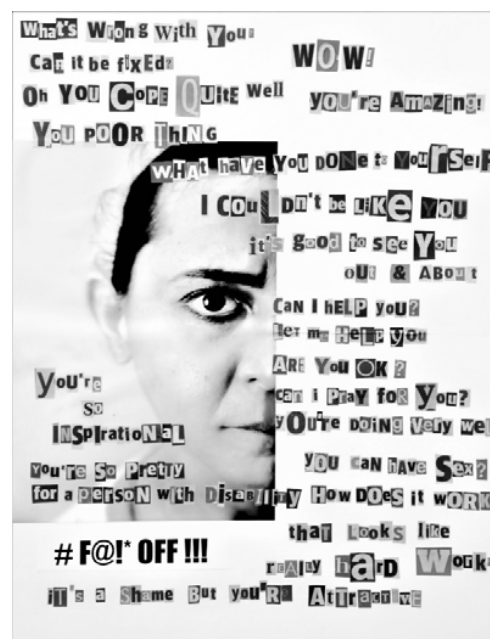


Fig. 1 #F@!* Off!!! Artist: Denise Beckwith Medium: Photographic and newspaper collage, 2018

Fig. 1 is of a mixed-media artwork, comprising a collage of cut-out newspaper fonts and a photographic self-portrait. The black and white high contrast photograph shows only a close-up of the right-hand side of the artist's face, cut vertically down the centre, from the forehead, through the nose and ending at the chin. This photograph takes up one-third of the artwork and is centred in the artwork; as if the artist's whole face was in the photograph. The backdrop of the photograph is white and so is the backdrop of the artwork. This gives a floating appearance to this half-face portrait. The space where the left-hand side of the artist's face would be is filled with individual black and white newspaper cut-out letters, which form new words, like a ransom letter. These letters are also arranged across the forehead and into blank canvas space on which the floating portrait sits. The artist's right eye is staring directly at the camera, with a hard cold stare and closed mouth. Text headline statements are: 'What's wrong with you?', 'Can it be fixed?', 'Oh, you cope quite well', 'You poor thing', 'Wow! You're amazing', 'What have you done to yourself', 'I couldn't be like you', 'It is good to see you out

and about', 'Can I help you?', 'Let me help you,' 'Are you ok?', 'Can I pray for you?', 'You're doing very well', 'You can have sex?', 'How does it work?', 'You're so inspirational', 'You're so pretty for a person with disability', 'It's a shame but you're attractive'. At the bottom of the artwork, below the portrait are larger letters that read, '#F@!* Off!!!'.

II. METHODOLOGY AND METHODS

This phenomenological research provided the opportunity to get to know 19 women who were either born with or acquired physical disability throughout the course of their lives. A phenomenological approach enabled the sexual identities, lives and experiences of the women to be explored in an in-depth manner. The women ranged in age from 23-81 years. 12 participants identified as heterosexual, three identified as bisexual, two identified as lesbian, one participant identified as queer and one participant identified as polyamorous. This last participant saw polyamory as more than a relationship status and described it as an actual extension of her sexual orientation. As our society dissects women as well as completely silences them, it was important to reinstate some of the power of the women by their determining how they self-identified including selecting their pseudonyms. Additionally, the first question asked to each woman was, 'Can you describe to me the language you use to refer to yourself as a woman with disability?' Their responses varied from emphasising their physical disability to alternatively wanting to emphasise other traits and abilities.

Shuo: "I am a woman disabled by Hypoxic Ischemic Encephalopathy. I haven't got Hypoxic Ischemic Encephalopathy, I am disabled by it. There is a difference. It's a distinction I like to make when I remember. I am disabled by it, but I haven't got it."

Lyndsey: "I usually describe myself as someone with a mobility issue and a medical issue. I usually say I am a woman first and I also identify as being queer or lesbian, having a physical and mobility disability. Interestingly, I always say I've got a good brain. It is about trying to connect with people so they see I am someone who has a sharp intellect and to distract attention from my disability. I'm a person first and foremost."

The women were also asked to select card identifiers detailing traits they identified as relevant to them and their identity. They were then asked them to prioritise the card identifiers. Figs. 2 and 3 are examples from Claudia and Cassandra.

