

The myth of asexuality? Disability stigma as a barrier to sexual relationships in South Africa

Literature review

This literature review was conducted as part of the applied research “The myth of asexuality? Disability stigma as a barrier to sexual relationships in South Africa” lead by the University of East London, in partnership with the Southern African Federation of the Disabled, SINTEF Technology and Society and Stellenbosch University.





[The Psychology and Social Change Research Group of the University of East London](#) aims to be a leading national and international research hub for psychological research with an emphasis and commitment to social change. This is a broad overarching theme for the Group, and involves diverse and varied activity across theoretical and methodological arenas, and driven by a number of different topic areas. To this end the group takes a leading role in developing research in the areas of 'politics, community and society', 'health and technologies', and with a continual focus on issues of 'social equality and justice, security and human rights'.



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The mission of the FIRAH (Foundation of Applied Research on Disability) follows two main directions, which are complementary and merge:

- The call for projects: selection and funding of applied disability research projects
- The coordination of the Resource Center. Internationally concerned, the Resource Center Applied Research and Disability aims at creating connections and bonds between researchers and field stakeholders¹. It develops and disseminates research in order to promote an inclusive social transformation and to facilitate the full involvement of persons with disabilities.



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¹ Field stakeholders

Persons with disabilities, their families, and their representative organisations. Any Human Rights organisation working with persons with disabilities. Service providers and other organisations working with Persons with disabilities. Service providers and other organisations working in mainstream that are required to meet the needs of persons with disabilities such as architects, teachers, companies, industries etc. Researchers and research institutes. Local, national and international decision makers.

Acknowledgment

The present document was conducted as part of the applied research “The myth of asexuality? Disability stigma as a barrier to sexual relationships in South Africa” led by the University of East London, in partnership with the Southern African Federation of the Disabled, SINTEF Technology and Society and Stellenbosch University. It was funded by FIRA’s (International Foundation of Applied Research on Disabilities) call for projects in 2014. The review was conducted by:

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The goal of this literature review is to report on existing knowledge about applied research on the theme of the myth of asexuality in South Africa. It resulted in the selection of relevant research papers which were each categorised using a set of predetermined criteria. Of these research papers 12 were selected as being particularly relevant or interesting because of their potential for being applied with practical effect, especially with persons with disabilities and their own organisations

What FIRA means by the very general terms of applied research is:

- First, it is proper research based on precision and methodologies which allow the implementation of a scientific approach involving teams of one or more researchers or academics whose research is one of the statutory missions.
- Applied research differs from basic research. Its ultimate purpose is to increase independence and social participation of people with disabilities. It is not only aimed at producing theoretical knowledge but also tackling practical issues related to the needs and concerns of people with disabilities and their families. The collaboration between these people, professionals and researchers is a fundamental element to the achievement of this type of research.
- This type of research is designed to produce directly applicable results. In addition to usual publishing (scientific articles, research reports) applied research is also designed to produce other publications called “means of application²” which can take various forms: development of good practices, methodological guides, training tools, and are destined to different field stakeholders (people with disabilities, professionals, policies makers).

² **Means of application**

Shaping of the findings and knowledge gained from applied research into products, services and contents to meet the expectations and needs of people with disabilities. These application supports are adjusted to be used by field stakeholders.

This work does not intent to be comprehensive but to identify the results and knowledge generated by research that could be useful for field stakeholders in order to improve the quality of life and social participation for people with disabilities.

Each title in the annotated bibliography contains a link with free or paying access to the work in question.

Each reading note contains a link to the relevant research documentary note on the Resource Centre website.

This document can be freely disseminated provided the source, author and relevant organisations are acknowledged.

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Editorial

Sexuality has often been a site of oppression and discrimination for persons with disabilities. This has taken many forms, including the sexual behaviours of some persons with disabilities being seen as problematic, or even pathological, or persons with disabilities being regarded as incapable of procreating. This has been a particular experience for persons with physical disabilities.

One of the most frequent forms of oppression is the exclusion of persons with physical disabilities from being able to lead fully sexual lives, including accessing sexual and reproductive healthcare. Although sexual health has increasingly been seen as a human right (World Health Organisation, 2006), personal accounts and research have indicated that persons with physical disabilities are often excluded. One of the drivers of this exclusion is the prevailing myth that persons with physical disabilities are asexual. This results in society viewing persons with physical disabilities as unsuitable partners, or not in need of sexual health education or care.

There has been an increased international attention given to the sexual health rights of persons with disabilities (e.g. the World report on Disability, WHO, 2011), and there has been a call for increased research in this area. In the southern African context, this has partly been raised in relation to the potential risk for HIV infection. HIV and AIDS are also very much linked to sexual reproductive health rights for women with disabilities in particular.

Few published studies have focused on the sexual and reproductive health concerns of persons with physical disabilities in South Africa. The few studies that are published on persons with disabilities generally suggests that they receive limited education and care on matters of sexual and reproductive health, and may experience sexual violence and rape, partly due to intersecting misconceptions about disability, sexuality and gender.

There has been no recent review of the prevalence of the myth of asexuality for persons with disabilities since Milligan and Neufeldt (2001) and Di Giulio (2003), and no review specific to South Africa. In order to inform and support a study aiming to challenge these myths a review of the relevant literature about persons with physical disabilities was conducted and is presented here. The review looked at published and grey literature in South Africa specifically as well as the rest of the world, looking at this from the perspective of societal attitudes towards persons with physical disabilities, and access to sexual and reproductive health services.

Summary

The following summary reviews the knowledge that the extant research projects conducted in South Africa (see Reading Notes) have contributed to the field of disability and sexuality, including the ways in which actors in the field may have benefitted directly from findings. Additionally, attention is given to gaps remaining within in the area and to suggestions for future research. To facilitate these objectives the summary begins with a brief overview of the research background.

Background

Although sexuality was entrenched as a human right under the UN Convention on the Rights of Persons with Disabilities (UN, 2006), the prevailing societal myth of persons with disabilities as asexual and physically incapable of intimate relationships has been slow to dissipate worldwide. Persons with disabilities still face a variety of structural (e.g., inaccessible facilities) and social barriers (e.g., attitudes) which restrict both the expression of their sexuality and their access to sexual and reproductive healthcare. Traditional paradigms used to research this issue have generally adopted a medical perspective, focused predominantly on the needs of healthcare practitioners. However, a gradually emerging body of research has contrasted this by challenging the ways in which society may reproduce myths of asexuality (Anderson & Kitchin, 2000).

While South Africa has become increasingly progressive post-1994 and has certainly taken steps toward emancipating persons with disabilities from sexual exclusion, there remains a paucity of research on disability and sexuality, including with persons who have physical disabilities. Problematically, within South Africa (as well as other contexts), this gap in knowledge is related to broader health concerns, notably in regards to HIV, and vulnerability to infection of persons with disabilities. Therefore, extant applied research in South Africa, as well as the present project, forms part of a corpus of work addressing the urgent need for research on the sexuality of persons with disabilities in South Africa.

