

The sexual lives of people with disabilities within low- and middle-income countries: A scoping study of studies published in English

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Abstract

Although approximately 80% of the global population of people with disabilities reside in low- and middle-income countries, very little is known about their sexual lives due to a lack of empirical data. The purpose of this scoping review is to provide a data-driven overview of low- and middle-income countries concerning *what* topics in disability and sexuality have been investigated, *where* this research has been carried out, and *how* this research has been conducted. It is concluded that: a) disability and sexuality research in African countries focuses predominantly on contexts of vulnerability, b) the sexuality of people with disabilities within many low- and middle-income countries has received little or no empirical investigation, c) and there have been very few experimental studies on disability and sexuality conducted in low- and middle-income countries in general. Recommendations for future research are discussed.

Introduction

Sexual health as currently understood rests on the rights of individuals to freely express their sexuality in consensual relationships, to participate in activities such as marriage and starting a family, obtain detailed information about sexual issues, and access the highest possible standard of sexual healthcare.¹ Given that sexuality is viewed in human rights documents as a central aspect of being human,¹ the realisation of sexual health, in common with other aspects of physical and mental wellbeing, should ideally be attainable for all persons. It is therefore unfortunate that this realisation remains far from ubiquitous worldwide, especially for people with disabilities, who often comprise the most marginalised and vulnerable group socially, sexually and in relation to systems of care, including health care.^{2–4}

A review of the social and empirical evidence on disability and (a)sexuality conducted in 2001 highlighted that people with disabilities tend to face disproportionate levels of difficulty leading fulfilling sexual lives compared to people without disabilities, despite possessing the same sexual needs and desires.⁵ The review identified that people with disabilities tend to encounter several barriers when expressing their sexuality and accessing sexual and reproductive healthcare, located at the individual (e.g., poor body image),⁶ societal (e.g., negative attitudes)⁷ and structural (e.g., inaccessible environments)⁸ levels. In a context of increasing concern about disability rights globally,⁹ the field of disability and sexuality has continued to attract increasing interest from researchers in the 21st century. As of January 2017, a keyword search within a leading scientific research database (Web of Science) using “disability” and “sexuality” and their synonyms, attests to the growing literature in the area (Figure 1) and demonstrates the sizeable amount of empirical work that has been conducted since the 2001 review.⁵ Whilst this work has generally focused on understanding or removing barriers to fulfilling sexual lives among people with disabilities in high-income countries, some studies have highlighted sites of concern of particular relevance to people with disabilities within low- and middle-income countries (LMICs).^a For example, there is now much evidence to suggest that people with disabilities often experience additional barriers when accessing HIV treatment or preventative care, which may increase their vulnerability to the disease in contexts where HIV and AIDS is widespread, such as sub-Saharan Africa.¹⁰

^a We classify countries as “low” and “middle-income” based on the terminology of the World Health Organisation and the World Bank.³⁰ Note that these organisations further divide middle-income countries into lower-middle and upper-middle. Our use of middle-income therefore encompasses both categories.

