

Title: Disabled people's voices on sexual well-being

Abstract

Disabled people have equal right to positive sexual well-being including sexual citizenship, however, this may not always be experienced and support for sexual well-being is less likely to form part of services offered by professionals in health and social care services. Inspired by disabled people, phenomenological research into the experience of sexual well-being for a group of physically disabled adults was undertaken. The results show that sexual well-being is understood in several ways. The notion of sexual well-being raises issues of the physical body, connection to notions of normality and what support disabled people want from health and social care professionals. There is a clear link between sexual well-being and other aspects of physical and emotional well-being making it an issue which needs to be proactively addressed by health and social care professionals in ways which are directed by disabled people.

Keywords: physical disability, lived experience, sexual well-being, professional practice

Points of interest

- This paper considers disabled people's experience of sexual well-being.
- In-depth interviews are used to explore issues around sexual well-being.
- We discuss how professionals can use respectful, non-judgmental approaches to enable discussion of sensitive issues, including sexual well-being.
- We argue that sexual well-being is an important part of general well-being and should be part of health and social care practice with physically disabled people.

- We suggest that professionals require knowledge about sexual well-being to be able to address the issues that matter to people and to encourage different thinking around disability and sex.

Introduction

The **sexual well-being** of physically disabled people is often unrecognised in the public domain and research (Shuttleworth 2010; Schaub et al 2017). The media reinforces normative conceptions of sexual activity, sexual behaviour and determines what is 'sexy', sexually disenfranchising disabled people (Dune and Shuttleworth 2009). Unrealistic portrayals of sex, where the participants are conventionally beautiful and having fantastic, spontaneous sex, is a myth perpetuated by the media (Dune and Shuttleworth 2009). The message communicated through such portrayals undermines self-esteem and corrodes sexual relationships for most people (Connelly 2014), but for physically disabled people an additional presumption of asexuality is reinforced by the dearth of realistic and positive cultural representations of disability and contributes to the 'otherness' of disabled people, increasing fear and ignorance (Wendell 1996; Kaufman et al 2007; Stevens 2010; Briant 2013). Media portrayals of sex communicate anxiety about non-normative bodies and contributes to the sexual disenfranchisement of physically disabled people (Shildrick 2007; Kangaude 2010); disability becomes equated with asexuality (Shakespeare et al 1996; Milligan and Neufeldt 2001; Kaufman, et al, 2007; Bywater and Jones 2007; Owens 2015). 'Being deemed asexual is the most egregious sexual harm that disabled people contend with because it is a direct assault on our personhood' (Stevens 2010, 62): it is a failure to recognise people's full humanity which adds to the negative effect of impairment impacting on the person's sense of their sexual allure (Walters and Williamson 1998) and sexual well-being (Stevens 2010).

However, disabled people's legal right to sexual well-being is made clear within current legislation: Article 8 of the Human Rights Act 1998 states that everyone has the right to respect for their private life and family life which, according to the European Court of Human Rights, includes the protection of 'sexual autonomy, confidentiality, dignity, forming and maintaining personal relationships and allowing them to develop' (de Than 2015, 95). Article 19 of the International Convention on the Rights of Persons with Disabilities (2006) also makes clear that governments have responsibility to enable disabled people's 'full enjoyment' of this right through their 'full inclusion and participation in the community' (Parker and Clements 2008, 509).

What is sexual well-being?

The World Health Organisation's (WHO) definition of sexual health incorporates multiple dimensions of well-being:

'Sexual health is a state of physical, emotional, mental, and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction, or infirmity' (WHO 2012, 6).

However, the word 'health' suggests clinical concerns whereas the term 'sexual well-being' suggests a broader concept relating to how people experience their lives and links to the notion of general well-being which has gained significant recent international attention in relation to quality of life, economic progress, productivity and the promotion of health (Penny 2015). This attention has led to measures of well-being becoming part of international tools used to judge social progress (for example in the UK the Office of National Statistics started to measure well-being by including well-being questions in the annual survey).

In England adult social care legislation is underpinned by the well-being principle (Care Act 2014, s1) which requires that all care and support interventions are focused on improving

well-being related to specific aspects, or domains, of life. The four well-being domains within the Care Act 2014 most relevant to sexual well-being are relationships, physical, mental and emotional health, personal dignity and protection from abuse and neglect. The connection between sexual and general well-being makes it an issue of relevance to well-being focused, person-centred health and social care practice but often sexual well-being is left out despite **sex and sexual** expression being fundamentally linked to identity (Nusbaum and Rosenfield 2004).