Knowledge contributed to the field

The discussion below is divided into the primary areas in which the South African literature has contributed to knowledge to the field on disability and sexuality.

Sexuality experiences of persons with physical disabilities

Research conducted in South Africa that has accessed the sexuality experiences of persons with physical disabilities has challenged some of the traditional notions of disabled sexuality. For instance, Potgeiter and Khan (2006) present discourses which contradict notions of youth with disabilities as asexual beings, instead painting them as sexually expressive individuals who consider themselves to be romantically attractive. Through these discourses, onus is placed on removing disabling social or structural barriers, rather than requiring persons with physical disabilities to make a litany of adjustments (p. 19).

In another example, Chappell's (2015) research uncovers hidden discourses among Zulu speaking youth, both disabled and able-bodied, that operate as sites of resistance to outdated conceptions of sexuality held by caregivers. For youth with disabilities this hidden language allows them to challenge ablest constructions of sexuality which may be deeply embedded in their parent or caregiver's cultural view of sexuality.

The way in which culture influences the sexuality experiences of persons with disabilities is also of interest to McKenzie (2013). Her findings suggest that sexuality is shaped by early interactions within the family and community, as well as by later experiences during adulthood. For example, McKenzie finds that women with disabilities were required to navigate the expectation that they were unable to have children from the community growing up. As such, this work is another instance of research which focuses on the ways in which society reproduces common myths of asexuality.

Additionally, some authors, like Wazakili, et al. (2006) are concerned with clarifying how sexuality experiences may impact on youth with physical disabilities accessing HIV services. These enable recommendations to policymakers to be made, for the purpose of delivering more comprehensive interventions to improve access to HIV treatment.

Sexuality, disability and marginalised identities

Research conducted in South Africa that has accessed the sexuality experiences of persons with physical disabilities has clarified how sexuality is the product of disability and the intersection of other marginalised identities, like culture or gender. Chappell (2015) finds that (Zulu) youth with disabilities do not discuss sexuality with their caregivers because of outdated cultural customs, in particular the concept of *ukuhlonipha* ("respect"). Wazakili et al. (2006) present similar results. In that study, both youth with disabilities and their parents recognise that it is taboo to discuss sexuality matters in Xhosa culture. These cultural silences on sexuality perpetuate constructions that youth with physical disabilities are asexual and limit their agency as sexual beings.

The literature also demonstrates how gender may intersect with culture and disability to produce a disadvantaged identity for women with disabilities and a (relatively) advantaged identity for men with disabilities. For example, both men with disabilities and their parents were found reluctant to date females with physical disabilities (e.g., Wazakili et al., 2006). There is also evidence that women with disabilities consider sexual abuse to be the biggest problem they faced, while for men this was reported to be unemployment (Hanass-Hancock, 2009). In this case, cultural myths of disability and sexuality may exacerbate the vulnerability of women with disabilities to sexual abuse. For example, traditional Zulu cosmology adheres to the notion of "virgin cleansing", i.e. equating an act of intercourse with a virgin as a sexual purification ritual. As women with disabilities are believed to be asexual, this increases their vulnerability to sexual abuse.

Finally, the literature also examines how poverty may shape sexuality experiences. Studies attempt to be as representative as possible by collecting data from different economic environments (e.g., Rohleder et al., 2012) and some explicitly aim to access the sexuality experiences of persons with disabilities in low income areas (e.g., Wazakili et al., 2006). McKenzie (2013) explores this issue in depth. Her findings suggest that situations of poverty may reinforce exclusion (sexual and otherwise) of persons with disabilities from an early age. For instance, as children with disabilities are not considered a good economic investment by their parents, she notes that they are often excluded from sexuality education within the family.

Disability, sexuality, and vulnerability to HIV

The South African literature has contributed knowledge to how disability, sexual experiences and other marginalised identities may impact vulnerability to HIV infection. For instance, given that cultural conceptions

of gender, disability and sexuality put women with disabilities at risk of sexual abuse, these cultural views also increase the vulnerability of this population to HIV (Hanass-Hancock, 2009). Unwillingness from parents or caregivers to discuss sexuality or provide sexuality information to persons with disabilities because of these views may perpetuate misunderstandings about HIV, such as that it can only be contracted from a stranger (e.g., Hanass-Hancock, 2009; Wazakili et al., 2006; Wazakili et al., 2009).

The knowledge contributed by the literature on this topic is not solely based on first person experiential data. Rohleder et al. (2012) conduct a descriptive study of HIV knowledge among persons with disabilities across three provinces in South Africa. These results are useful in guiding future targeted interventions on HIV prevention. For example, the findings illustrate some areas of HIV prevention where persons with disabilities lack knowledge (e.g., Having fewer sex partners) and also suggest that, despite recognising the importance of condoms, there exists considerable ambivalence about their use. The study also identifies high levels of unsafe sex behaviours within the sample, the presence of which, while troubling in terms of HIV vulnerability, also challenge the myth that persons with disabilities are asexual.

Other studies (e.g., Chirawu et al. 2014; de Reus et al., 2015; Mavuso & Maharaj, 2015) contribute knowledge to persons with disabilities' vulnerability to HIV by investigating access to sexuality education and access to sexual and reproductive healthcare. These topics are explored below.

Access to sexuality education

The research conducted in South Africa has also investigated access to sexuality education among persons with disabilities. As illustrated by previous examples, one barrier to access is cultural norms that effectively prohibit sexuality information being distributed to persons with disabilities by families and the community (e.g., Hanass-Hancock, 2009; McKenzie, 2013; Wazakili et al., 2006).

Another aspect that has received considerable attention in the literature is the role that professionals play in delivering sexuality education and information to persons with disabilities. Chirawu, Hanass-Hancock, and colleagues surveyed 99 educators in schools across South Africa to investigate this. It was found that while educators on the whole viewed delivering sexuality education to persons with disabilities positively and felt competent in doing so with "soft" topics (e.g., hygiene), they were less comfortable with others (e.g., masturbation; de Reus et al., 2015). Furthermore, educators felt that they had not received adequate materials with which to deliver sexuality information and that they could be better supported by the parents of children with disabilities (Chirawu et al. 2015). Similar findings were identified by Louw et al. (2014) who also felt that professionals in other roles (e.g., rehabilitation), as well as the government, should be responsible for sexuality education.

A study by Wazakili et al. (2009) complements the above work by exploring the role of rehabilitation professionals in delivering sexuality education from the perspective of youth with disabilities. Participants reported contact with such professionals from an early age, but this did not generally address sexuality issues. Furthermore, participants were unaware of any disability specific education programmes. However, at the same time, they expressed the wish to be involved in mainstream programmes in the future.