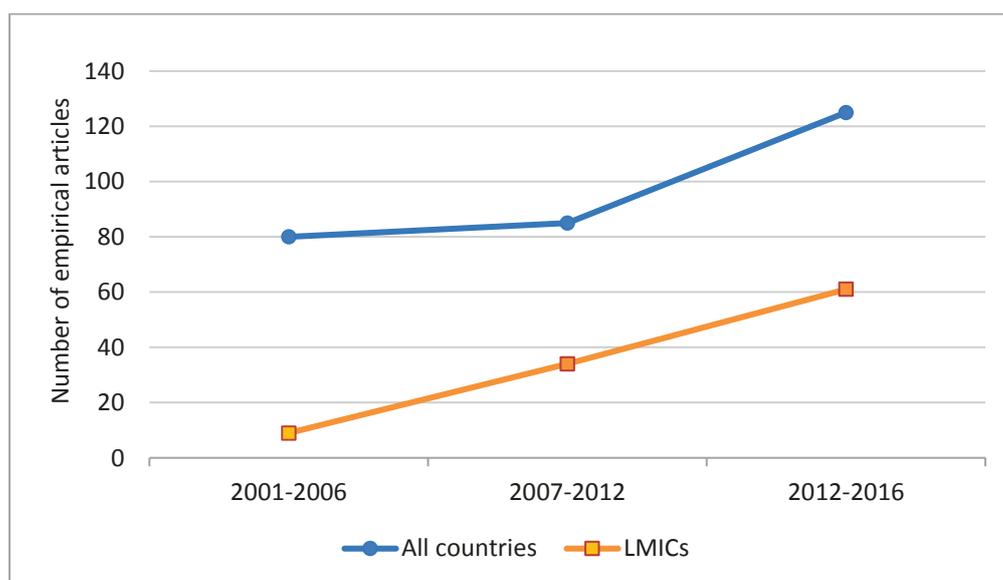
Other studies have highlighted the unique barriers that displaced people with disabilities face when trying to access sexual and reproductive healthcare within refugee camps.¹¹

Although comprehensive reviews of certain issues pertinent to the sexual lives of people with disabilities within low- and middle-income countries have been conducted (e.g., disability and HIV)¹² discussion of the literature from these settings has largely been absent from previous general reviews of disability and sexuality.^{5,13} This may in part be because the number of studies conducted in high-income settings continues to dwarf those conducted in low- and middle-income settings (see Figure 1)^b. Approximately 80% of persons with disabilities live in LMICs⁹ and if researchers, policy-makers, service providers and activists are to claim to understand disability and sexuality globally, it follows that data on the topic from LMICs is essential.

In this article, we present the findings of a scoping review of research conducted on disability and sexuality within LMICs in the 21st century. Specifically, our research questions are:

- a) What topics in disability and sexuality have been investigated in LMICs?
- b) Where has disability and sexuality research in LMICs been carried out?
- c) How has disability and sexuality research in LMICs been conducted?
- d) What are the gaps in the disability and sexuality literature in LMICs?

Figure 1. Empirical research articles published on disability and sexuality in the 21st century.



^b These data are based on our own search of the literature, detailed in the “Method” section.

Methodology

The goal of a literature review is to collect, analyse and present available research evidence in a given field of interest. There are several methodologies for literature reviews, some more systematic and organised than others.¹⁴ Both systematic reviews and scoping reviews use strict, transparent methods to identify, organise and analyse all relevant literature in connection to a research question. However, while scoping reviews are well suited to give an overview of a potentially large field of research and to identify gaps in knowledge, systematic reviews are concerned only with the best quality research within a narrow, clearly defined field of research and research questions. The objectives or research questions for a literature review determines the choice of method for the review.¹⁴ For the purpose of the literature review presented in this article, a scoping review was the most suitable method, with its broad research questions and inclusion of various types of research publications. We searched for English language peer-reviewed journal articles containing empirical research on disability and sexuality that had been conducted within LMICs and had been published in the years 2000 to 2016. Specifically, we used a combination of search terms pertaining to *disability* (e.g., disab*, handicap*, bifida, crip*, sclerosis) and *sexuality* (e.g., sexual*, asexual*, romance, intim*, dating, HIV) within several scientific databases (PsycINFO, PsycARTICLES, and Web of Science). In addition to the database search, we undertook a manual search of literature published post 2000 in *African Journal of Disability, Disability & Rehabilitation* and *Sexuality and Disability*. All searches were conducted by the first author. The collated material was reviewed by the other authors who have published widely or work in the field, and were thus able to contribute pertinent sources based on their own knowledge and research networks.

