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UNDERSTANDING THE SEXUALITY OF PERSONS WITH INTELLECTUAL DISABILITY IN RESIDENTIAL FACILITIES: PERCEPTIONS OF SERVICE PROVIDERS AND PEOPLE WITH DISABILITIES

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KEYWORDS: sexuality, oppression, intellectual disability, infantilization, stereotypes, institutionalization

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The sexual expression of persons with intellectual disability is a neglected area, more particularly in residential facilities. This article is based on research to explore the perceptions of sexuality of persons with disability in residential facilities in Gauteng, South Africa. Results pointed to stereotyping, infantilisation and the sexuality of persons with disability not being prioritised at institutions, as evidenced in oppressive practices and policies pertaining to lack of privacy, denial of intimate relationships, lack of sexuality policies and paucity of sexual health education programmes at the residential facilities.

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BACKGROUND AND MOTIVATION

The broad definition of disability as applicable to the study on which this article is based is “loss or elimination of opportunities to take part in the life of the community equitably with others that is encountered by persons having physical, sensory, psychological, developmental, learning, neurological or other impairments, which may be permanent, temporary or episodic in nature, thereby causing activity limitations and participation restriction with the mainstream society” (The Disability Rights Policy of the Gauteng Provincial Government, 2010:8).

Shutterworth and Mona (2002) focus on disability as it relates to sexuality, the focus of this study. They discuss physical impairments and mobility issues that serve as constraints when it comes to meeting partners. They also open the debate on whether persons with disability should have an intimate relationship with a non-disabled person, as well as discussing to what extent they are considered as ‘equal’ to any other member of society. In the light of anti-oppressive theory, this inequality results in some people tending to take advantage of or dominating a ‘weaker’ partner.

Furthermore, people with disabilities are more vulnerable to sexual assault than the general public. Reasons for vulnerability also include poor understanding of the nature of the disability and the limitations presented by it, difficulty negotiating equality in relationships and difficulty reporting abuse (O’Hara & Martin, 2001; Valenti-Hein, 2000). Also, persons with the disability may themselves not feel that they have a right to make their own decisions about sex because of their upbringing, or they may be manipulated into an abusive relationship by means of rewards or flattery (Polusny & Follette, 1995). Shutterworth and Mona (2002) discuss the cultural persecution and widespread discrimination and exclusion of persons with disability, particularly those with intellectual disability (who may or may not experience a sensory or physical disability), from access to sexual health education and intimacy.

Persons with intellectual disability in the study experienced several of these injustices, as will be outlined in the article.

Perceptions of the sexuality of people with disabilities are primarily negative and yet sexuality is a key part of human nature. Lamentably, the sexuality of persons with disability is viewed differently from the way it is perceived for able-bodied people. Tepper (2000) and Shakespeare (2000) assert that sexuality is a form of pleasure and expression of love, yet is regarded as unacceptable for persons with disability, with prohibitive societal values preventing the provision of sexual health education and sexuality counselling for such persons. The result is that people with disabilities are deprived of, or

limited in forming, lasting, loving friendships and relationships, and/or a sexual life (Shutterworth & Mona, 2002).

To add to the problem, Servais (2006) highlights that people with disabilities seem to be perceived as ill or tragic victims, perpetuating negative attitudes concerning their sexual freedom and expression. Lack of services and programmes to address this concern has resulted in a number of crimes such as rape committed against people with disabilities (Andersson, 2010).

In refining the research focus, extensive consultation was undertaken with management staff at the selected research sites at two residential centres for persons with disability, in Gauteng, South Africa. It was established that those with intellectual disability and with cerebral palsy would suit the research purpose in that they were considered to suffer extensively from denial of sexual expression as well as being represented significantly in the numbers of people who resided at these facilities.

THEORETICAL FRAMEWORK

Anti-oppressive theory (AOP) informed this study, since oppression is often deep-rooted (in values carried down across generations) and in denial of appropriate opportunities and experiences.

According to Campbell (2003, in Turner, 2011:350), the following are some of the core values and principles embodied in anti-oppressive practice, which is pertinent to this study:

- “Shared values of equity, inclusion, empowerment and community;
- An understanding that the thoughts, feelings and behaviours of individuals are linked to material, social and political conditions;
- Recognition of the link between personal troubles and public issues;
- Recognition that unequal distribution of power and resources leads to personal and institutional relationships of oppression and domination;
- The importance of encouraging, supporting and ‘centring’ the knowledge and perspectives of those who have been marginalised and incorporating these perspectives into policy and practice. This applies to persons with disabilities, as decisions are made on their behalf and often not meeting their needs;
- Conceiving of social work as a social institution with the potential to either contribute to, or to transform, the oppressive social relations that govern the lives of many people;
- Having a vision of an egalitarian future...”.