Access to sexual and reproductive healthcare

The South African literature has also contributed knowledge to the barriers persons with disabilities face when attempting to access sexual and reproductive healthcare. A particularly illustrative example is a recent piece of research conducted in Durban by Mavuso and Maharaj (2015). Their findings situate sexual and reproductive health services as a large component of the lives of persons with physical disabilities. However, their participants noted several social (e.g., negative attitudes, behavioural discrimination) and structural (e.g., inadequate transportation, inaccessible facilities) barriers when using healthcare services, which contributed to an overall detrimental experience of them.

It is worth noting that the Mavuso and Maharaj (2015) appears to be the only paper whose primary focus is on access to sexual and reproductive healthcare (as defined by this bibliography), though other papers such as Hanass-Hancock and Rohleder et al. also present findings that inform this area.

Methodology

Research conducted in the South African context has utilised a plurality of methodologies to investigate the sexuality of persons with physical disabilities. Both qualitative (e.g., Wazakili et al. 2009) and quantitative (e.g., Rohleder et al. 2012) studies have been conducted and in many cases, the chosen methodological approach has been of benefit to actors within the field, notably the research participants themselves.

For instance, many studies concerned with accessing the sexual experiences and perceptions of persons with physical disabilities have focused on deprived contexts. For example, Wazakili et al. (2006, 2009) recruit participants from Nyanga, a large township suffering from high levels of poverty and violence. McKenzie (2013) adopts a similar recruitment strategy. In addition, her analysis focuses explicitly on how poverty may shape experiences of sexuality. As such, though all experiential studies bring the discourses of persons with physical disabilities to the foreground, these give voice and agency (e.g., as sexual beings) to a particularly vulnerable group of youths with physical disabilities.

Chappell (2015) takes this aim one step further in their study investigating hidden discourses of sexuality among Zulu youths with disabilities. The author utilises a participatory methodology and train three Zulu youths with disabilities to act as co-researchers in the study. As such, this paper's methodology is particularly valuable to other researchers in demonstrating how persons with disabilities can be given social agency and status as sexual beings during the research process and not just through the research outcomes.

In a separate paper, Chappell et al. (2014) investigate the benefits that involvement as co-researchers can have for research participants. Their findings demonstrate the intrinsic value of "letting go" of pre-existing identities, which allows the co-researchers to construct and negotiate their own meanings from the research findings. Additionally, they suggest that the co-researcher process encourages individuals to extend their repertoire of self-positions (e.g., I as co-researcher), allowing for personal development.

Conversely, the rigidity of quantitative studies (Louw et al. 2015) means that they are less able to treat participants as anything more than objects of the research process. However, the results of these studies are more generalizable, and therefore can inform the wider field to some degree.

Relationship between the literature and the present project

Although the above discussion has presented some key ways in which the extant South African literature has contributed to a better understanding of sexuality and (physical) disability, it is important to highlight that, in comparison to other contexts (e.g., USA, Europe), the available literature is sparse (see annotated bibliography and Interim Report). As such, this project fills a much needed gap and also investigates areas which have hitherto, to our knowledge, received no empirical attention (see below).

Furthermore, the project lays important groundwork for future research to address new emerging theoretical and practical issues, as well as apply innovative qualitative and quantitative methods to gain a more comprehensive and accurate understanding of disability and sexuality in South Africa.

Future research

Presented below are some pressing gaps identified in the South African literature, which have received little or no empirical attention to date.

The attitudes of non-disabled South Africans

Some studies have investigated the views of parents of children with disabilities and have also explored whether these perceptions are a product of the wider community (e.g., McKenzie, 2013). Yet, no study has systematically examined the attitudes that non-disabled South Africans hold toward the sexuality of persons with physical disabilities.

Given that data collected from persons with disabilities suggest they encounter negative societal attitudes toward their sexuality, there is a pressing need to better understand the perceptions of the general population. To our knowledge, the present project is the first piece of empirical research to address this (see Study 1).

Interventions to improve attitudes and access to sexual healthcare and information

Although the South African literature has elucidated some of the social and structural barriers to disabled sexuality (e.g., Mavuso & Maharaj, 2015), very little work has been conducted on solutions to these problems. There is a need to test interventions to improve both attitudes and access to sexual healthcare and information. By accessing the experiences of persons with physical disabilities, as well as the attitudes of non-disabled South Africans, the present project lays the groundwork for research to begin in this direction. A particular challenge will be to ensure that any interventions are flexible enough to be adapted to suit the needs of South Africa's diverse population. For example, interventions delivered via audio as part of an on-line questionnaire may need to be translated and transferred to portable devices in order to reach non-English speakers residing in low income townships in the country.

Sexuality, disability and other marginalised identities

The South African literature has paid attention to how disability intersects with other marginalised identities, such as culture (e.g., Hanass-Hancock, 2009), youth (e.g., Chappell, 2015), and poverty (McKenzie, 2013). However, there are identities that have as of yet received little empirical attention. For example, the

experiences of persons with physical disabilities who belong to a sexual minority (e.g., bisexual; gay or lesbian) have not been explored. Moreover, although research has investigated gender differences and how these shape sexuality experiences and access to sexual healthcare (e.g., Rohleder et al. 2012), knowledge of the intersection between disability and motherhood is sparse. These differences are representative of disparities present in the global literature and as such, signify that there needs to be a wide call to action to rectify them.

Methodological developments

The South African literature has made good use of a wide range of methodologies, both qualitative and quantitative. However, there is ample room for further methodological innovation.

As one aim of the extant qualitative work conducted has been to empower and give agency to persons with physical disabilities as sexual beings (e.g., Chappel et al. 2014), this should be further developed through the use of innovative participatory methods. The present project addresses this aim by using Photovoice (Wang & Burris, 1997). Photovoice is a participatory research technique in which participants are trained as co-researchers and photographers. Participants are asked to take photographs that represent their everyday experience, and are then invited to provide narrative discussion in relation to illustrative images (Vaughan, 2014). The photographs are used as both visual data and as stimuli to elicit personal narratives. One benefit that this approach confers is the creation of a corpus of intuitive and easily understandable data, which can be disseminated among the general public to enhance interest and knowledge of disabled sexuality (see Interim Report).

A key aim of quantitative work is nearly always to generalize findings to the wider population. This aim can be furthered by using multi-level modelling in future studies of this type. Multi-level modelling is a statistical technique that can be used to accurately represent observed data which have a hierarchal or clustered structure (e.g., two individuals may share the same culture, but be nested in different superordinate structures, like schools or provinces). Multi-level models represent hierarchal data more accurately than regression-based approaches and allow for close inspection of the “added value” of group-level factors (Field, 2009). Inferences can also be made to a wider population. Thus, existing South African research dealing with hierarchal data structures could be extended using multi-level modelling. Below are two examples of such work:

- Research investigating barriers to sexual education among persons with disabilities within different special education schools (e.g., Chirawu et al. 2014; Louw et al., 2014).
- Research investigating risk factors of HIV among persons with physical disabilities across different provinces in South Africa (e.g., Rohleder et al., 2012).

