

'Disability and HIV in Africa: Breaking the barriers to sexual health care'

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Abstract

Three decades in to the HIV pandemic, the issues affecting people with disabilities remains less known. Increasing attention has been given to this overlooked population when it comes to HIV prevention, treatment and care. This is related to the significant unmet sexual and reproductive health care needs facing people with disabilities worldwide. This article discusses the barriers to sexual health for people with disabilities in Africa, and presents an argument about how mainstream HIV prevention work and research does not adequately attend to the sorts of systemic barriers that exclude people with disabilities, which a more targeted, and critical approach could.

Keywords Disability, HIV, sexual and reproductive health, Africa, critical health psychology

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Introduction

Commendable achievements have been made in the global effort to prevent and treat HIV and AIDS. The UN Millennium Development Goal of reversing the spread of HIV has been partly achieved with HIV prevalence rates falling in many parts of the world. There has also been a significant increase in the provision of antiretroviral medication for persons living with HIV in order to halt the development of AIDS. However, as critical health psychologists well know, these headline statistics tend to obscure the many enduring inequalities that exist. Despite over 30 years since HIV was first identified, and the enormous scope of work that has been done, persons with disabilities have tended to be relatively overlooked in global HIV prevention efforts. Recent estimates reported in the in the first ever *World Report on Disability* (World Health Organisation, 2011) indicate that there are approximately 720 million persons with disabilities living in the world today, with many living in low income countries (such as many of the countries in Africa) compared to high income countries. Research and health care work tended primarily to focus on the disabling effects of HIV infection and AIDS-related conditions. However, the risk for HIV among people with pre-existing disabilities was not really thought about. This is beginning to change, with a growing awareness of the equal, if not increased risk to HIV infection for people with disabilities. Comprehensive reviews looking at the risk for HIV among people with disabilities have been published elsewhere, and will not be reviewed again here (for such reviews see Groce et al., 2013, Hanass-Hancock, 2009, and De Beudrap et al., 2014). Rather, an argument is made for how mainstream HIV prevention work and research does not adequately attend to the sorts of systemic barriers that exclude people with disabilities, which a more targeted, and critical approach could.

The rights of persons with disabilities to equal access to health care has been on the global health agenda in recent years. Article 25 of the United Nations (2006) *Convention on the Rights of Persons with Disabilities* (CRPD) emphasises the rights of persons with disabilities to equal access to the highest standards of health care. However, when it comes to HIV prevention and care, and indeed sexual and reproductive health care more broadly, there is a long way to go in achieving this in many regions of the world, including countries in Africa. The UN have increasingly highlighted the need to consider persons with disabilities in HIV prevention. For example, the UN General Assembly in 2011 acknowledged the importance of the UNCRPD and its adoption to the global HIV prevention effort. The report notes “with concern that prevention, treatment, care and support programmes have not been adequately targeted or made accessible to persons with disabilities” (p. 5). The WHO (2011) *World Report on Disability* similarly notes that persons with disabilities experience “significant unmet needs (pg 61) when it comes to HIV, sexual and reproductive health care. In a review of the national strategic plans for HIV and AIDS in countries in Eastern and Southern Africa, many failed to integrate issues around disability, with seemingly limited targeted interventions for people with disabilities (Hanass-Hancock et al., 2011).

Critical health psychology emphasises the need to consider and address the broader social and structural determinants of ill-health and the structural barriers to health care (e.g. Campbell, 2003), rather than just individual health behaviours. Such an approach is aligned with a critical social model of disability, which understands *disability* as occurring in the myriad barriers to inclusion experienced by persons who