These values and principles seek to challenge oppressive conditions and redress social injustice (Turner, 2011). AOP addresses the need for the eradication of oppression at all stages, as it may manifest as personal, interpersonal, structural and cultural. Oppression occurs when a person acts or a policy is sanctioned unjustly contrary to an individual or group because of their connection to a specific group (Blauner, 2001). This includes depriving people of the opportunity to participate in all aspects of their lives, or imposing belief systems to experience basic freedoms and human rights (Blauner, 2001).

Furthermore, people with disabilities are commonly understood to occupy marginal positions in society (Anderson & Kitchin, 2000), hence their needs and desires are not valued or prioritised. Oppression, being exercised by influential people and decision makers, entails control over the weak (Dominelli, 2002), and in this study specifically, over marginalised and oppressed disabled persons regarding their sexual expression.

AIM AND OBJECTIVES OF THE STUDY

The aim of the study was to understand the sexuality of persons with disability living in residential care facilities. Objectives were establishing what policies there were on sexuality in the institutions;

exploring service users' and providers' perceptions about sexuality; and exploring challenges as well as possible solutions regarding sexual expression.

RESEARCH METHODOLOGY

The overall research approach was qualitative in order to obtain an in-depth understanding of the participants' perceptions and experiences. The study was exploratory and descriptive in design. The 'insider' perspective, viewing the world from the perspective of people with disabilities and service providers, was necessary to implement the descriptive and exploratory designs. The fact that the topic was an unexplored area in South Africa warranted the use of an exploratory design (Babbie, 2012).

A purposive, convenience sampling technique was used to select the samples from a 'desirable' and 'convenient' group of people (McBurney & White, 2009) to fulfil the research purpose. The samples were drawn from two residential facilities for persons with disability in Gauteng. They were easily accessible and convenient to use as the researcher had a prior professional relationship with staff from both centres, which were located close to the researcher's place of employment.

In selecting the number to be used in both samples, prior information and permission were obtained from both facilities at the planning phase of the study. In the first sample the number of four service users from each centre was determined in view of the prospect of data saturation being reached with this size; participants were between the ages of 20 to 55 (when sexual needs are usually expressed) and competent in verbal communication.

The other sample consisted of eight service providers from the same facilities, four from each facility, as they were considered to have first-hand experiences with people with disabilities. Data triangulation was thus effected using two sets of samples from the same facilities. The participants had to have had at least nine months of work experience at the facility to provide sufficiently detailed information on the topic of study.

Data collection involved the use of individual interviews with service users and focus group discussions in respect of the service provider group. In both instances, thematic content analysis helped identify and interpret themes emerging from the data.

LIMITATIONS OF THE STUDY

Two main challenges were encountered during the study.

- During the data-collection exercise, even though rapport was built between the researcher and the participants, two participants were uncomfortable and therefore unwilling to be audio recorded. The researcher took notes instead and these were analysed. This was inconsistent with the data-collection process used with the other participants. Use of supervision and extensive note taking may have limited the extent of influence of this anomaly.
- One of the service providers did not participate in the focus group but was interviewed individually. The participant's input was of great value to the research study as the person held a key position at the institution – hence data from this source were included but collected in a different way. This may have compromised data analysis. However, to ensure validity the researcher adhered strictly to the interview guide used for the group.

ETHICAL CONSIDERATIONS

Ethical clearance was secured from the University of KwaZulu-Natal as well as permission to collect data from the board members, management and participants at both residential facilities. Due to the sensitivity of the research topic, and the fact that the participants themselves (people with disabilities) are a vulnerable group, the researcher used a written informed consent form, in isiZulu and English, to ensure full comprehension and voluntary participation. In addition, the following ethical principles were observed: voluntary participation, privacy and confidentiality, respect for human dignity, and

harm reduction during the research process. These principles were easily respected in that the researcher is a social worker whose code of conduct embraces such principles.

Results and discussion

The research findings from both data sets are discussed jointly so as to present a composite picture of the topic under study. Where necessary, the different sample groups' data are presented and discussed separately. Names of service users have been changed to protect and preserve anonymity. Emerging themes as per the objectives of the study are outlined below.