Reading notes

Reading notes were selected with attention to the following Resource Centre criteria:

- Criteria 1 (C1): Link between the research results and a concrete application of the principles of the UN Convention.
- Criteria 2 (C2): Collaboration researcher / those active in the field.
- Criteria 3 (C3): Research leading to applied or applicable results, for the improvement of quality of life of persons with disabilities.
- Criteria 4 (C4): Research methodology (i.e. peer-reviewed).

For ease of understanding, these criteria are referenced within each reading note, where they are met.

Each reading note contains a link to the relevant research documentary note on the Resource Centre website.

Reading note 1. Secret languages of sex: disabled youth's experiences of sexual and HIV communication with their parents/caregivers in KwaZulu-Natal, South Africa

[Access to the reading note and to complete documents in the documentary database of the Resource Center](#)

Keywords

Child and teenager; Emotional and sexual life; Family: caregiver

Author's note

Various health promotion strategies have been implemented in South Africa aiming to encourage young people to talk about issues of sexuality and HIV with their parents/caregivers. Although parent/ caregiver sexual communication may be an effective method of influencing sexual behaviour and curbing the incidence of HIV, very little is known about how young people with disabilities in South Africa communicate about these traditionally difficult subjects with their parents/caregivers. Based on findings from a participatory study conducted amongst 15–20-year-old Zulu-speaking youth with physical and visual disabilities, this paper explores how they perceive youth– parent/caregiver communication about sexuality and HIV. Using Foucauldian discourse analysis, the paper outlines how disabled youth–parent/caregiver sexual communication is governed by cultural customs, sexual secrecy and constructs of innocence. It also argues that the experiences and perceptions of young people with disabilities are critical to the development of future interventions to assist parents/caregivers develop communication strategies that help disabled young people make sense of sexual behaviour.

Commentary

In this peer-reviewed paper (C4), Chappell employs a participatory research design to explore how youth with physical and visual disabilities communicate about their sexuality and HIV with their parents or caregivers. Although communication with parents/caregivers has been identified as pivotal to reducing risky sexual behaviours and HIV infection among South African youth, how disabled youths experience this communication has been thus far neglected. Chappell addresses this gap (C1). Chappell trains 3 youths with disabilities as co-researchers, thus explicitly recognising the sexuality and social agency of persons with disabilities (C2, C1). His approach also confers the practical benefits of allowing access to hard to reach population (i.e. Zulu speaking youth with disabilities) and thus giving them a voice (C2). Chappell's findings suggest that constructions of youth as "innocent" or "sexually passive" by their parents/caregivers are accentuated for disabled youth. Moreover they suggest (Zulu) youth with disabilities view their parents/caregivers as lacking sexual knowledge due to outdated cultural customs (e.g., *ukuhlonipha*- respect). Chappell's analysis further uncovers a hidden discourse that Zulu speaking youth- both disabled and abled-bodied- use to communicate their sexuality with their peers. These findings speak to the need to educate parents/caregivers to communicate effectively about sexual topics with youth who have disabilities (C3). They also identify hidden discourses among Zulu speaking youths as an important area of future research, both as a site of resistance to ableist constructions of sexuality and as a site of vulnerability which may enforce risky sexual behaviours (C3). This paper's methodology is also particularly valuable to other researchers in demonstrating how persons with disabilities can be given social agency and status as sexual beings during the research process and not just through the research findings (C1, C3). Although Chappell does not explicitly acknowledge it, his findings, derived from Zulu speaking youth with disabilities, are somewhat culture-bound, and as such, may have limited applicability within certain context.

Reading note 2. Troubling power dynamics: Youth with disabilities as co- researchers in sexuality research in South Africa.

[Access to the reading note and to complete documents in the documentary database of the Resource Center](#)

Keywords

Child and teenager; Emotional and sexual life

Author's note

Although a proliferation of participatory studies has explored youth sexuality in the African context, very few studies have included youth with disabilities. This is inevitably a result of the misconceptions surrounding disabled sexualities and youth with disabilities' competence in undertaking research. This article argues against these misconceptions by outlining a participatory sexuality study that worked with youth with disabilities as co-researchers in South Africa. In discussing the experiences of the young disabled co-researchers, the article troubles the constructs of power and empowerment in youth participatory research.

Commentary

This peer-reviewed article (C4) is derived from the same piece of participatory research as Chappell (2015), which was conducted among Zulu speaking youth with disabilities. In this paper, Chappell et al. focus explicitly on the experiences of three young disabled co-researchers and how they challenge notions of power and empowerment during the research process. The methodology that Chappell et al. use recognises the sexuality and social agency of persons with disabilities (C2, C1). Additionally, as this paper focuses specifically on the co-researcher experience, it comprises a particularly useful resource for researchers and co-researchers on future projects utilising a participatory research design (C3). The findings highlight the fluid nature of power and how relationships may change during the research process. They also demonstrate the intrinsic value of "letting go" (p. 394) and allowing the co-researchers to construct and negotiate their own meanings from the research findings. Lastly, the co-researcher process allowed individuals to extend their repertoire of self-positions (e.g., I as co-researcher), allowing for personal development. Although valuable as a guide for those wishing to perform participatory research with persons who have disabilities in South Africa (C1, C3), Chappell et al. hint that there may sometimes be unavoidable obstacles to implementing this approach. In this case, the authors intended to have four co-researchers, but one individual's parent was not comfortable with letting their child assume this role.

Reading note 3. Protect or enable? Teachers' beliefs and practices regarding provision of sexuality education to learners with disability in KwaZulu-Natal, South Africa

[Access to the reading note and to complete documents in the documentary database of the Resource Center](#)

Keywords

Education, Emotional and sexual life

Author's note

Literature argues that people with disabilities have heightened risk of exposure to sexually transmitted infections, including HIV due to lack of HIV knowledge, access to health services, and increased risk of sexual abuse and poverty. People with disabilities lack access to sexuality education. Teachers should be at the forefront to address this; however there is little understanding of the knowledge, attitudes, practices and needs of teachers of learners with disabilities in regards to sexuality/HIV education in Africa. A pilot study was conducted in ten special schools (eight urban, two rural) representing four types of disabilities in South Africa. Data was collected from 99 teachers using scales investigating beliefs and practice in teaching sexuality education, perceived subjective norms, self-efficacy, and materials/professional preparation. Frequencies, means, standard deviations and Cronbach's alphas were calculated for all scales. The data shows that overall teachers have positive attitudes towards teaching all elements of comprehensive sexuality education. However, they find it easier to discuss "soft topics" around relationships and personal skills (e.g., hygiene) than to talk about sexual behavior and functions. Teachers expressed confidence in their ability to teach sexuality education but indicated that their professional preparation and materials are not adequate to provide accessible sexuality education to their learners. The study highlights the need to develop appropriate materials and to build teachers' capacity to deliver sexuality and HIV education to learners with disabilities.