Responses varied from woman to woman. Some chose to describe their disability in a medical way. Others focused on intersecting identities such as feminist and others chose to highlight roles that they have such as being a mother.

The women who participated were recruited via snowballing sampling where word-of-mouth and disability and social networks were major avenues of recruitment [7]. All 19 women participated in a semi-structured interview.

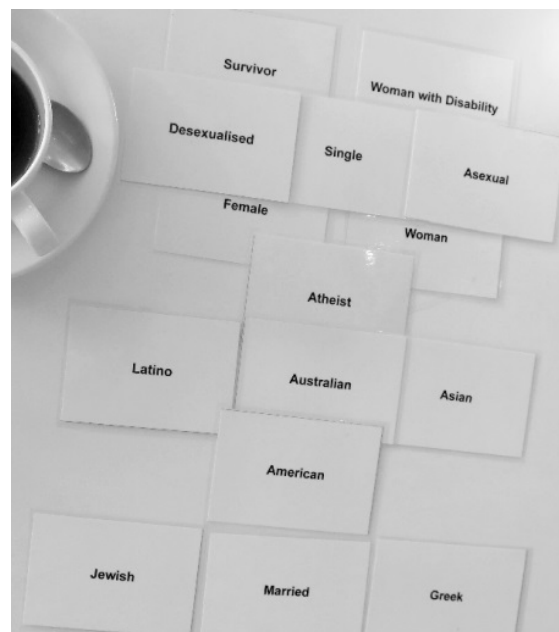


Fig. 2 Claudia's Card Identifiers. 15 white cards with writing photographed on a table displayed in hierarchical order starting from inner (high identification) to outer (lower identification)



Fig. 3 Cassandra's Card Identifiers. Six white cards with writing photographed on a table displayed vertically higher to lower in hierarchical order

17 participants continued participating in PhotoVoice elicitation, enabling them to take four photographs representative of their sexuality and sexual expression. 17 women who participated in the PhotoVoice phase of the research participated in another semi-structured interview.

The first semi-structured interview was an exploration of personal identification for the women, their sexual education background, sexual identity formation and potential experiences of violence. The second semi-structured interview

used the SHOWeD Model to better understand why the women took the photographs they did and explicate what could be learnt from them by the wider community [8]. Hence, the interview and photo elicitation provided a platform for women with physical disability to discuss their experiences of sexual education provision and violence as a means of heightening social awareness.

III. FINDINGS AND DISCUSSION

The sexual orientations of the women illustrate women with disability are sexually aware, active and open to sexual diversity. Amelia reinforced this point.

Amelia: "I think being disabled, you have to be more creative, accepting and willing to experiment. You are more open to different experiences... I imagine it's almost forced me, in a way, to consider more options than I would otherwise have."

There is this misconception that sexuality is not an inherent part of a woman with disability's identity. Yet, women with physical disability experience envy when they hear their non-disabled counterparts comment on being objectified. Women with disability would like to be objects of desire of an intimate partner but the ableist constructs of normalcy and beauty result in women not being seen as the ideal sexual partner [1, ch.4], [9]. This is reflected in Lyndsey's comment about a functional assessment being the motivation for enquiring about sexuality and sexual functioning.

Lyndsey: "It wasn't until I did a functional assessment that someone actually asked me about my disability and sexuality."

The sexual identity formation of children with physical disability is influenced by parents. Parents have an inclination to be dismissive of the need to develop their children's sexual identity through understanding and knowledge; they may assume that this requires specialist knowledge and is done by somebody else as a result [10]. The experience of Shuo, a woman with congenital physical disability, reflects this. Shuo spoke about the influence of her parents on early attitudes concerning sex and sexuality.

Shuo: "My parents tried to make me quiet and passive, at least where my sexuality was concerned."

The research highlights that women with disability open themselves up to sexual intimacy and sexual expression. They demonstrated their resourcefulness by using sexual products and the support of others to engage in sexual activity. Kim investigated possible options of support relevant to acquiring information about how to pursue a healthy and happy sex life with her partner and minimising the risk of pain. In order to do this, she sourced the support of an occupational therapist. Kim, who is a woman who experiences chronic pain due to physical disability she acquired later in life, thought sex was no longer an option for her and her partner.