have impairments (Oliver, 1990). Critical health psychology has much to say in bringing to light the dynamics of exclusion that form barriers to appropriate sexual and reproductive health care, including HIV prevention and care, for persons with disabilities, and make recommendations for breaking down such barriers. Some of the broader social and structural determinants, such as poverty and low levels of education, are no different for people with or without disabilities, although people with disabilities are more likely to live in relative poverty and have lower levels of education (see Groce et al 2013 for a review). My focus on this article is on some of the prevalent social constructions of disability and sexuality that play a prominent role in excluding many people with disabilities from sexual health education, services and care. It is important to acknowledge that I refer in this article to “persons with disabilities” as a general term, for the purposes of convenience, but this is of course not a homogenous group, and includes a multitude of different people with different experiences of impairments and disability. When it comes to discussing sexuality more broadly, sometimes the type of disability most often under consideration are physical and intellectual/learning disabilities. However, similar issues may be salient for people with sensory, psychological and other forms of disability.

Disability, sexuality and stigma

Tom Shakespeare (2000) argues that for many people with disabilities, sexuality has been an arena involving “distress, and exclusion, and self-doubt” (p.160).

Historically, the sexual lives of people with disabilities have tended to be sights of oppression and control, for example through the forced sterilization of people with intellectual disabilities as a means of controlling sexuality and prevent reproduction (Hubbard, 1997). While there has been an increased recognition of the right for people with disabilities to be able to live fully sexual lives, some persistent myths often remain. Two traditional myths have been that many people with disabilities are asexual (Milligan and Neufeldt, 2001) or that some may be hypersexual, even sexually dangerous (Craft, 1987). It is interesting that of the literature on HIV and people with disabilities that has been published, the majority look at risk for HIV among people with mental health (psychiatric) disabilities (see Groce et al., 2013), perpetuating the link between disability and ‘dangerous’ sexuality.

The few studies that have been conducted in regions in Africa suggest that such myths are prevalent (e.g. Potgieter and Khan, 2005; Rohleder et al., 2010; Sait et al., 2009), but is of course, not the experiences of many people with disabilities in Africa (and worldwide) who do indeed have sexual lives with intimate partners (e.g. Wickenden et al., 2013). Anecdotal evidence has been reported suggesting that myths of asexuality may contribute to acts of ‘virgin rape’ in some parts of Africa (Groce and Trasi, 2004; Yousafzai et al., 2004). This refers to the belief that a man who has HIV can be cleansed of the virus by having sex with a virgin. Although the assertion that ‘virgin rape’ is a prevailing motivation for rape of young girls (not necessarily disabled) has been contested for lacking evidence (Jewkes et al., 2002).

The sexuality of people with disabilities is something which ignites fear and anxiety among many. Psychosocial disability theorists, drawing on social psychoanalytic theory, argue that for many non-disabled people, people with disabilities come to represent the unwanted and disavowed aspects of our humanity, such as our vulnerability, our imperfections, and notions of ‘damage’ (Marks, 1999; Watermeyer, 2013). Shakespeare (1994) refers to people with disabilities potentially being

“dustbins for disavowal” by non-disabled people, who position themselves as opposite to this. As Watermeyer (2006) puts it:

By constructing and regarding disabled people as broken, damaged, defective and dysfunctional, members of the broader nondisabled society are able to reaffirm and reinforce an identity of being the opposite of those unwanted characteristics (pp. 33-34).

This work also focuses our attention on the impact of such representations on people with disabilities themselves. Some people with disabilities may internalize these social constructions, developing a sense of internal oppression and denigration. As Shakespeare and colleagues (1996) report, many people with disabilities have reported growing up with a sense that sex is not meant for them. In research from South Africa (McKenzie and Swartz, 2011; Sait et al., 2009), young people with disabilities, and their parents, report high levels of disability stigma which undermine the development of a healthy sexuality. But where sexuality is often a site of oppression, stigma and discrimination, it goes without saying that sexuality also becomes an arena of acceptance at a fundamental level. As McKenzie (2013) argues, while sexuality is often times a painful and difficult aspect of a disabled individual's life, it is also an important area in which persons with disabilities may receive affirmation and acceptance, important for the development of a sense of self-worth.