Sexuality policy

Service providers exhibited limited knowledge on the existence and details of their institutions' sexuality policy. Rather, they cited prohibition of romantic relationships between staff and residents, which is commonplace in many work settings. Some of their responses were:

"So far I do not have a proper policy, the residents can have a relationship but not with staff. We are yet to meet as a board to discuss it." (Home Manager 1)

"We have not put (these) in place, but we encourage them to have healthy friendships." (Home Manager 2)

The lack of sexuality policies in these residential facilities is a typical indication of how service providers overlook and marginalise (in the light of AOP theory) the sexual needs of persons with disability. Sexuality policies in residential facilities are important as they ensure that people with disabilities are treated fairly and humanely, and that the institutions run effectively. The absence of sexuality policies translates into institutions not even recognising that persons with disabilities have sexual needs; a basic human right is denied to them and this needs to be addressed as an anti-oppressive issue, as outlined by Blauner (2001) and Turner (2011).

Privacy

Hollomotz (2009) highlights that people with intellectual disabilities are denied their sexual rights and privacy as they are perceived as children, which can be very frustrating (Cuskelly & Gilmore, 2007). To confirm this, service users had this to say:

"Yes I have my own privacy but we share bathrooms with men, it is not that comfortable." (Busi)

"It is there, but sometimes you are disturbed by caregivers or the cleaner, who knock at your door (and enter without permission)" (Gugu)

From these comments we note that service users' privacy is not taken seriously, and despite caregivers knocking before entering a room, they will usually not wait for permission to enter. Kempton and Kahn (1991) confirm this finding, stating that it is impossible to secure a private space for sexual intercourse for institutionalised persons with disability.

Sex education

The majority of service providers had limited knowledge on what sex education means, as reflected in the following responses:

"I have not explored that area but I think it is important to protect them from diseases and bad relationships" (Home Manager 1)

"Sex education, what does it mean though? It's a bit difficult. They can have sex, you cannot deny them that, but they should be taught all the basics because as you know some of them are not ok mentally" (Caregiver)

Sex education is vital in preventing undesirable consequences, such as sexual abuse. Interestingly and sadly, all the female participants in the study indicated that they had been abused in their childhood, a finding also noted by Andersson (2010).

The following comments authenticate this concern, where persons with disabilities were asked if they had been approached by someone for sexual favours.

“Yes when I was young I almost got raped. I reported the person to my aunt.” (Busi)

“Yes someone did ask for sex from me, he did rape me...haaa he never got arrested.” (Gugu)

“Yes since I was like 15, but I really do not want to get into detail ...” (Amy)

“Yea it was a long time ago before I came here, I was young, he actually forced me but I never reported him ...” (Sue)

Perhaps it is because persons with intellectual disability are considered unable to comprehend sex education that they are denied it, with disastrous consequences. Furthermore, access to sexual health education is limited for people with disabilities (Shutterworth & Mona, 2002), as most of them do not have the opportunity to go to school as a result of their disabilities.

Women rather than men with disabilities appear to be more vulnerable to abuse than their non-disabled counterparts (Gomez, 2012), presumably because their disability makes them easy targets. This study could not confirm this claim owing to the small sample size, but did find that all the female participants had been raped/abused.

Attitudes and beliefs about disability and sexuality

People with disabilities are subjected to negative attitudes and prejudices around their sexuality, most damning of which is that they are ‘over-sexual’. Eastgate (2011) argues this could be as a result of the lack of sex education, as they may not know when to express their sexual urges or differentiate between appropriate behaviour in public and in private places.

Service providers confirmed this assertion.

“You know what, their feelings are too much!” (Caregiver)

“They crave for it every day that’s the truth! Even when bathing them some always have erections...” (Caregiver)

Such responses clearly suggest that service providers thought that people with disabilities are over-sexed. This was borne out by non-disabled community/staff shunning them, evident of the oppressive practices (Blauner, 2001) to which persons with disabilities are subjected. The erection of the service user cited in the above comment could well have been purely physiological, because of the sensation of bathing.

Life-long children and infantilisation

Assumptions are that persons with disability are incapable of living their lives without full-time care from their carers and this has resulted in their being infantilised. Furthermore, policies related to sexuality are restrictive in that they are based on people with disabilities being viewed as vulnerable and tragic (cf. Servais, 2006) and as children. Hence, opportunities to form intimate relationships are close to none. In the study the service providers who were interviewed referred to their service users as their children, even though the residents were all adults. The following extracts validate this finding:

“...we have a good relationship. You know I treat them just like my own kids. I love them ... shame.” (Caregiver)

“They can behave like children sometimes. [Name of resident] when she is angry she does not want to be bathed, she can even take off her clothes. But we are used to them so we understand them.” (Caregiver)

Being viewed as children is related to the residents' mental age not corresponding with their chronological age as a result of their intellectual or developmental disabilities. Hence the finding that persons with disability are life-long children is logical, albeit alienating and marginalising them, and entrenches their dependency. The relevant dimensions of AOP theory are discussed by Blauner (2001) and Turner (2011).