Kim: "I have spoken to an occupational therapist and it was very helpful in relation to knowing certain positions. What happened was we were both pushed into the position. We straight away thought some things are not going to work. We thought, "Oh we're not going to be

able to have sex anymore."

Amelia talked about sexual aids and equipment assisting her sexual expression and participation. This is not often thought about as sex aids are seen as simply items to produce excitement and arousal rather than facilitating sexual participation.

Amelia: "Liberator wedges are big foam wedges essentially – big cuts of foam that are basically covered in a velvety plush material and are very sturdy. They are made for people who require support getting into certain sexual positions, as they may have difficulty maintaining that position."

Sexual products, which are designed for sexual pleasure, also have a functional purpose. This is illustrated by Toni, a woman with physical disability, whose body needs to be placed and held in certain positions to ensure that sexual participation is pleasurable.

Toni: "I've ordered through the mail a set of straps and bondage. I bought the straps for two reasons: it helps to keep my feet in place and it also has that exciting element to it that I'm bound. It's a matter of being creative. Toni explained, "The straps hold my legs in place and sex is much more pleasant for me."

Occupational therapists and other allied health practitioners have a role to play in ensuring women with physical disability can express their sexuality and sexual identities openly. This requires women with disability being given information that is accessible and practitioners being open-minded in relation to the topic of sexuality and sexual expression [10], [11, ch.19], [12, ch.4], [13].

Internalised ableism is experienced by women with physical disability. The comments below demonstrate this. Ableism and internalised ableism both originate from media outlets and as a result of socialisation [9], [14, ch.4]. Women spoke of an expectation of passivity or submissiveness that is expected of them as women with disability, attributable to disability identity and social messaging [1, ch.8], [11, ch.19].

Elizabeth: "I feel I used to be the bird in the cage and the cage was society's expectations. A person with a disability isn't meant to drink, swear, smoke or have a sex life."



Fig. 4 One of Elizabeth's PhotoVoice images, her parrot in a wire bird cage

When speaking about ideals in a partner and relationship, Mindy spoke about a desire to be seen as equal and independent which would lead to an intimate relationship.

Mindy: "I want a partner who will see me as equal and see me for myself. I always want them to see me as capable, independent and not offer help all the time or say, "Are you all right?" When I am out in public, I am in my wheelchair because I can't walk long distances. The opposite sex sees a woman in a wheelchair rather than simply me."

Mindy's comments illustrate the impact social messaging has on the potential formation of relationships. Attitudes play a large role in the perception of people with disability as sexual beings: if a person looks complicated, they are automatically asexualised and not seen as objects of desire [1, ch.8], [11, ch.19], [15].

The researcher originally thought that sexuality and sexual expression would be the most dominant topics of discussion given the sexual lives of women are often marginalised in comparison to their male counterparts [14, ch.8]. However, violence, both in intimate relationships and whilst accessing the wider community, was the major focus for many of the women which impacted on their ability to develop intimate relationships.

Two participants, Polly and Titi, spoke about using considered violence in the form of bondage, discipline, sadism and masochism (BDSM) as a means of transcending chronic pain associated with spinal impairments, acquired and congenital. BDSM is often thought not to be a possible outlet of sexual expression for women with physical disability, which is reflected in Toni's comment dismissing BDSM as being of interest to people with disability.

Toni: "Able-bodied people see people with disability as asexual, creepy and deviant with no control. People with disability are thought to have a lot of sex and be involved in BDSM or kinky sex. People with disability wouldn't be into that, they wouldn't be interested in it. However, if they are, there is something wrong with them."

However, the case study exploring the sexual life of Bob Flannigan proves that BDSM is a sexual outlet explored by people with disability and this was reinforced by participants, Polly and Titi [16].

Polly: "My partner and I see if we can find a way of channelling pain to redirect the energies of coping with pain and make it enjoyable. I try and make friends with pain."

Titi: "I'm part of a BDSM community. I'm a top. It's a mind-altering kind of thing where pain does become pleasure."

Polly and Titi like the control aspect of BDSM as they spoke about women typically needing to be passive objects of sexual interest to others, usually men.

Titi: "We're socialised to be passive in that regard. We're socialised to be objects, to actually ask for, which would then be put as demand by the other side to ask for pleasure."