Sex and identity

Humans are physical beings and the details of our physical selves are important to how we interact with the world; as Merleau-Ponty (1962 cited in Finlay 2009) states the world is experienced through the body, but it is the world which makes us conscious of our bodies, suggesting the importance of the individual's social and cultural context in their, and others', responses to their body and sense of identity. Notions of normality are important to our identity; they are the preconditions of participation which become internalised through unnoticed social disciplinary processes which only come to light when our ability to meet the standards is threatened (Wendell 1996). Sexual expression is part of personal identity, and to: 'strip sexuality of its significance or to silence it is to damage the very notion of being human' (Foucault (1990) cited in Bywater and Jones 2007, 59). Personal identity is lived from the inside but becomes externalised by the narratives to which we are exposed and through which we interweave our own narratives, so to deny sexual identity through ascribing a non-sexual nature to physically disabled people is to deny a core component of being human.

Professionals' role with sexual well-being for disabled people.

A key part of ethical practice is the acknowledgement of power dynamics within relationships between users of health and social care services and professionals (HCPC 2012, updated 2018). Professionals often determine what is considered the focus of any interaction (driven by agency priorities and financial constraints) rather than the individual concerned. Person-centred approaches and well-being focused policy (including the Care Act 2014 in the UK) can potentially empower disabled people to determine what is individually important and enable professionals to promote the concerns identified by disabled people rather than agency priorities. Health and social care professionals working with physically disabled people need to be aware of the marginalisation and discrimination disabled people experience (Oliver et al 2012). The perceived lack of social status and the negative discourse associated with disability creates a social environment which disadvantages people living with disability (Oliver et al 2012), including opportunities for sexual expression and developing sexual well-being (Milligan and Neufeldt 2001). Professionals have a responsibility to promote well-being which includes encouraging disabled people to develop an attitude towards their body which is realistic, without 'launching into 'let's learn to love our bodies' or ignoring the issue altogether' (Myers and Milner 2007, 94). Professionals cannot condone the damage done to physically disabled people by the assumption of asexuality. Promoting sexual self-esteem which aids confidence, health and contributes to safeguarding from sexual abuse becomes an imperative for preventative-focused work. This means enabling the individual to feel sexually informed, competent, attractive and acceptable to others by acknowledging their sexual identity and working with them to find ways to express their sexual self (Mayers et al 2003). But professionals feel ill-prepared to engage in work supporting disabled peoples' sexual well-being (Dyer and das Nair 2013) and there has been limited research into what support disabled people want from professionals. This study aims to bridge the gap in knowledge and

the following section describes the methodological approach taken, leading into the findings of the research project.

Methods

The dilemma of the researching practitioner

The research underpinning this paper emerges from doctoral study undertaken by the first author who, at the time of the study, was a social worker with a specialist team providing support to physically disabled adults. The research was prompted by the experience of an individual who had sought advice from sexual health services but had been informed that support would only be offered if he was sexually active. Frustration at not being able to express himself sexually had a profound impact on his well-being and prompted the author's professional concern and curiosity about the lived experience of physically disabled adults and the meaning they ascribe to their experience of sexual well-being, or its absence.

Undertaking research whilst also practicing as a social worker requires continuous reflection, especially in respect of the power differentials within the research relationships. The author was aware of their positionality as a white, middle aged, female social worker already known to most of the participants prior to the study, and how this positionality enabled privileged access to individuals. Social workers have latent power associated with their professional status, as well as overt legislative power (Banks, 2006); the involvement of participants already known to the researcher raises issues of power and the possibility of individuals participating as a favour, feeling obliged or saying what they thought was required.

Exercising reflexivity enabled these tensions to be balanced by providing clear and repeated information about the research project goals and by participants' previous knowledge of the authors' professional and trustworthy conduct which consistently demonstrated the author's motivation being built on their commitment to the core ethical values of social work: concern

for the dignity and worth of the individual, their well-being and social justice (Banks, 2006).

The pre-existing, respectful relationship enabled the participants to discuss issues they would not do with an unknown researcher.

Phenomenology: exploring the lived experience

Phenomenology, with its concern for human well-being and lived experience (Galvin and Todres 2013), is pertinent to the experience of physically disabled people who continue to face discrimination regarding their sexual well-being (de Than 2015; Liddiard 2018) despite improvements in inclusion and visibility of disability resulting from campaigns by disability organisations and subsequent equality legislation (in the UK this includes the Equality Act 2010). Phenomenological approaches use relationships of openness, participation and empathy to create human understanding (Finlay 2009) and the value placed on embodied lived experience makes it an approach especially suitable for research which explores the unique and diverse experience of disability. This research project was specifically concerned with individuals whose eligibility for health and social care services was defined by their physical bodies and therefore, whose interaction with their social and cultural context shaped their and others' responses to their body (eligible/ineligible?), and the nature of this interaction informed their understanding of the social world (a benign source of support/a place of judgement and rejection?).