Constructions of disability and notions of vulnerability intersect with other identities. It comes as no surprise that when one considers disability and gender, that girls and women with disabilities may often experience added discrimination, oppression and abuse. The literature often refers to the “double burden” of being female and experiencing a disability. In reviews examining the risk for HIV among people with disabilities, women were found to be significantly affected (De Beudrap et al., 2014; Groce et al., 2013; Hanass-Hancock, 2009). Women with disabilities may experience difficulties in forming secure, lasting relationships, as women with disabilities may be perceived as a burden and not valuable spouses, with the result that women may be abused and abandoned by their spouses (Hanass-Hancock, 2009; Kiani, 2009). Faced with insecurity and poverty, some women with disabilities may turn to transactional sex as a means to survive (Smith et al., 2004), increasing the risk for potential abuse and HIV infection. Research consistently indicates higher incidents of sexual violence among people with disabilities- women in particular – than in the general population (e.g. Aderemi et al., 2013).

Thus the myth of asexuality can have a damaging effect on the self-esteem, sexual health, wellbeing, and sexual safety of people with disabilities. These issues in turn are potential risk factors for HIV. Yet the myth of asexuality may also be an attitudinal barrier that excludes people with disabilities from sexual health care and research.

Barriers to accessing sexual and reproductive health care

The World Health Organisation (2009) has highlighted the significantly unmet needs for sexual and reproductive health care experienced by people with disabilities. They go on to state how the barriers and challenges faced by people with disabilities with regards SRH often have little to do with their disability (impairment), but more to do

with social attitudes. Persons with disabilities report experiencing attitudinal as well as structural barriers to accessing sexual and reproductive health care (Nixon et al., 2014; Saulo et al., 2012; van Rooy and Mufune, 2014). Research has found that people with disabilities face various physical barriers to accessing HIV testing and counselling services (Yousafzai et al., 2004; Yousafzai et al., 2005). Such barriers may include facilities that are inaccessible to wheelchair users, or information that is not available in Braille or Sign Language interpretation. Such barriers might account for the reported lower levels of HIV testing utilization among persons with disabilities when compared to the general population (as found by Aderemi et al., 2014 in Ethiopia). Such barriers may have different effects on access for people with differing types of disabilities and severities (Aderemi et al., 2014; Groce et al., 2013).

Barriers to sexual and reproductive health care are not unique to countries in Africa, of course. Such barriers have been found in more resourced countries, such as Northern Ireland (Anderson and Kitchen, 2000) and Canada (McColl et al., 2010). But, in the context of greater levels of relative poverty, under-resourced public health care systems, and increased levels of risk for HIV, such barriers can be considered the sort of “structural violence” that Farmer (2004) refers to in relation to health; that is the oppressive barriers and forces that are built into the political, economic and environmental structures in which health is embedded. For people living in rural areas in countries in Africa, some barriers may seem insurmountable, such as people with mobility impairments accessing services that are located far away. For example, in a peri-urban area in South Africa, Saloojee and colleagues (2007) found that one of the most cited reasons that parents reported for not accessing health care and education for their child with disability included financial and transport difficulties. In Zambia, Smith and colleagues (2004) found that many women with physical disabilities that they interviewed struggle to access health care services due to a lack of assistive devices and suitable transport.

Barriers may also include assumptions and attitudes held towards the sexuality of people with disabilities. For example, in Zambia, persons with disabilities who were HIV-positive report not only mobility and communication barriers to accessing HIV-related health care services, but numerous attitudinal barriers too, including their presence at such health care services being questioned because of an assumption of asexuality (Nixon et al., 2014). Issues of sexuality and sexual health have also been reported as absent from rehabilitation services received by young people with disabilities (Wazakili et al., 2009). As a result of such barriers, persons with disabilities themselves may feel that they cannot or should not access such services. For example in a survey study in Nigeria (Olaleye et al., 2007), 70% of 103 young people with disabilities surveyed did not know that they could access sexual and reproductive healthcare services.