Besides BDSM, a form of controlled and considered violence, other forms of violence experienced by the women ranged from physical violence, emotional violence to more disability-specific types of violence including having mobility aids moved out of reach, not being provided personal care assistance, left in isolation, and forced sterilisation for convenience [17]. When physical violence was discussed, as mentioned above, it was perpetrated by non-disabled men and men with disability. The latter was a surprising aspect of the research as it is assumed men with physical disability would not have the strength to perpetrate violence against another person or would not perpetrate it, as arguably, their masculinity does not meet the prescribed hegemonic ideals of masculinity [18].

Mae: "So with my understanding of disability, I saw him as almost able-bodied because as a leg amputee, he still had full function of all his limbs and he could stand and he could hop around and use crutches. He started to resent me...the violence would escalate...I was too reliant on him... I'd start to become independent and I'd start doing things for myself and he would be angry at that and again, the violence would escalate."

Cassandra: "He had paraplegia and he would get angry because things wouldn't work sexually for him. He was physically violent. He tried to strangle me one time on the bed. That's why I got rid of him. You wouldn't think it happens, but it does."

There is a disability hierarchy among both people with disability and mainstream society [19]. People with disability are positioned based on three factors: the amount of help they require, the associated costs of their disability and their general attractiveness. The disability hierarchy has been shown to contribute to the desexualisation of women with disability or automatically assign asexuality to women with more complex physical disabilities versus those with less obvious physical impairments [15]. The disability hierarchy was illuminated through the comments of Mae and Cassandra as both emphasised their domestic violence partners had a leg amputation or paraplegia respectively, thus emphasising the difference in impairment types further distancing themselves from their perpetrators [19].

Women spoke quite explicitly about violence they had experienced. Cleo Patra, as a woman with cerebral palsy as a result of acquiring meningitis in childhood, highlighted the unique forms of violence women with disability experience.

Cleo Patra: "My mother consented to me being forcibly sterilised because in her eyes I was too profoundly disabled to be in any relationship. She told me no man would want to marry me. She also told me I was also not capable of being a mother."

Cleo Patra did marry, proving wrong her mother's prediction. However, her husband perpetrated unique forms of violence such as leaving her in bed, moving mobility equipment out of reach, withholding fluids and leaving her alone in their house, socially isolated [17].

Cleo Patra: "He would leave me in bed and walked out of the house. He wouldn't give me anything to drink for a

whole day either. He would go away and then nobody would come and help me. I needed him to help me get into my wheelchair.”

Wheelie Crone as a woman who acquired disability prior to her teenage years married a non-disabled man and he perpetrated violence against her, manipulating and controlling her body in order to perpetrate the violence. Mae spoke about mental manipulation from her perpetrator resulting in dependence and self-doubt.

Wheelie Crone: “He was physically violent toward me and he discovered very quickly if he sat on my legs and held my right hand and arm he could then just hit me as hard as he could and I couldn't do anything about it.”

Mae: “I guess to all intents and purposes, when you're in an abusive relationship, disability or not, the perpetrator makes you totally reliant on them, taking away all your independence so you're this completely helpless person that can't do anything for themselves.”

The above comments illustrate physical and mental manipulation being used as tools of violence by parents, men and the medical profession to control women with physical disability. As discussed, violence is being seen in its broadest sense. This includes women with physical disability feeling as though they are not respected as fellow women by non-disabled women as is emphasised by Mindy, a young woman with cerebral palsy.

Mindy: “I went to a hen's night and some of the women said, “Oh, just shut your ears, this is not for you.” I felt like the child in the group, which I was not. Reflecting on it, I did feel inferior to them and not at the same level.”

Some women spoke about a feeling of needing to settle or of gratefulness to be in a relationship as this is not a certain outcome for women with disability.

Empowerment: “I felt I had to settle with what was given to me – so, again settling. I think a lot of people settle, regardless of disability or not.”

Mae: “It's going to take a special man to want to love you”. I was told that by my mum. I was a single mum and I was in a wheelchair. “It's going to be a special man to want to take you on”.”

Some women experienced medical forms of violence. Forced sterilisation was an example of this, illustrated by Cleo Patra and her forced sterilisation for the purposes of convenience. Kate is another participant who spoke about medicalised violence due to having vaginismus, which is associated with her disability, cerebral palsy, dismissed due to her sexual orientation.