Through this search we identified 103 articles deemed appropriate to include in the scoping study. Sixty-one of these had been published between 2012 and 2016 (see Figure 1, bottom line). Note that as this scoping study was concerned with material conceptualising disability and sexuality as a human rights issue,¹ literature investigating the sexuality of people with disabilities as a purely medical (e.g., sexual dysfunction in multiple sclerosis patients) or forensic (e.g., sexual offending) was not catalogued.

Findings

What topics have been researched in low- and middle-income countries?

The empirical research identified through the scoping review spans six overlapping topics (see Table 1). The general findings for each topic are summarised below:

1. *Community, parental and professional attitudes.* While the attitudes of people with disabilities are not uniformly negative, people with disabilities are not seen as fully sexual by community members. Parents of children with disabilities may be reluctant to accept the sexual desires of their offspring especially if they have intellectual disabilities. Professionals may not know how best to address or teach common sexual topics when working with people with disabilities.
2. *Access to sexual and reproductive healthcare.* There are many barriers to accessing sexual and reproductive healthcare among people with disabilities, several of which are exacerbated by poor infrastructure and greater levels of poverty in LMICs. Examples include inaccessible healthcare facilities, poor provision of adequate transportation, and negative attitudes of healthcare providers.
3. *Access to sexual education.* There are also several barriers to accessing sexual education, for example, lack of provision of accessible information and lack of knowledge among teachers and parents.
4. *Self-attitudes/knowledge/experiences.* People with disabilities may engage in risky sexual behaviours and possess low levels of knowledge about safe sexual practices. Although many face challenges to leading sexual lives, such as low sexual self-esteem people with disabilities are sexual beings and have the same needs as people without disabilities.
5. *Sexual abuse/violence.* People with disabilities, particularly women, children or individuals with intellectual disabilities, may be vulnerable to sexual abuse, exploitation and violence
6. *Intersectionality.* Disability and sexuality may intersect with other factors, such as gender and culture, to disadvantage certain people with disabilities in terms of their access to sexual healthcare or ability to live a fulfilling sexual life.

Additionally, the above themes are frequently explored in the context of HIV and HIV prevention.

From these data, we noted that research conducted in certain regions tended to focus on certain issues. Specifically, we identified that, of the 63 studies conducted in Africa, 38 (60%) focused on disability and sexuality primarily in terms of sexual abuse and violence or HIV. Conversely, of the 40 studies conducted in low- and middle-income settings, the range of issues investigated was much broader with just two (5%) papers focused on sexual abuse and violence or HIV.

Addressing contexts of vulnerability that people with disabilities may experience in relation to their sexuality is of the utmost importance to promoting sexual health among this large, but marginalised, population, especially in LMICs, where threats may be grave (e.g., HIV). To focus solely on vulnerability of people with disabilities in the African region, however, is to skew knowledge about disability and sexuality in this context. In fact, there are many ways in which people with disabilities are not vulnerable and are able to live fulfilling sexual lives in Africa, as well as elsewhere in the world. For example, in South Africa, Chappell¹⁵ finds that youth with disabilities who are not taught about sexuality by their parents may develop hidden languages of sexual communication with their peers as means of secretly resisting dominant cultural conceptions of their sexuality (and the assumption that they are asexual). Chappell, Rule, Dlamini, and Nkala¹⁶ also draw attention to the emancipatory ability of participatory research with people with disabilities (e.g., positioning them as co-researchers) to challenge problematic sexual constructions and to encourage the exercise of agency regarding sexual identities. Given that there is far less research conducted in low- and middle-income settings in general compared to high-income settings, there is certainly room for this emancipatory dialogue to emerge within the literature on disability and sexuality conducted in the African region.

Where has research in low- and middle-income countries been carried out?