Negative attitudes about the sexuality of people with disabilities are frequent barriers, but we should also not disregard how challenging it may be for those healthcare professionals who do attempt to be more open to the sexual rights of people with disabilities. These may include personal discomfort and fear about potential to do harm, as well as facing potential conflicts between their attempts to be more open and the cultural or institutional norms in which they work (Swartz and Mall, 2012). Similar tensions were found in research on the views of educators who faced

conflicts with some of their schools' policies and institutional norms (Mall and Swartz, 2014; Rohleder et al., 2012).

Mainstream HIV prevention research and interventions often rely on attendees at sexual health clinics. Unless specifically targeted, such work would inevitably exclude people with disabilities who experience barriers to full access to such services. Where general (or household) population surveys are used, the myth of asexuality may result in people with disabilities not being specifically identified as relevant respondents. For example, in a national survey of schools and organisations supporting people with disabilities in South Africa, a small number of survey questionnaires about issues of HIV and sexual health and disability were returned incomplete by some schools and organisations who felt that questions about sex and sexual health were of no relevance to the people with (more severe) disabilities that they supported (Rohleder, 2008).

Barriers to HIV and sexual health education

Studies from countries in Africa indicate that people with disabilities are less likely to have accessed information about HIV prevention (Aderemi et al., 2013; Chirese et al., 2010; Rohleder et al., 2010). In our work in South Africa (Eide et al., 2011), we found low levels of HIV prevention knowledge. We further found differences with regards gender, with women with disabilities having accessed less HIV-related educational information and having lower levels of knowledge.

Some of this is accounted for by the general low level of education for people with disabilities when compared to the general population (Munthali et al., 2004). In the less-resourced countries in Africa, scarce resources may result in parents choosing to exclude their disabled children from education, in favour of their non-disabled children (Groce, 2003), with the expectation that the educated, non-disabled child will have better prospects of getting a job. In an impoverished peri-urban area in South Africa, Saloojee and colleagues (2007) found that few children with disabilities were attending school. Parents cited the perception that their child would not cope at school as a dominant reason given. Low levels of education for people with disabilities have been found to be predictors for low levels of HIV prevention knowledge which in turn is predictive of less access to HIV testing services (Eide et al., 2011). As with other social health determinants, girls and women with disabilities are at a particular disadvantage.

Where young persons with disabilities are at school, educators report a lack of training and low level of confidence, and inadequate resources in providing sex education in accessible formats to people with disabilities (Chirawu et al., 2014). Such challenges for teachers may also be compounded by their own assumptions of the sexuality of people with disabilities, for example viewing the sexuality of people with learning disabilities as 'problematic' (Aderemi, 2014; Rohleder and Swartz, 2009). Such anxieties exist for parents of children with disabilities too (Mall and Swartz, 2012; Sait et al., 2009).

Breaking the barriers

Addressing the barriers to accessing health care generally has been identified as the highest health research priority for people with disabilities (Tomlinson et al., 2009). Global organisations such as the United Nations and the World Health Organisation

has increasingly put the unmet needs of people with disabilities on the sexual health agenda. This increased momentum is welcome, but movement at the local and national level remains slow. The need to address these failings at multiple levels, and in partnership with disabled peoples organisations (DPOs) have been highlighted. For example, WHO (2009) guidance on promoting inclusive sexual and reproductive health care for persons with disabilities recommend five actions:

- Design sexual and reproductive healthcare services that ensure that people with disabilities are served
- Develop programmes in partnership with disabled people's organisations (DPOs)
- Raise awareness within healthcare organisations about the needs of people with disabilities and improve access to services
- Address disability and sexual and reproductive healthcare at national level (policies, laws etc)
- Promote research in this area