Data collection

Phenomenological research seeks depth and the number of participants is therefore limited. Purposive sampling for this project identified ten potential participants representing a range of ages, genders, different relationship statuses, with both acquired and congenital physical disabilities. Human interactions, valuing embodied communication, were core to the research described in this paper and therefore face-to-face contact was essential in meeting the

research aims. Interviewing as a method is founded on the modernist construction of participants as rational and self-reflexive beings (Aldred and Gilles 2002) which has the potential to be progressive by including marginalised groups often excluded from participation in research, such as disabled people (Shuttleworth 2010). Research concerning disability, especially in relation to sexual well-being, has been criticised for excluding disabled people, focusing on function and avoiding topics which make researchers uncomfortable (Shuttleworth 2010). In this study unstructured interviews enabled the research participants to speak privately in a location of their choice and to describe in their own words their unique perspectives. Interviews were conducted between participants and the first author. Four of the participants were known professionally to the interviewer (but not currently working together) and the other two were recruited through work-based colleagues. The participants were provided with information about the project, including the methodological approach, and the interviewer's qualifications and skills as part of giving informed consent. Purposive sampling was used because the criteria for inclusion (physical disability and involvement in statutory social care services) meant there was a small population to draw from.

Reflexive engagement, allowing participants to start where they wished in their account, to self-prioritise their experiences and to choose their own terms meant the interviews were approached in ways open to possibility, with a sense of discovery and an assumption that the social world 'is not a place where we can assume that we all share the same understanding of different things' (Sheppard 2004, 144). The use of keywords which emerged from extensive preparation ensured relevant content whilst retaining flexibility. Keyword prompts:

- physical experience;
- felt experience;

- emotional effects;
- barriers, personal, environmental, social;
- opportunities;
- professionals, help, hinder.

Flexibility was required regarding the number of interviews carried out with each participant due to the individual nature of disability. The interviews were audio recorded and transcribed verbatim by the interviewer. The transcripts were given to participants to make comments and amend as they required.

In-depth, unstructured interviews offer a partnership of knowledge creation where the conversation is guided by the respondent with the researcher providing input as part of the discussion and a relationship of equals is sought rather than one between expert researcher and participant (Alston and Bowles 2003).

Location

The research project took place in south west England. There is a lack of ethnic diversity amongst the participant population, however, this is representative of the general population of the location (95.5% white: 2011 census, Dorset For You) (excluding Poole and Bournemouth).

Ethics

Ethical approval for this research was gained from the Research Governance Review Group at [location retracted for peer review] and separately from the first author's employing agency. All participants in the research project were able to give informed consent to

participate which relies on the provision of good quality information and the opportunity to ask questions. However, truly informed consent is not possible at the outset of unstructured interviews due to the uncertainty of how the conversation will develop and requires ongoing consent (Miller and Bell 2002) giving participants freedom to withdraw, signal discomfort about a topic, change the subject or retract any statement at any stage. Participants have the right not to reveal their innermost thoughts which might emerge through an interview (Duncombe and Jessop 2002) so ethical research necessitates a clear exit strategy.

Ethical research practice requires inclusion of seldom heard voices who may be excluded from participation due to disability related issues such as access or communication. One participant in this study was unable to communicate without skilled assistance. This individual's input has been extremely valuable, adding the perspective of the literally 'voiceless'.

The Social Research Association Ethical Guidance (SRA 2003) states that social researchers have a responsibility to ensure the inclusion of individuals who might otherwise be excluded for reasons of 'communication, disability, comprehension or expense' (Social Research Association 2003, 4.5). Facilitating this participant's involvement meant approaching consent giving in a way which was acceptable to him whilst also meeting ethical standards. This involved reading the research information aloud, whilst being audio recorded, to ensure that they heard the information, clarified any questions and were able to give informed consent. This follows advice from the Equality and Human Rights Commission (EMRC) provided to medical professionals when gaining consent from patients with disabilities: 'If leaflets are used to describe issues, then these need to be either available in different formats or communicated to the patient in an alternative manner, eg by being read out' (EHRC 2010). Principles of inclusion and enabling self-determination in these circumstances justify this approach, which could otherwise be considered coercive. It is ethical to enable involvement

and unethical to exclude people with such disabilities, for without support they will be absent from research which will not be 'facilitating the process by which individuals with disabilities can tell their own stories' (Ashby 2011, 133).