Commentary

In this peer-reviewed article (C4), Chirawu et al. seek to elucidate teachers' knowledge, attitudes and practices when delivering sexuality and HIV education to learners with disabilities in South Africa by using a mixed methodology. This is a companion article to de Reus et al. (2015) and focuses on the quantitative aspect of the study. Misconceptions about sexuality among persons with disabilities mean that they are especially vulnerable to contracting sexually transmitted infections such as HIV. Prior research has noted that teachers have some concerns over delivering sexuality education to learners with disabilities, however there has been little systematic investigation into teachers' knowledge, attitudes and practices toward this group. Chirawu et al. help address this gap (C1). The authors recruit teachers (N = 99) from 10 special schools, catering from a variety of impairment types (e.g., cerebral palsy, intellectual), in the province Kwa-Zulu Natal. As Chirawu et al. point out, sexuality research with educators of learners with disabilities is rare. Therefore, this study represents a valuable collaboration with actors in the field (C2). A questionnaire, comprising different attitudinal measures, was given to teachers who participated in the study. Findings revealed that although overall attitudes toward providing sexuality/HIV education to learners with disabilities were positive, teachers were hesitant to discuss some topics (e.g., sexual activity) with them. Additionally, teachers reported moderate confidence in their ability to deliver sexuality/HIV education, but expressed the need for more teaching materials in these areas. These findings highlight the need for service providers to provide adequate sexuality/HIV educational materials to learners with disabilities. The results also suggest that future

interventions should target the subjective norms that are held about the sexuality of persons with disabilities. These recommendations provide valuable guidance to the field (C3). Chirawu et al. note that, due to the small sample size, the results of this study are unable to be generalised to all of South Africa. An additional limitation is that, as the study looks at a range of disabilities, impairment specific issues may have been missed.

Reading note 4. Challenges in providing HIV and sexuality education to learners with disabilities in South Africa: the voice of educators.

[Access to the reading note and to complete documents in the documentary database of the Resource Center](#)

Key words

Education; Emotional and sexual life

Author's note

People with disabilities are at increased risk of exposure to HIV, yet they lack access to HIV prevention, treatment care and support including sexuality education. Lack of knowledge, skills and confidence of educators teaching sexuality education to learners with disabilities is related to this increased vulnerability. This study identifies possible challenges educators of learners with disabilities face when teaching sexuality and HIV education. Five focus groups were conducted in three purposely selected types of special schools representing four impairment groups in KwaZulu-Natal, South Africa. Educators recognise that teaching about sexuality is part of the South African Life Orientation curriculum and understand its importance to learners. However, they identified a number of challenges to such work, including barriers in communication and language, cultural values and expectations, learners' knowledge and behaviour, handling of sexual abuse cases and the teachers' own life experiences. Educators feel a lack of support from parents, departments of education, fellow educators and members of the community. They report the need for training and adapted HIV and sexuality education tools and resources to accommodate learners with disabilities. This training needs to provide knowledge on disability and HIV, offer guidance on disability appropriate communication strategies, deal with sexual abuse and include educational tools for the classroom.

Commentary

In this peer-reviewed article (C4), de Reus et al. (2015) seek to elucidate teachers' knowledge, attitudes and practices when delivering sexuality and HIV education to learners with disabilities in South Africa by using a mixed methodology. This is a companion article to Chirawu et al. (2014) and focuses on the qualitative aspect of the study. Misconceptions about sexuality among persons with disabilities mean that they are especially vulnerable to contracting sexually transmitted infections such as HIV. Prior research has noted that teachers have some concerns over delivering sexuality education to learners with disabilities, however there has been little systematic investigation into teachers' knowledge, attitudes and practices toward this group. De Reus et al. help address this gap (C1). The authors recruit teachers and support workers (N = 47) from 5 special schools, catering from a variety of impairment types (e.g., cerebral palsy, intellectual), in the province Kwa-Zulu Natal. In light of the rarity of sexuality research with educators of learners with disabilities, this approach represents a valuable collaboration with actors in the field (C2). The authors conducted focus groups within each school and the data was then analysed using thematic content analysis. Findings revealed that educators sometimes struggle to implement sexuality with learners who have disabilities and consider many sexual topics (e.g., condom use, masturbation) as culturally taboo. At the same time, there was an overall awareness that learners with disabilities were sexually active, but lacked knowledge about some areas of sexuality and were particularly vulnerable to sexual abuse. Therefore, educators recognised the need to provide sexuality education, though some did not feel confident doing so. The findings highlight both the need for educators to receive adequate training dealing with the sexuality of learners with disabilities and identify some areas which this training could target (e.g., educators' self-efficacy beliefs). These recommendations provide valuable

guidance to the field (C3). De Reus et al. emphasise that, as the present research is relatively small scale, further studies are required to gain a more representative understanding of educators' needs. Although the authors suggest that the quantitative work of Chirawu et al. addresses this somewhat, it is fair to say that still more representative research could be conducted within this area in the future.

Reading note 5. Interweaving conceptualizations of gender and disability in the context of vulnerability to HIV/AIDS in KwaZulu-Natal, South Africa.

[Access to the reading note and to complete documents in the documentary database of the Resource Center](#)

Keywords

Education, Emotional and sexual life

Author's note

In KwaZulu-Natal disability and gender are associated with myths and stereotypes that exacerbate the vulnerability of persons with a disability (PWD) to HIV/AIDS. The present analysis results from a three year qualitative study of 25 persons with disabilities and their caregivers. It outlines the interweaving patterns of stereotyping gender and disability and how this may increase the vulnerability of PWD to HIV/AIDS. The paper emphasizes that access to prevention and treatment is still an unfulfilled goal and that an enormous gap in service delivery persists. Sexual abuse and exploitation have become a major threat to fighting HIV/AIDS within the group of PWD. PWD are particularly vulnerable to HIV/AIDS through the threat of sexual abuse. Potential contributors to this are sexual purification rituals, sexual exploitation and the process of the judicial system. The notion that PWD are asexual, virgins, sexually overactive, cursed, dirty or clean increases their exposure to abuse and subsequently HIV/AIDS. Additionally, misconceptions regarding sexuality, gender and HIV/AIDS have exposed women and girls with disabilities, in particular, to abuse and HIV. Yet, effective responses are still scarce and persons with disabilities are often denied access to sexual education as well as prevention and treatment of HIV/AIDS.