Of the 103 articles identified in the scoping study, 27 (26%) reported research that had been conducted in South Africa, while fifteen (15%) reported research that had been carried out in Turkey (see Table 1). Thus, literature from just two countries accounts for almost half of the articles present in the dataset. These are both upper middle-income countries with high levels of inequality, but with a research infrastructure bigger than those in many poorer countries. In order to obtain a truly global and accurate picture of the sexual lives of people with disabilities in low- and middle-income settings the breadth of research must be expanded in order to encompass nations that, to date, have received little empirical

attention. For example, we identified only one study in the dataset that had been conducted in mainland China, the largest nation in the world.^c The study¹⁷ found that in rural China, marriage and procreation between non-disabled men and women who have intellectual disabilities is both frequent and accepted (at least on the surface), in part due to a gender imbalance between women and men (123 males to females in 2008) and the stigmatisation attached to men of low socioeconomic status. Similarly, the only study¹⁸ identified in the dataset conducted exclusively in Nepal suggests that rural Nepalese non-disabled women hold relatively positive attitudes toward the sexuality of people with disabilities, with nearly three quarters believing that people with disabilities can marry and have children. These examples illustrate the importance of extending the scope of current research to areas that have as of yet received scant empirical attention, as this may elucidate discourses that challenge or extend extant knowledge of the sexual lives of people with disabilities in low- and middle-income settings.

How has research on disability and sexuality been conducted in low- and middle-income countries?

Fifty-six (54%) articles identified through the scoping review utilise quantitative methods of inquiry, while 47 (46%) utilise qualitative methods. The range of methods used across this body of research is diverse (e.g., case studies, life stories, interviews, focus groups, cross-sectional surveys, experimental studies). Each of these methods has the potential to contribute to social change in different ways, with narrative approaches, for example, providing case material with which policy-makers and service providers can identify and which may inform the revision of practices. On the other hand, larger-scale studies may be more influential in the context of the global imperative for evidence-based policy reform.

In wealthier countries, a number of studies have conducted experimental evaluations of interventions designed to remove barriers to sexual and reproductive health rights for persons with disabilities, largely through evaluating training courses for healthcare professionals.¹⁹ We did not find such randomised studies in LMICs, but there was some quasi-experimental work. For example, Hanass-Hancock and Alli²⁰ conducted a formative (descriptive) evaluation of a real-world HIV workshop intervention. Randomization and rigorous pre-post assessment was not possible in this study.

^c However, this could in part be an artefact of our searching only for articles published in English.

More systematic field experiments would be difficult to implement in this area, but there may be useful lessons to learn from other field experiments conducted in LMICs. For example, in the area of prejudice reduction, Paluck^{21,22} conducted a field test of the impact of radio programmes featuring reconciliation messages on community attitudes in two LMICs, Rwanda and the Democratic Republic of Congo. Field tests of naturally occurring mass-media programmes may represent a promising avenue by which to explore the question of how to change problematic attitudes towards the sexuality of people with disabilities. Field experiments, furthermore, would allow researchers to test the efficacy of interventions (e.g., HIV training workshops) against real-world conditions, while retaining the ability to make causal inferences.

Vignette-based approaches may offer a useful method both for eliciting data on attitudes towards disability and sexuality and piloting methods to change such attitudes. In order to understand factors affecting attitudes, Morales et al.^{23,24} presented a series of vignettes to participants. These varied the demographic (e.g., gender, partner age) and situational (e.g., contraceptive use) factors of a sexual relationship involving two people with a learning disability. They explored the determinants of the perceived acceptability of such relationships among community, family and professional samples in Mexico. We found no studies using vignette methods to explore the impact of interventions to change attitudes towards disability and sexuality.