All research requires consideration of ethical practice, being a researching practitioner raises additional concerns, principally around intentionality and power differentials. Within social work anti-oppressive practice is both promoted and demanded by the professional values and the Codes of Practice (Health and Care Professions Council). However, oppression can occur even when the oppressor is motivated by the best of intentions (Strier 2007). Without constant attention to, and reflection on, assumptions and sources of power it is easy to oppress. Finlay (2011) suggests there is no clear-cut solution to this dilemma, but the researcher needs to remain mindful of their ethical responsibilities throughout the research process. The research on which this paper is based was conducted with attention paid to the author's several roles (citizen, social worker, researcher) each one subject to personal values, ethical principles or professional codes. However, inquiry into such a sensitive, personal topic as sexual well-being requires more than external codes of practice. These are ethical considerations which can-not be solved 'solely by the application of abstract rules or guidelines' (Mauthner et al 2002, 1). It is more about having 'ethical ways of thinking' (Mauthner et al 2002, 1) which go beyond traditional moral philosophy to embrace reflexivity where the researcher's emotions and feelings are part of the research process. This links to the suitability of phenomenology, where the 'phenomenological attitude' (Finlay 2011, 73) starts with the participant's perception with close attention paid through 'curiosity, empathy and compassion' whilst sufficient distance remains to 'challenge and be critically analytical where appropriate' (Finlay 2011, 78). The pre-existing relationship between the researcher and all but one of the participants influenced their willingness to contribute. While this may be considered as leading to potential bias, it is also apparent from participants that their

willingness to share their thoughts was because of the pre-existing respectful relationship.

With more time and resources additional participants unknown to the researcher could have been recruited via the snowballing method with time given to rapport building.

Data analysis

Unstructured interviews can be difficult to analyse due to the amount of data generated and potential for wide variation in content (Butler-Kisber 2017). Data analysis aims to answer the research question by breaking down data into its component parts (or units of meaning) and trace these back to the underlying sources, thereby exposing the general principles which can be used to explain the phenomenon being researched (Denscombe 2010). To achieve the aim the interviews were transcribed verbatim by the author, then checked to ensure accuracy and imaginatively return to the physical and emotional site of each encounter. This enabled an understanding of a sense of the whole interview, its content and feeling and stepping into the world of the other. Transcription facilitated a close consideration of each interview, listening in detail to the non-verbal signals of participants' emotions, such as sighs and laughter, and reflection on the researcher's contribution to, and influence on, the content of each interview. The transcripts were read and reread to reveal what the participants felt, thought and experienced as sexual well-being; letting the data speak through repeated rereading/relistening, allowed meaning to surface. Dwelling with the data displaces the researcher's world view and allows other voices to enter, hearing and feeling their strength, fear and frustration, sharing humour about the universal human predicament of life within frail physical bodies. Analysis was an inductive process allowing the data to provide the structure. Each transcript was broken down into meaning units which emerged 'like knots in the web of experience around which meaning is spun' (Van Manen 1984, 59). Shared

elements amongst the meaning units enabled grouping into overarching themes which were checked with participants to ensure the researcher's interpretation was not imposed on the participants' meaning. The overarching themes provide the framework for rich descriptions of the meaning of sexual well-being uncovered by the study.

Results

Brief introduction to participants

The research included six participants, three women and three men, who are identified in this paper by their pseudonyms: Amy, Kevin, Jack, Zack, Penny and Betsy. They varied in age from 18 to 55. Amy and Jack have complex congenital disabilities, Zack and Kevin have neurological disabilities, Penny experienced a spinal injury and Betsy a stroke with further medical complications.

The focus of the research was sexual well-being however, and with whomever, this might be experienced by the participants. Therefore, whilst an individual's sexuality is a core aspect of their identity sexual orientation was not a primary focus for the research study.

The results reveal participants' insights into the meaning and significance of sexual well-being. New knowledge gained from the participants' unique perspectives supports findings from previous research, indicating the persistence of stereotyped attitudes towards disabled people (Oliver et al 2012). The study also provides new insights into the skills required from professionals which builds on other literature (Dunk West 2007; Myers and Milner 2007; Sloane 2014). The participants have disclosed exclusive data related to the phenomenon of sexual well-being and the researcher's status as both social work practitioner and researcher enables a unique, insider, perspective unavailable to other researchers.

The meaning of sexual well-being

The meaning of sexual well-being emerging from the study draws together both physical and psychological elements. The participants reveal that sexual well-being is the experience of, and possibility for, sensual pleasure, where the self is fully present as human body and human emotion. It is the capacity to communicate, give and receive intense sensual pleasure alerting the self to possibility.

Kevin: Being close to another, knowing I am alive through sensual pleasure.

Betsy: Sexual self-esteem.

Zack: Having sexual fun.

Amy: Being healthy, being desirable.

Penny: Physical and emotional connection to another and having a normal life.

Jack: Being the powerful centre of sexual attention.