Commentary

In this peer-reviewed article (C4), Hanass-Hancock investigates how harmful cultural stereotypes about disability and gender intersect within the South African province of KwaZulu-Natal. Although the vulnerability of persons with disabilities to HIV is becoming recognised within South Africa, Hanass-Hancock argues that generalised preventative measures will not be successful nationwide. In particular, she highlights that, within the province of KwaZulu-Natal, culture-specific beliefs about disabled sexuality put persons with disabilities, especially women, at risk of sexual abuse and exploitation. In turn, this abuse presents a substantive risk factor for the continued spread of HIV among persons with disabilities. Therefore, to help provide a more effective response to HIV in KwaZulu-Natal, Hanass-Hancock investigates the cultural beliefs held about both gender and disability within the province (C1). In-depth interviews and ranking exercises were conducted with 25 persons with disabilities who were living in KwaZulu-Natal. These aimed to shed light on three areas: a) Cultural interpretations of disability, b) Living conditions and access to healthcare services among persons with disabilities in KwaZulu-Natal, and c) Sexual culture and HIV. This qualitative methodology is relatively inclusive of persons with disabilities, as it allows their voices to be heard to a greater extent than, say, a quantitative methodology (C3). However, greater involvement could have been achieved through the use of a participatory research design (e.g., Chappell, Rule, & Mfana, 2015). Findings identified that disability was associated with sexual myths that increase the vulnerability of persons with disabilities to HIV (e.g., the beliefs that persons with disabilities are virgins and sex with a virgin can cure HIV). They also elucidated the sexual expectations tied to each gender within KwaZulu-Natal, for example that men should be sexually active and women should be submissive to their partner. In the case of persons with disabilities, these gendered expectations interact with disability stereotypes and result in tangible disadvantages, such as lack of acceptance as a partner.

Findings also highlighted the problematic ways in which some people respond to the sexual vulnerabilities (i.e. abuse) of persons with disabilities (e.g., denial; trivialisation). Findings highlights the need to address sexual abuse and exploitation among persons with disabilities in South Africa, in particular pointing to the problematic intersection between disability and gender stereotypes as an area of future focus (C3). It is worth noting however, that the generalisability of the study is limited, given the small sample size.

Reading note 6. Investigating educators' views of sexuality, HIV and AIDS education in working with students with disabilities in South African schools.

[Access to the reading note and to complete documents in the documentary database of the Resource Center](#)

Keywords

Education; Emotional and sexual life

Author's note

The misconception that persons with disabilities are asexual and sexually inactive often relegates teaching sexuality education in special needs schools to a priority of low importance. The access, or lack thereof, to such information causes students with disabilities to be at an increased risk of HIV infection; therefore, providing them with sexuality education is imperative. The purpose of the present study was to examine the teachers' and childcare providers' views of teaching sexuality, HIV, and AIDS programs in special needs schools. A survey questionnaire was employed to collect the data. The results showed that among the four major study constructs, teaching practices had the highest mean scores ($M = 4.2$). A correlation matrix among the 10 study variables indicates the strongest positive associations for teaching practices with cure for HIV ($r = .37, p < .01$) and the seriousness of the AIDS problem ($r = .35, p < .05$) with programs related to HIV and AIDS. The study confirmed the teachers' high levels of knowledge regarding HIV and AIDS and that they were taking the teaching of sexuality education to students with disabilities seriously. The teachers, however, questioned who should be held responsible for teaching this sexuality education, which may have an impact on their attitudes and beliefs as well as their teaching practices of the topic.

Commentary

In this peer-reviewed article (C4), Louw et al. investigate educators' attitudes toward teaching sexuality and HIV education to learners with disabilities in South Africa. Misconceptions about sexuality among persons with disabilities mean that they are especially vulnerable to contracting sexually transmitted infections such as HIV. Prior research has noted that teachers have some concerns over delivering sexuality education to learners with disabilities, however there has not been much systematic investigation into teachers' attitudes toward delivering sexuality and HIV education. Louw et al. help address this gap (C1). The authors recruited teachers ($N = 78$) from special schools across South Africa which catered for a variety of impairment types (e.g., cerebral palsy, intellectual). These participants filled out a questionnaire which assessed their attitudes toward delivering sexuality and HIV education to learners with disabilities. In light of the rarity of sexuality research with educators of learners with disabilities, this approach represents a valuable collaboration with actors in the field (C2). Findings suggest that educators' held a high level of knowledge about HIV, viewed HIV as a serious issue, and were comfortable teaching learners with disabilities. Many had received general training in delivering sexuality education to learners with disabilities, but HIV-specific training was lacking. However, educators felt that other staff members, the government, and parents should be responsible for delivering sexuality education as well. The results highlight the need for educators to be better supported when delivering sexuality education to learners with disabilities by having access to training and HIV-specific materials as well as the need for co-ordination between stakeholders (e.g., government) in this area (C3). Louw et al. do highlight some methodological limitations to the study, notably small sample size and low scale reliability ($< .60$). Therefore, though a valuable small-scale exploration of the area, further research is needed to help generalise the findings and rule out potential confounds.

Reading note 7. Disabled people in rural South Africa talk about sexuality.

[Access to the reading note and to complete documents in the documentary database of the Resource Center](#)

Keywords

Child and teenager; Emotional and sexual life; Family: caregiver

Author's note

Disability is emerging as a human rights issue of public concern, rather than an individual tragedy requiring medical attention. The issue of sexuality remains relatively neglected in this agenda, particularly as regards the exploration of the complexities of sexuality encountered by disabled people themselves. This paper focuses on the experiences of sexuality of disabled people and parents of children with disabilities in settings of poverty in the Eastern Cape Province of South Africa. Three individual interviews and two focus groups were conducted with disabled adults and parents of children with disabilities. Thematic analysis of the interviews identified three principal themes (1) sexuality development in the family of origin, (2) sexuality in the community and (3) adult sexuality and creating families. Each of these larger themes encompasses various sub-themes that are discussed in the findings. The paper concludes that while sexuality is a very difficult aspect of life for a disabled person due to myths and discrimination against disabled people, it is also an important arena for affirmation and establishing self-worth. It is therefore critical to consider the development of a healthy sexuality amongst disabled people and the promotion of their sexual rights.

Commentary

In this peer-reviewed article (C4), McKenzie explores the sexuality of persons with disabilities and the parents of children with disabilities, with particular focus on sexuality experiences shaped by contexts of poverty. Within the South African context the vulnerability of persons with disabilities to HIV is now widely recognised. McKenzie argues that while this is a useful perspective, ultimately the sexuality of persons with disabilities must be considered as shaped by other contexts as well. Her stated aim is to elucidate factors that may contribute to or detract from healthy sexuality that have been missed by prior research which has adopted this narrow focus (C1). In particular, McKenzie investigates how disabled sexuality in South Africa may be influenced by poverty. To ascertain this, she conducts interviews and focus groups with persons with disabilities and the parents of children with disabilities in an area of South Africa beset by poverty (King Sabato Dalindyebo district within Eastern Cape). McKenzie's efforts to reach the indigenous population of this area mean that her study represents a valuable collaboration with those in the field (C2), particularly as poverty is often synonymous with the exclusion of these voices. The author finds that disabled sexuality is shaped by early interactions within the family and community, as well as later experiences during adulthood. Importantly, this suggests that the disadvantage and inequality that persons with disabilities face in terms of their sexuality (and other areas) begins early. For example, within the context of poverty, children with disabilities are not considered a good economic investment by their parents. This leads to them being excluded from important facets of life, like sexuality education. These findings can be used to promote sexual rights for persons with disabilities within the South African context and represent in particular a call for action towards addressing poverty as a barrier to these rights (C3). The paper also usefully attests to the self-efficacy of persons with disabilities as some the participants were now in healthy intimate relationships and had jobs (C3). As is common in this type of qualitative research however, the generalisability of the findings is limited.