Kate: “When I have said, “I'm a queer woman.”

Doctor's responses have included, “Well, why are we bothering to fix it then?” Even if I only slept with women, I would need to be able to have a speculum inserted and I'm not able to do that.

Kate's experience is reflective of an automatic asexualisation of a women with disability as medical practitioners were reluctant to treat an existing condition and it is also evidence of the narrow lens through which the

sexuality and sexual health of women with disability is seen.

Emphasis is placed upon the procreational aspects of sexual participation which is not often considered for women with disability, let alone those with a physical disability, because the perception is that there is a high level of physical activity associated with motherhood [20]. Conversely, women who have physical disability felt their gender was reinstated once they became a mother [21]. They believe they have reached an expectation of normalcy as the commonality of raising a child leads to women with physical disability having expectations of being accepted by non-disabled women [22]. Mae reinforced identity reclamation through becoming a mother.

Mae: “I guess I was part of the able-bodied female tribe. Other women said to me, “Oh, you can have babies too just like us?”

The medical profession wants to control and assert their authority over the bodies of women with physical disability, automatically assuming it is necessary for a woman with low level spinal cord injury to have a caesarean section is only one example of this. The participant Empowerment had this experience:

Empowerment: “My obstetrician said, “Just be aware that you might have to have a caesarean.” Her thoughts might have been clouded by the fact that she had preconceived ideas of what disability is all about, until she did her own research and then she realised it was possible for me to give birth naturally.”

Scarlette, who is a woman with a form of dwarfism, found out she was pregnant quite late into her pregnancy and was told by a gynaecologist if she had come to him earlier they could have *managed* it.

Scarlette: “I was told the gynaecologist was top-notch and when he looked at the report from the ultrasound that I had saying I was 20+ weeks pregnant he looked at me and said, “You realise if you came to me earlier we could have done something about this.” Bastard, absolute bastard.”

It can be seen that there is less focus on the diverse sexual expression and experience of women with disability. It is hoped this research goes some of the way to broadening the understanding of what constitutes violence in the lives of women with physical disability so they can be supported more appropriately. Furthermore, it is essential to see the women as resourceful and resilient.

Businesses also need to see women with disability as consumers. This will enable women with physical disability to be seen through a lens of opportunity: for example, the fashion industry needs to learn that clothing can facilitate their sexual expression and therefore needs to be accessible. This perspective is not widely understood and women with physical disability are again excluded. Participants' comments below reflect the various experiences encountered when trying to express their sexuality and femininity through clothing.

Mae: “Fashion needs to be multi-use and to cover not just people who stand and walk and all that stuff. For people with bad hands, get rid of really tiny buttons. I wear really bright clothes. It's how I reshaped and framed

myself for the person I am that people see now.”

Toni: “I can look sexy sitting down. I think it has taken me such a long time to realise that because we don't have role models.”

Shuo: “I wore track suits, which were easy to put on, nearly all the time. I ended up hating track suits. I felt *neutered* in them.”

Clothing can be oppressive, infantilising or an expression of sexiness and appeal which is not often afforded women with physical disability as they are seen as objects of pity and asexuality [1, ch.4], [11, ch.19].

IV. CONCLUSION

Intersectionality is the recognition that identity is multi-layered and cumulative, with roles and life experience contributing to identity development [23], [24]. Intersectionality enables women with physical disability to identify in the way they wish, which is the premise of this research. Intersectionality enables the women to have choice and control over how they are recognised. The intersecting nexus is what will bring about change for women with physical disability in terms of their sexuality, sexual expression and responses to experiences of violence. Adopting an intersectional approach is the only way women with physical disability will overcome barriers of environmental, attitudinal and informational exclusion. The women who participated in the research do not want to be seen as victims but rather as survivors, who are still open to the idea of sexual intimacy and love even though they have experienced violence in its broadest sense.

Women with disability want to be seen as more than their physical disability and want the right to participate in sexual lives that express their sexual wants, needs and free from violence. Information provision, resources and services need to be made accessible to women starting from the provision of accessible services right down to the attitudes of staff within the services. Not supporting women with disability to express their sexuality and sexual identity can further marginalise them, as experienced by these women. Social exclusion and marginalisation are forms of violence.

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