Sexual well-being is humanly validating and allows us to acknowledge that all humans have a fundamental need to give and receive love and affection (Maslow 1954 Milligan and Neudfeldt 2001). The importance of sexual pleasure is highlighted, supporting Tepper's (2000) argument regarding the lost discourse of pleasure.

Kevin sums up his experience of the absence of sexual well-being:

Kevin: We're hard wired to produce little ones, we are just animals that, unfortunately, can reason. Which makes life even more... It's really crap because you can see where you are going wrong. Part of me is thinking so nobody's... I'm not going to find someone that I love.

The significance of self-confidence and sexual self-esteem (McCabe and Taleporos 2003)

which Kevin expresses indicates that sexual well-being is more than sex, but about attractiveness, desirability and confidence:

Kevin: My confidence... my confidence is... I don't want to go through this again... the last time I had sex I felt used and it was horrible. Part of me is thinking sex is the problem.

His negative experience of a relationship where sex left him feeling 'used' reduced his confidence to seek romantic attachment. He says he could go to places to meet people but:

Kevin: There's always that thing, I don't know... I've no problem meeting new people. But when it comes to the romance side of things, that's when it, yeah that's the thing. I mean, on the internet it's, some slight flaw, there are so many sweeties in the sweetie shop, right there's a slight scratch so put that one on one side. I'm not very good at selling myself. You need, ultimately that's down to confidence. But at some stage, you see, it comes down to what do you do for a living, and then it's, well, why don't you work anymore?

The lack of self-confidence which Kevin expresses relates to the negative construction of disability; in Western societies status is associated with financial success, employment and independence seen in terms of self-sufficiency (Goodley et al 2014). Disabled people continue to experience marginalisation and discrimination (Oliver et al; Liddiard 2018). Despite progress towards social inclusion (for example the Equality Act 2010 in the UK) fewer disabled people are in employment and greater numbers of disabled people live in poverty than non-disabled people (Goodley et al 2014; Joseph Rowntree Foundation 2015) impacting on opportunities to participate in activities where relationships can be made. Marginalised groups are devalued, assigned low-value roles or struggle to find a socially

valid role which enables integration and social acceptance. Social Role Valorisation Theory (Wolfensberger 1983 cited in Barnes, 1997) holds that the good things within a society will be accessed by those assigned valid roles. The negative discourse of disability, along with the narrative of illness, age and disability being a burden, reinforces role devaluation (Briant et al, 2013; Quarmby, 2011). Such stigmatisation profoundly impacts on well-being (Gofman 1963). Kevin also expresses the pressure he feels from stereotyped gendered role expectations, he is unable to work and feels disregarded by others because he does not display stereotypical male characteristics such as being physically strong, financially successful or independent. His experience supports other research findings, for example Seidler, 2006; Tepper 2000; Goodley et al 2014).

Sex as a connection to normality

The participants discussed sex as a connection to normality; two discussed how they associate the idea of sexual well-being as firmly linked to normative sexual activity, but differed on their perception of what sexual activity might include:

Jack: Girl, fucking. Sperm comes easy, that my body parts are healthy. Big man-involves being a big man, being macho. In control of a girl, getting her to do things.

The total lack of control Jack has over his body, and the absence of any sense of embodied equality leads him to look for control in other ways. He expresses his desire for control through fantasising about sexually controlling another person. However, his lack of sex education, inexperience of sexual or romantic relationships or participation in general peer exchanges to help develop a mature understanding of equal relationships, means he lacks insight into the potentially exploitative nature of his sexual fantasy. Jack's lack of experience and social opportunities supports literature indicating disabled peoples' exclusion (Milligan and Neufeldt 2001). Jack sought advice from sexual health professionals but was informed

that until sex became a relevant issue in his life information or support would not be offered. Not acknowledging Jack as a sexual person, or giving attention to his emotional well-being, also missed an opportunity to engage Jack in sex education which could have explored the nature of respectful relationships.

In contrast Penny had a broader definition of what constitutes sexual well-being, including pleasure-focused physical contact. Penny describes the sensitivity to touch in some areas of skin and the sensual pleasure this offers which is highlighted in other research (Richards et al, 1997). This pleasure is part of her definition of sexual well-being as it signifies the intimacy she experiences with her partner. For Penny, this intimacy feeds her sense of self and connects her to everyday life because it is:

Penny: Normal. It's part of life. And it's a release too.