In summary, the literature we accessed is largely descriptive. Though more descriptive studies are needed, there is an even larger gap in terms of experimental research, particularly in regard to interventions. We acknowledge, though, that the question of the external validity and scalability of intervention research in LMICs, especially where there is poor infrastructure, a degree of social instability, and rapid social change, is complex. The question of how research impacts on policy, and policy on practice is even more so. These broad practical, methodological and strategic questions would need to be considered alongside more proximal questions of the design and evaluation of interventions^{25,26}

Discussion

There has been a growing international recognition of the human rights of people with disabilities, marked by the adoption of the United Nations Convention on the Rights of Persons with Disabilities.²⁷ The achievement of optimal sexual health for any human being is dependent on realisation of basic human rights, such as the right to non-discrimination, to

privacy and confidentiality, to be free from violence and coercion, as well as the right to education, information and access to health services.²⁸ The UNCRPD includes the right to optimal sexual health.²⁷ That we know very little about the sexual health and sexual lives of the majority of the world population of people with disabilities is an urgent concern.

As with many areas, there is a dominance of research resources in the ‘global north’, yet much of the global health issues and concerns are in the ‘global south’. We cannot simply rely on the export of knowledge and interventions about disability and sexual health to areas where we know very little about the contextual realities of people with disabilities living there. Furthermore, although the term ‘persons with disabilities’ suggest a discrete population group, there is obviously a great deal of heterogeneity within this group. We need to know more about the various structural, attitudinal and social-cultural barriers to sexual health for people with disabilities across diverse contexts, and for a range of disabilities. As Groce and colleagues²⁹ point out in relation to HIV prevention, treatment and care for people with disabilities, a two-pronged approach is needed; with disability being included in ‘mainstream’ research and programmes, as well as targeted, disability-specific research and programmes. Furthermore, as the scoping study also reveals, where there has been some attention to disability and sexual health, it has tended to focus predominantly on vulnerabilities, and we need to know much more about emancipatory practices. This work cannot be achieved without building partnerships across sectors: disability organisations, researchers, policy makers and practitioners.

References

- 1 World Health Organization (WHO). Promoting sexual and reproductive health for persons with disabilities. Geneva: World Health Organisation; 2009.
- 2 Braathen, SH., Sanudi, L., Swartz, L., Jürgens, T., Banda, H.T., Eide, AH. A household perspective on access to health care in the context of HIV and disability: a qualitative case study from Malawi. *BMC Int Health Hum Rights* 2016; **16**: 12.
- 3 Groce, NE., Trani, JF. Millennium Development Goals and people with disabilities. *Lancet* 2009; **374**: 1800-1801.
- 4 MacLachlan, M., Mannan, H., McAuliffe, E. Access to health care of persons with disabilities as an indicator of equity in health systems. *Open Med* 2011; **5**: 10-12.
- 5 Milligan, MS., Neufeldt, AH. The myth of asexuality: A survey of social and empirical evidence. *Sex Disabil* 2001; **19**: 91-109.
- 6 Taleporous, G., McCabe, MP. The impact of sexual esteem, body esteem, and sexual satisfaction on psychological well-being in people with physical disability. *Sex Disabil* 2002; **20**: 177-183.
- 7 Aunos, M., Feldman, MA. Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities. *J Appl Res Intellect Disabil* 2002; **15**: 285-296.
- 8 Anderson, P., Kitchin, R. Disability, space and sexuality: access to family planning services. *Soc Sci Med* 2000; **51**: 1163-1173.
- 9 World Health Organisation (WHO). World report on disability. Geneva: World Health Organisation; 2011.
- 10 Hanass-Hancock, J. Interweaving conceptualizations of gender and disability in the context of vulnerability to HIV/AIDS in KwaZulu-Natal, South Africa. *Sex Disabil* 2009; **27**: 35-47.
- 11 Tanabe, M., Nagujjah, Y., Rimal, N., Bukania, F., Krause, S. Intersecting sexual and reproductive health and disability in humanitarian settings: risks, needs, and capacities