This work cannot be done without tackling the broader social and structural factors that continue to exclude people with disabilities from HIV, sexual and reproductive health care. Health psychology has an important role to play in this agenda. As has been argued numerous times, critical health psychology can offer much in seeking to change the social and structural determinants of health. In the context of HIV, Campbell and colleagues (2003 and 2009) illustrate the importance for research and interventions that facilitate social action, helping to develop enabling and competent communities that are able to bring about change at a social/community level. In order to address the barriers to sexual health experienced by people with disabilities, we must work beyond the focus on individual impairment and function, and address the issue of power that positions many people with disabilities in Africa (as elsewhere) in positions that exclude them from the sexual lives and sexual and reproductive health care that they have a right to. One key area is to deconstruct the many assumptions and myths that exist about the sexuality of people with disabilities. Sexual health and HIV prevention research needs to specifically target people with disabilities, and adopt research designs that break the systemic barriers that exclude people with disabilities from participation.

There are many organisations (Handicap International and Southern Africa Federation of the Disabled, to name just two) that have already been active in programmes that are inclusive of people with disabilities and their communities that aim to address the many social and structural barriers that exist to sexual health. In South Africa, the Disability HIV and AIDS Trust (DHAT) is a disabled people's organisation (DPO) that has developed a strategic partnership with the Southern Africa AIDS Trust to build the capacity of organisations to respond to issues of HIV and disability. Other examples of work is that of Hanass-Hancock and colleagues (Alli et al., 2012) who have developed a research and training project called *Breaking the Silence and Closing the Gap*, which aims to exchange knowledge and develop competencies in inclusive HIV interventions for people with disabilities, involving people with disabilities themselves, health care workers and health services management. But much more research is needed that not only explore the issues, but that provide the evidence for what sorts of interventions work and how. Action research, which involve partnerships for capacity building with disability organisations has much to offer here. The involvement of people with disabilities in

rehabilitation research in Africa is an important way in which research *for* social action can be ensured, and which develops findings that can be actively used by DPOs for informing and developing policy (Mmatli, 2009). Such initiatives are already occurring. For example, the African Network for Evidence-to-Action on Disability (AfriNEAD) is an intersectoral forum that focuses on translating the evidence of disability researchers into action and policy that is aligned to the UNCRPD (Kachaje et al., 2014).

Health psychologists can also offer valuable input in how health prevention information can and should be framed in a way that does not perpetuate assumptions and barriers. For example in work on sexual health education and persons with learning disabilities in the UK, Finlay and colleagues (2015), challenge the notion that difficulties around 'understanding' exist as a difficulty *within* the capabilities of the individual with learning disabilities. By using conversation analysis of recorded sex education sessions with young people with learning disabilities, observations could be made of the challenges and barriers to understanding that develop in the *social interaction* between the individual with a learning disability and others (in this case the educators). Such work can be used as a powerful tool, not only to inform the difficulties that the individual with a disability may experience, but more importantly they can be used to challenge the interactional assumptions and practices of others who are working with the individual. Such work can also help to challenge the many social constructions that prevail about disability and sexuality.

Concluding thoughts

While my focus above has been on problems, this is not the only reality. There has been a growing emphasis placed on positive constructions of disability and sexuality. In the United Kingdom, for example, much has been said anecdotally about how the 2012 Paralympics has contributed significantly to challenging the assumptions and myths held about people with disabilities in this society. In recent years, crip theory has emerged as an influential critical disability studies theory, which challenges and attacks the normative assumptions held about 'normality' and 'abnormality', 'disabled' and 'abled' (see Goodley, 2014). These questioning and deconstructive positions have done much to challenge people's assumptions about the 'normal' (sexual) body and inclusivity in society. But this sort of discourse and opportunity to rethink is a far cry removed from the everyday reality of many people with disabilities living in some of the poorest regions of the world. The vicious cycle of HIV and poverty (and disability) is well known. Any focus on health in Africa needs to include disability, and given the severity of the HIV epidemic on the continent, particularly in southern Africa, the sexual health of persons with disabilities cannot be ignored. In addition to sexual health care and research that specifically targets people with disabilities, any mainstream work needs to pay attention to the various barriers that exclude people with disabilities from accessing such services and research.

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