Underpinning this statement is intimate knowledge of her body. She can anticipate the effects of activity in regions of her body without sensation (for example, how long her skin can tolerate pressure before damage occurs as she does not experience pain as a warning). Extensive communication with her partner, which she describes as a source of pleasure in itself, along with openness to her altered body, has enabled her to adapt to her impairment over many years. She has used this information to design personal sexual activity rather than try to emulate the spontaneous, often athletic sex portrayed in the media:

Penny: There's no point in hyping yourself up because if it doesn't work it doesn't work. You know, if your legs are in that bad a spasm they are going to kick all over the place you can't do anything about it. So you have to either not have full sex or, you know... hand job or whatever. Or... you just go with the flow and think 'oh well' not tonight.

Kevin illustrates his perception of the connectedness between his body and mind:

Kevin: Um unhappiness affects it. Big style, happiness affects it... When I'm in a relationship, I've been in a relationship and things have been going all right, life is a heck of a lot easier... whether it is, you know, knowing there is someone who cares, just that support I suppose, I don't know.

His comment reflects the relationship between mood and physical well-being (DoH 2014).

But he perceives his body as something unpredictable which impacts on his relationships and self-perception:

Kevin: It's a thing I have a problem with making commitments with people, so I have to make a proviso that I am ok on the day... because you were feeling bad you feel like you are letting them down.

Disconnect between the desired self, promoted by stereotypical views and the real physical self (Shuttleworth 2000) is also something Zack reflects on. His inability to perform 'normally' is a regret for Zack whose body is experienced as different from what he previously inhabited – he expresses his desire to return to the old 'him' where he fulfilled traditional roles including husband, father and 'breadwinner':

Zack: The one thing I'd love to do is to become active down below, if that makes sense. But that is what I used to be like, yes, I've got what I've got, and I don't like it but that's one of those things. I'd love to go back to what I was... I dream about it yes, but that's as far as it goes 'cos I know at the moment I can do nothing about it.

There's nothing more that I'd love to do than grab hold of a girl and have some fun.

Zack seems resigned to his situation, unable to imagine approaches to sexual well-being which differ from normative forms of sexual activities.

Perception of asexuality due to physical disability

Physically disabled people are subject to the same socialisation and expectations as the general population, also internalising notions of frequent, exciting, acceptable, 'normal' sex (Harris 2002; Dune and Shuttleworth 2009). The promotion of normative notions of sexual expression is a form of stigmatisation which renders the non-normative person asexual as they are excluded, deliberately or as a matter of omission, from the opportunities where romantic and sexual relationships often occur (Milligan and Neufeldt 2001):

Researcher: Are there things going on and places you would like to go to?

Jack: Yes. Clubs.

Researcher: Is getting there a problem?

Jack: Yes, money, access.

When people believe the myth of asexuality themselves it limits their possibilities as sexual beings and damages self-esteem (Kaufman et al 2007):

Amy: I suppose not so much as asexual as not seen as a sexual being. You see someone in a wheelchair or someone with crutches maybe and I suppose some people don't see them as a possible partner.

Betsy: Is there such a thing as a sexual side to a disabled person? And socially I think there is the assumption that once you start walking with a stick you don't want to (have a sexual relationship).

Amy: I think the instant someone sees that I am in a wheelchair they must go 'Oh, she's not a potential love interest'.

These comments reflect stigma experienced by disabled people (Oliver et al 2012). Non-normative bodies create anxiety in others that leads to the denial of sex having any place in

the lives of physically disabled people (Shildrick 2007; Kangaude 2010) a point which Penny supports from her personal experience:

Penny: I had one lady accuse my partner of abusing me by making me pregnant, making me have sex. And then there was another lady... I um, I had all four children with me, the last was a tiny baby... this lady looked at me and said, 'Are they your four children?' And she said 'It shouldn't be allowed, disgusting. How can you look after children, how can you cook their dinner, how can you feed them?'

Penny's experience reflects Kevin's comments regarding societal gendered expectations; for Kevin it is his inability to find employment which reinforced a sense of 'otherness', for Penny attitudes towards disabled people becoming parents is stigmatizing (Oliver et al 2012).

Jack expresses this point in a different way:

Jack: Carer. A girl sees me with a carer it gets in the way.

Researcher: What do you think the girl thinks?

Jack: Difficult. But I am worth getting to know.

The constant presence of others 'looking after' Jack highlights his difference from the stereotypical view of independent masculinity and makes it difficult for him to make personal relationships. He frequently experiences people addressing his carer rather than himself, illustrating the discrimination disabled people continue to experience.

What qualities, skills and attitudes are wanted from professionals

Non-judgemental attitude

All the participants expressed the fundamental importance of sensing acceptance and the absence of judgment from professionals. This key point emerges from the felt experience of

being judged by professionals despite codes of practice which require empathy and non-judgmental approach as basic professional values.

Betsy: I think they need to leave their personal opinions at the door. Because the opinions that came out during my experience were so strong.