Relationships and intimacy

The study found that masturbation or self-pleasure was more common among people with disabilities than was having a partner. In accord with AOP, this is also an indication of how influential people (in this case policy makers and service providers) limit and oppress residents at such facilities, as healthy adult relationships are not encouraged. One of the participants had this to say:

"I'm a grown woman I have needs (suggesting sexual needs) ... I have a chair (laughs)(for my physical comfort) ... I have said too much already." (Amy)

Disadvantaged groups, such as people with disabilities, feel that their pleasure is of little concern compared to that of 'normal' people. Amy's response suggests an inability to freely express her needs for sexual expression as they are not endorsed or recognised at the facility.

People with disabilities are stereotyped as not having healthy sexual outlets, and also not being capable of having intimate relationships with non-disabled people (Esmail, Darry, Walter & Knupp, 2010) and that in such a relationship, the non-disabled partner has to inevitably assume the role of care-giving. The other societal assumption is that people with disabilities should partner with people who also have a disability (Sakellariou & Algado, 2006) as indicated in the comment below.

"Some people do not actually love them, they just want to use them, which is why I prefer they date their own (kind)." (Home Manager 2)

Such attitudes marginalise persons with disability (cf. AOP theory) and do not allow a life of normalcy or integration of persons with disability into society.

Reproduction

Although attitudes towards people with disabilities have historically been negative, there has been some change with regard to marriage and procreation (Cuskelly & Bryde, 2004). However, the finding in the study is that there is no change or progress with regard to disabled persons being in a healthy marriage or having any children. Service users, on the other hand, desired intimate relationships and children. The following comments exemplify this sentiment:

"I wish I could find a man and have kids. I also want to go to school so that I can have a bright future." (Busi)

"I want to have someone who can love me the way I am. I wish to have children and take care of them." (Gugu)

Hinsburger and Tough (2002) attribute the denial of prospects for intimacy and reproduction as being related to their being viewed as asexual or over-sexual, strongly indicating the need for sex education.

Follow-up questions pertaining to users' understanding of sexual health, reproduction and contraception were asked. Examples of their responses were:

"It is prevention against pregnancy. I get injection at the clinic even though it makes me fat ... it assist me because I do not menstruate because I used to have period pains." (Busi)

"I use the injection, it helps reduce my feelings. If you do not want injection, there are pills and condoms to prevent STIs." (Gugu)

Busi's response indicates both that people in residential facilities were required to use contraceptives that they did not have knowledge about, as she stated that the contraceptive was administered to ease period pains. This removes 'choice' and independence (as discussed by O' Hara & Martin, 2001), again

marginalising this group of persons (cf. AOP theory). Gugu, on the other hand, was more aware of why she was having the injection, indicating that it reduced her sexual urges. One wonders what such a realisation does to an individual, where removal of feelings becomes a pharmaceutical matter.

CONCLUSIONS AND RECOMMENDATIONS

The results of this study demonstrated that there are many misconceptions related to the sexuality of persons with disability that in effect infantilise them, preventing their sexual expression, or considering them asexual or over-sexual. Misconceptions also relate to such persons not needing romantic relationships and love, particularly from non-disabled persons and not being candidates for marriage and parenthood. Such marginalisation is exacerbated by a clear lack of sexuality policies at residential facilities along with inadequate sexual health education programmes and privacy concerns preventing the freedom to express oneself sexually.

It was sad to note that all the female service users interviewed were also victims of sexual abuse, a worrying trend that needs to be addressed urgently.

In the light of these findings a number of recommendations are suggested, some of which were suggested by participants in the study.

Firstly, there should be clear and specific guidelines, which must be monitored, around the sexual expression of people with disabilities. Compliance and implementation should be encouraged through training and ongoing professional development. Service providers should be empowered by this to “talk sex” more freely with persons with a disability. Furthermore, service users should be consulted to provide input into the formulation of these policies.

Sexual health education should target a variety of persons, not only those with the disability, but also their families, service providers and the public in general. This could change negative attitudes towards persons with disability having intimate relationships, as well as dealing with their reproductive issues and preventing abuse.

People with disabilities should not be infantilised, but rather given the opportunity to be treated as adults and to make adult decisions about their sexuality. Persons with disability should not be oppressed; their right to have a voice in how they wish to express themselves sexually must be respected.

Practical day-to-day changes could be introduced at facilities, such as addressing privacy with separate ablution facilities for males and females, and recruiting staff of the same sex to cater for service users. Regarding the frustration with unannounced visits in their rooms, the authors suggest that service providers should knock and wait for a response before entering a room, and there should also be clear schedules for when monitoring or care-giving has to occur.

Finally, further quantitative research is necessary to quantify the extent of the problem in order that the concerns highlighted in this study can be based on statistical evidence to support policy and service change.

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