Reading note 8. Access to sexual and reproductive health services: Experiences and perspectives of persons with disabilities in Durban, South Africa.

[Access to the reading note and to complete documents in the documentary database of the Resource Center](#)

Keywords

Emotional and sexual life.

Author's note

Sexual and reproductive health is recognised as an essential component of good health and personal development. However, a number of studies suggest that persons with disabilities (PWD) are often marginalised by sexual and reproductive health programmes. In this study in-depth interviews were conducted with sexually active women and men of reproductive ages with different types of disabilities in order to examine access to sexual and reproductive health services in Durban, South Africa. The majority of respondents revealed that sexual and reproductive health services are a big part of their lives. However, there seemed to be a huge gap between their need for services and their rights to access these services. Gender compounded the negative experiences for women with disabilities. Women mentioned that health providers appear surprised that they will need family planning services, and they are not given choices about suitable birth control methods. The findings reveal a need to address access to sexual and reproductive health services for PWD.

Commentary

In this peer-reviewed article (C4), Mavuso and Maharaj investigate the experiences that persons with disabilities have of accessing sexual and reproductive healthcare in Durban, South Africa. Despite steps toward the sexual and reproductive rights of persons with disabilities in South Africa being taken in theory, the authors draw attention to the fact that more improvement is required in practice. Therefore, they set out to document the current experiences of persons with disabilities when accessing sexual and reproductive healthcare in Durban (C1). To do this, they interviewed a sample of 16 individuals with disabilities, who reside in a large home that facilitates independent living and co-habitation (i.e. with spouses and children). Given that many research projects still do not leave room for persons with disabilities to speak on their own behalf, this represents a valuable collaboration with actors in the field (C2). Mavuso and Maharaj's findings are numerous. Firstly, they note that the sexual perceptions of respondents appear to be gendered (e.g., males view sex as self-gratifying, women use sex to establish emotional attachment). In terms of sexual and reproductive healthcare, participants asserted that attempts to provide sexuality education to persons with disabilities were poor. This criticism applied across both public and private spheres of life. For instance, respondents reported receiving a lack of accessible public educational material and did not gain this information from their families either, whose members generally endorsed the myth that persons with disabilities are asexual. Furthermore, participants noted several social (e.g., negative attitudes, behavioural discrimination) and structural (e.g., inadequate transportation, inaccessible facilities) barriers when using healthcare services, which contributed to an overall detrimental experience of them. In light of the above, the authors are able to provide practical recommendations of how access to sexual and reproductive health services in South Africa should be improved (e.g., more mobile clinics within the community; C3). Many of the barriers to access identified in the study are grounded in the (mis-) perceptions of sexuality that participants perceive South Africans without disabilities to hold. However, an overall limitation of this area of research is that there has been very little

direct investigation of the views that the general South African population hold about persons with disabilities. Pursuing this investigation would enable more targeted recommendations to be made to improve access to sexual healthcare.

Reading note 9. Sexual self-esteem and body image of South African spinal cord injured adolescents

[Access to the reading note and to complete documents in the documentary database of the Resource Center](#)

Keywords

Child and teenager; Emotional and sexual life;

Author's note

Although adolescents sustain a large portion of spinal cord injuries, the area of spinal cord injured adolescents and the issues surrounding their sexuality are under-researched. This is the first South African study on the sexuality of spinal cord injured adolescents and attempts to address this paucity. It is generally postulated that the sexuality of adolescents who have sustained SCI will be detrimentally affected by the consequences of having a physical disability, resulting in developmental lags relative to non-disabled peers. The focus of this article is to explore the impact of spinal cord injury on adolescent's sexual self-esteem and body image. A qualitative study was conducted, with data being collected via in-depth individual interviews, which were subsequently analyzed thematically. A disparity was found between dominant ableist discourses of the SCI adolescent as a sexually immature and passive spectator, and the lived experiences of the participants involved in the study. The study concluded that entrenched socially constructed attitudes appear to limit the opportunities for spinal cord injured adolescents to express their sexuality more than the limitations by their disabilities.

Commentary

In this peer-reviewed article (C4), Potgieter and Khan qualitatively investigate the impact of spinal cord injuries on South African adolescents' sexual self-esteem and body image. The sexuality of persons with spinal cord injuries, particularly adolescents, has received very little attention in prior research. The authors argue that one reason for this gap is the way that sexuality has been constructed in traditional academic discourse, i.e. stressing physical changes in the body that facilitate sexual development, versus cultural or societal factors. Potgieter and Khan challenge this in their work by exploring the discourses of spinal cord injured adolescents directly (C1). The authors conducted biographical interviews with seven adolescents, accessed through South African schools. As this study is the first to focus on the sexuality of South African adolescents who had spinal cord injuries, agency is given to a section of the population who have previously been without a voice (C2). The findings illustrate a sense of confusion among spinal cord adolescents regarding whether they are objects of onlookers' sexual interest or pity and curiosity. However, respondents differed over the relationship they possessed with their own bodies. For example, some participants viewed their body positively as a site for celebration, while others were ambivalent or felt self-loathing as a result of negative bodily images. Potgieter and Khan bring to the fore discourses that challenge traditional notions of disabled sexuality (C3). They note the importance of work that dispels these constructions, particularly that which focuses on social and structural barriers to disabled sexuality. The points raised speak to the need for intervention research in the future; as such Potgieter and Khan's study represents (and claims to be) only a first step toward addressing prevailing myths of disabled sexuality among South African spinal cord injured adolescents.

Reading note 10. Gender differences in HIV knowledge and unsafe sexual behaviours among disabled people in South Africa.

[Access to the reading note and to complete documents in the documentary database of the Resource Center](#)

Keywords

Emotional and sexual life;

Author's note

Purpose: The international literature suggests that disabled people may be at increased risk for HIV infection. There is a growing increasing recognition of this in South Africa, although there remains a paucity of literature on how disabled people are affected by HIV/AIDS. This is a concern given the seriousness of the epidemic here. This paper reports on descriptive data exploring gender differences in HIV knowledge and unsafe sexual behaviours among disabled individuals in South Africa.

Method: Data was collected by means of a survey questionnaire from a total sample of 285 disabled individuals in three of the nine provinces in South Africa. Data was analysed by means of descriptive statistics.