Amy states what she feels is important:

Attitude is the thing (rather than services). There needs to be something said as well, you are here to discuss care but also if there is something they need to talk about going on in their lives I think that is an important thing.

Amy's comment highlights the importance of professionals being open to the issues which matter to people; openness is a core health and social care professional standard (HCPC 2018).

Knowledge

Participants identified how important it is that when working with professionals they are confident that the practitioner has knowledge about disability issues, including the impact of impairment on sexual identity and well-being. Without confidence in the practitioner's knowledge they would be unlikely to raise the subject, even at the expense of gaining help. This finding reflects Oliver et al (2012) argument that social workers who lack knowledge about of the issues important to disabled people are distrusted.

Jack states that he is:

Embarrassed to ask for help.

He has approached professionals before for advice but found the information poor and out of date and this has impacted on his confidence to make further inquiries. For example, Jack had sought information about different sexual activities suitable for someone with his impairment.

Betsy comments that inquiries about sexual well-being from professionals would be likely to receive positive responses:

In my experience it is something... I don't think is appreciated... you know, by professionals or anyone else. If you do get asked it's very perfunctory... it might be sort of briefly thrown in... sort of, 'Do we need to do some sort of check on you?' or something. It would have been quite nice actually if someone asked, but I don't think anyone has.

Professionals can positively influence self-esteem and confidence through having the knowledge to discuss issues which are important to the individual which includes recognising and acknowledging disabled people as sexual beings (Milligan and Neufeldt 2001).

Trust

Trust also emerged as significant to the skills and qualities participants seek from professionals. A core element of the social work role is to establish relationships based on trust which suggests that social workers are professionally suited to discussing sexual well-being. Participants stated that they would not talk about sexual well-being with a professional they did not feel they knew or trusted. This relates to the significance in humanised care work on building rapport, and establish open, empathetic relationships required to enable issues of personal importance to be safely discussed.

Zack: To be honest I spoke to nobody, you're the first, about sexual things. But a lot of it comes down to, I think, trusting somebody and being able to talk to them.

Amy: It's because I know you and feel comfortable with you, so...

Zack seemed to need permission to discuss his sexual expression needs and was surprised to have the opportunity to discuss sexual well-being:

I've never been asked that before, so I was being asked there and that took me...by surprise. As for talking to somebody, no not often. I keep quiet. No, I'm not used to it...

Discussion

This paper adds new insights about the meaning of sexual well-being from often silenced voices, particularly those with no means of communicating independently. The participants' reveal that sexual well-being is important to the participants and is much broader than penetrative sex, or even intimacy. It relates to psychological and physical factors that relate to one's lived experience of the body and feelings about 'normality'. Sex is a sensual experience made known via the physically embodied senses, primarily touch, hearing and sight. Sexual well-being involves the capacity for sensual pleasure which incorporates psychological acceptance of the self, in whatever physical form the body may be (Rowen et al 2015). When and if professional help is sought, that help needs to involve a non-judgemental attitude, trust and knowledge of sexual well-being.

The findings reveal that sex as a purely pleasurable physical activity can contribute to well-being through the experience of pleasure and increasing self-esteem derived from a sense of desirability. But without the emotional connection it is sexual activity rather than sexual well-being as described by Kevin who felt immediate pleasure from sex but this was overridden by

a later sense of being 'used' because the emotional connection was lacking. This suggests that well-being is an enduring quality rather than the more transitory notion of happiness which orgasm might bring. The constituent parts of sexual well-being revealed by the findings form part of the complex flow of life. The findings reveal that sexual well-being is a holistic experience which combines embodied sensual pleasure with a sense of one's own power, felt as confidence and desirability, along with emotional connection to others. The literature confirms the importance of all these factors including Tepper's (2000) work on sexual pleasure, research on the importance of sexual confidence and esteem (McCabe and Taleporos 2003), and evidence reporting on the impact of relationships on health and well-being (Markey et al 2007). Removal any of these component elements changes the experience, so it is no longer sexual well-being, but rather sexual activity, sexual power or emotional closeness.