- of refugees with disabilities in Kenya, Nepal, and Uganda. *Sex Disabil* 2015; **33**: 411-427.
- ¹² Rohleder, P., Eide, AH., Swartz, L., Ranchod, C., Schneider, M., Schür, C. Gender differences in HIV knowledge and unsafe sexual behaviour among disabled people in South Africa. *Disabil Rehabil* 2012; **34**: 605-610.
- ¹³ Di Giulio, G. Sexuality and people living with physical or developmental disabilities: a review of key issues. *Can J Hum Sex* 2003; **12**: 53-68.
- ¹⁴ Arksey, H., O'Malley, L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005; **8**: 19-32.
- ¹⁵ Chappell, P. Secret languages of sex: disabled youth's experiences of sexual and HIV communication with their parents/caregivers in KwaZulu-Natal, South Africa. *Sex Educ* 2015; **16**: 405-417.
- ¹⁶ Chappell, P., Rule, P., Dlamini, M., Nkala, N. Troubling power dynamics: Youth with disabilities as co-researchers in sexuality research in South Africa. *Childhood*, 2014, **21**: 385-399.
- ¹⁷ Pan, L., Ye, J. Sexuality and marriage of women with intellectual disability in male-squeezed rural China. *Sex Disabil* 2012; **30**: 149-160.
- ¹⁸ Simkhada, PP., Shyangdan, D., van Teijlingen, ER., Kadel, S., Stephen, J., Gurung, T. Women's knowledge of and attitude towards disability in rural Nepal. *Disabil Rehabil*, 2013; **35**: 606-613.
- ¹⁹ Hilberink, SR., Kruijver, E., Wiegerink, DJ., Vlieland, TPV. A pilot implementation of an intervention to promote sexual health in adolescents and young adults in rehabilitation. *Sex Disabil* 2013; **31**: 373-392.
- ²⁰ Hanass-Hancock, J., Alli, F. Closing the gap: training for healthcare workers and people with disabilities on the interrelationship of HIV and disability. *Disabil Rehabil* 2015; **37**: 2012-2021.
- ²¹ Paluck, EL. Reducing intergroup prejudice and conflict using the media: a field experiment in Rwanda. *J Pers Soc Psychol* 2009; **96**: 574-587.

- 22 Paluck, EL. Is it better not to talk? Group polarization, extended contact, and perspective-taking in eastern Democratic Republic of Congo. *Pers Soc Psychol Bull* 2010; **36**: 1170-1185.
- 23 Morales, GE., Ramirez, EOL., Esterle, M., Sastre, MTM., Mullet, E. Judging the acceptability of sexual intercourse among people with learning disabilities: A Mexico-France comparison. *Sex Disabil* 2010; **28**: 81-91.
- 24 Morales, GE., Lopez, EO., Mullet, E. Acceptability of sexual relationships among people with learning disabilities: family and professional caregivers' views in Mexico. *Sex Disabil* 2011; **29**: 165-174.
- 25 Cairney, P. Health and advocacy: What are the barriers to the use of evidence in policy?. In *The Politics of Evidence-Based Policy Making* (pp. 51-84). Palgrave Macmillan UK; 2016.
- 26 Perez-Gomez, A., Mejia-Trujillo, J., Mejia, A. How useful are randomized controlled trials in a rapidly changing world?. *Glob Ment Health* 2016; **3**: e6.
- 27 United Nations. Convention on the rights of persons with disabilities, United Nations; 2006
- 28 WHO. Sexual health, human rights and the law. Retrieved from http://apps.who.int/iris/bitstream/10665/175556/1/9789241564984_eng.pdf?ua=1 [Accessed 8th February 2017]
- 29 Groce, NE., Rohleder, P., Eide, AH., MacLachlan, M., Mall, S., Swartz, L. HIV issues and people with disabilities: a review and agenda for research. *Soc Sci Med*, 2013; **77**: 31-40.
- 30 World Health Organisation (WHO) *Definition of region groupings*. Retrieved from: http://www.who.int/healthinfo/global_burden_disease/definition_regions/en/ [Accessed 8th February 2017]

Table 1. Empirical research on disability and sexuality from LMICs identified through the scoping review. [See attached spreadsheet via email]