One of the primary barriers preventing health and social care professionals' engagement in sensitive topics such as sexual well-being and sexual abuse within adult relationships concerns risk aversion (Myers and Milner 2007; de Than 2015). Sex is considered a private matter and there is fear of becoming involved in a topic where boundaries can be perceived to be overstepped, or issues raised about which they have no guidance to help them navigate. The lack of a clear definition of sexual well-being, primarily for professionals and policy makers may add to notions of risk and be one reason why the professional support is not present. Yet what participants wanted in terms of professional support was actually simple, they were not seeking resolution to complex problems, rather they desired acknowledgement of their identity as sexual beings. **Health and social care legislation and policy require professionals to promote well-being, which includes sexual health (DoH 2013). Part of the professional role is empowering people to live independent lives, exercising choice and control (Care Act 2014); for professionals this means balancing the dual imperatives of**

promoting autonomy and protection. Recognition of physically disabled peoples' sexual identity is a key part of the professional support role as it counteracts the dehumanising and oppressive denial of full humanity (Stevens 2010) which can lead to risk of harm (Galvin and Todres 2013) and leads to an acknowledgement of the effect of physical impairment on normative methods of sexual expression. In addition, this recognition challenges negative discourses which focus on difference and characterise physically disabled people as non-normative (Payne et al 2016). However, sex can be different for a person with a physical disability and thinking about sexual well-being heightens awareness of the physical body, including individual experiences of impairment, pain and change. This means professionals working in this area require knowledge about the impact of impairment and disability on sexual expression and openness to acknowledge the individual's experience. Which includes an understanding that sexual well-being, or lack thereof, influences identity: being sexually active is perceived (through the media and by the participants) as 'normal' and, particularly for those who are not currently in relationships, can heighten their sense of 'deviance' and awareness of physical impairment. While there is increased media attention on disabled people and sex, still the overwhelming images and messages reinforce the ideas of what a 'good looking' person is, and that sex is spontaneous and frequent for the general population. This has impacted the participants as the influence of 'normality' and the heightening of the participants' feelings of deviance are another form of ableism, leading to social isolation (Payne et al 2016). This is made worse by professionals not getting involved and sex being a taboo subject (Myers and Milner 2007; de Than 2015).

Limitations

The original doctoral study drew on a limited population of physically disabled people in contact with statutory social services within a small English local authority area. The intention had been to recruit ten participants to capture depth and variation, however, only six people who were prepared to discuss the topic responded to the invitation. The small sample group restricts the breadth of the findings. Had time and resources allowed it would have been beneficial to widen the geographical area for participation.

The use of interviews as the research method created a potential weakness. Interviews are a core part of social work practice leading to potential reversion to familiar roles of social worker and social care client with the associated expectations (service delivery on the one hand and service provision on the other). To avoid this a clear definition of purpose was provided in the pre-participation information and repeated verbally during the initial contact and later interviews.

The quantity of data produced through interviews is extensive and phenomenological analysis of such a large amount of data is a skilled undertaking. The researcher acknowledges that the findings presented are their interpretation (shared with and verified by the participants) and it is possible that another researcher would have reached different conclusions. However, the aim of this research was to co-construct the discussion of the experience of sexual well-being, and the researcher's unique perspective as a researcher/social worker, known to most of the participants, may have enabled a much greater depth than would otherwise be possible. All the participants in this study live in the community. The perspective of people living in residential homes whose voices are not only 'muffled' by the social status of disability but are often silenced and made hard to reach by their accommodation status is an essential element of understanding the meaning of sexual well-being.

Conclusion

Disabled people have equal right, and desire, for sexual well-being, which is more than penetrative sex but linked to well-being (Diamond and Huebner 2012; Rowen et al 2015).

The presence of positive sexual relationships supports well-being, whereas the lack of them was described by the participants as leading to feelings of difference, isolation and assumed asexuality which impacts on esteem and physical and emotional well-being. However, the impact of austerity policies in the UK and other regions has created an extremely challenging environment for interventions or support which address needs beyond the basic; meaning that concern for sexual well-being can be considered inessential or an unnecessary draw on resources. The authors argue that two points emerge from this study which challenge such arguments, firstly that what is wanted from professionals concerns attitudes, knowledge and recognition which relate to fundamental professional skills, rather than costly services and secondly, in light of the increased interest in the impact of well-being on health, professionals need to take the link between well-being and sexual well-being seriously (McGrath and Sakellariou 2016) enabling disabled people to express their sexual nature, supported through professional education and social care policy (Shaub et al 2017).

To conclude the paper the authors offer the following recommendations of ways in which to develop effective practice around sexual well-being (adapted from the author's research, Bywater and Jones 2007, 131, and Dunk West 2007, 6).

- Alertness to discrimination around disability and sexual well-being
- Willingness to challenge discrimination in your own practice and your organisation
- Develop good communication skills, be able to talk comfortably – be someone people can talk to about sexual issues.
- Recognise that talking about sexual well-being is relevant to everyday life and is a legitimate topic within professional relationships.

- Develop knowledge about sexual issues, law, human physiology and sexual values to be able to offer limited information
- Keep your knowledge up to date (for example effects of medication).

Word count: 7286

Acknowledgements: The authors with thank the research participants for sharing their experiences and the anonymous reviewers for their helpful feedback.

Conflict of interest: There are no potential conflicts of interest.

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