Results: There are low levels and uncertainty of knowledge about HIV transmission and HIV prevention, with females tending to have lower levels of knowledge than males. Although the importance of condoms in HIV prevention was recognised, there were relatively high levels of reported unsafe sexual behaviours. Males reported higher number of monogamous and concurrent sexual partnerships and sex without a condom after alcohol use. **Conclusions:** The results support the literature that suggests that disabled people are at risk for HIV infection, and that both male and female individuals with disability are at risk.

Commentary

In this peer-reviewed article (C4), Rohleder et al. investigate the characteristics of persons with disabilities affected by HIV in South Africa, with particular attention to gender differences and frequencies of unsafe sexual behaviours. Rohleder et al. highlight that persons with disabilities have been overlooked in terms of their risk of HIV and prevention strategies. Given the lack of knowledge of how HIV may affect this population, the authors seek to describe the characteristics of individuals with disabilities living in communities affected by HIV in South Africa (C1). The authors survey 285 individuals with disabilities in three different provinces of South Africa and attempt to obtain as representative a sample as possible of persons with disabilities (e.g., collecting data from urban, semi-urban and informal settlements). The methodology used does not allow for as close collaboration persons with disabilities as more participatory research designs (e.g., Chappell, 2015), however, Rohleder et al. consult disability organisations in order to facilitate and complete data collection of their project (C2). The nature of the findings (see below) also means that the study is highly useful to actors in the field (C2). The findings illustrate some areas of HIV prevention where persons with disabilities lack knowledge (e.g., Having fewer sex partners) and also suggest that, despite recognising the importance of condoms, there exists considerable ambivalence about their use. Moreover, while the majority of the sample was found to have had sexual intercourse, levels of unsafe sexual behaviours (e.g., unprotected) were also high. The study also notes gender differences (e.g., males reported more sexual activity than females). As such, this research identifies some problematic ways in which persons with disabilities are affected by HIV, which allow the authors to make some recommendations for future targeted interventions (e.g., substance use may

not be a significant risk factor compared to lack of condom use; C3). Although effort has been made to collect data from as representative a sample as possible, nevertheless the authors caution that the data is not fully representative of South Africans. Additionally, they highlight the presence of missing data, which required imputation.

Reading note 11. Experiences and perceptions of sexuality and HIV/AIDS among young people with physical disabilities in a South African township: A case study.

[Access to the reading note and to complete documents in the documentary database of the Resource Center](#)

Keywords

Child and teenager; Emotional and sexual life; Family: Caregiver

Author's note

This study explored the experiences and perceptions of sexuality and HIV/AIDS among 15–24 year-old young people with physical disabilities in a South African Township characterised by high unemployment rates and lack of social services. Ten young people and ten parents participated in multiple individual interviews as well as in focus group discussions. The analysis of audio taped and transcribed responses identified common experiences and perceptions among participants. The results indicate that disabled young people have limited factual knowledge about sexuality and HIV/AIDS. The decisions and choices they make about sexual behaviour are not informed by what they know; rather, they are part of the whole life situation in Nyanga. Their need to be loved and accepted, need for job security and family life, were more important than practicing 'safe sex'. Therefore, there is need for HIV/AIDS programme developers to take into account the experiences and perceptions of the target population.

Commentary

In this peer-reviewed article (C4), Wazakili et al. explore the sexual experiences and perceptions of youth who have physical disabilities, as well as parental attitudes, within a South African township. The purpose of this study is to identify barriers that prevent these young persons from accessing sexual information, particularly about HIV (C3). In exploring this topic, Wazakili et al. help address the urgent need to understand the links between disability, sexuality and HIV, which has been neglected in the past (C1). The authors recruit their participants from Nyanga, a township suffering from high levels of poverty and violence. As such, this paper gives voice and agency (as sexual beings) to a particularly vulnerable group of youths with physical disabilities (C1, C2). The findings indicate that youths with physical disabilities face many (inter-related) barriers to accessing sexual information. These barriers are identified as negative socio-cultural attitudes toward the sexuality of persons with physical disabilities, a lack of awareness about HIV, and vulnerabilities toward HIV infection (e.g., sexual exploitation). Wazakili et al. assert that their study shows the need for policy developers to take into account the experiences of this population, though further specific recommendations are not given (C3).

The authors also caution against generalising the results of the study to other persons with disabilities, even within Nyanga, due to the qualitative nature of the methodology. They further acknowledge that, due to high crime and violence levels, youths living in some areas of the township were unable to be accessed. Notwithstanding, Wazakili et al. rightly suggest that their findings should be viewed as illustrating the complex web of ways in which young persons with disabilities experience both sexuality and HIV concerns (C1, C3). It is herein that the study is of particular value to the field.

Reading note 12. Should issues of sexuality and HIV and AIDS be a rehabilitation concern? The voices of young South Africans with physical disabilities.

[Access to the reading note and to complete documents in the documentary database of the Resource Center](#)

Keywords

Child and teenager; Emotional and sexual life

Author's note

Purpose. Although rehabilitation is an integral part of the lives of many young people with physical disabilities, sexuality education and HIV and AIDS prevention services are not. The purpose of this study was to record the voices of disabled young people regarding their experiences of sexuality and HIV and AIDS and to determine the role of rehabilitation professionals in this regard.

Methods. Sixteen young people with physical disabilities, aged 15–24 years participated in the study. Individual in-depth interviews were conducted with each participant, followed by focus group discussions comprising four to six participants. Responses were audiotaped and transcribed verbatim. Textual and contextual features of the Atlas.ti computer programme were used to support the thematic analysis of the data.

Results. The results indicated that most participants had received some form of rehabilitation for their physical impairment, yet sexuality and HIV and AIDS matters were not part of the rehabilitation process. Although the majority were aware of sexuality and HIV and AIDS issues, their limited factual knowledge did not persuade them to change their sexual behaviour or take preventive measures against contracting HIV infection.

Conclusion. Rehabilitation professionals need to widen their scope of practice to include the promotion of good sexual and reproductive health for disabled young people.

Commentary

In this peer-reviewed article (C4), Wazakili et al. examine the experiences that South African youth with disabilities have of sexuality and HIV, with specific reference to the role that rehabilitation professionals play in this respect. The authors note that persons with disabilities are often overlooked when it comes to the provision of sexuality education. Similarly, there is concern that rehabilitation professionals are neglectful when providing this information (e.g., due to lack of experience), contributing to this populations' vulnerability to HIV. In light of the need to better involve rehabilitation professionals in targeted interventions with this population, Wazakili et al. attempt to record the voices of South African disabled youth to ascertain what role these professionals should play (C1). As these voices are rarely heard in response to sexuality and HIV issues, the study represents a valuable collaboration with actors in the field (C2). Moreover, the authors conduct in-depth interviews and focus groups with individuals residing in Nyanga, a large township characterised by poverty and makeshift housing, meaning that agency is given to a particularly vulnerable group of persons with disabilities (C2; see also Wazakili et al., 2006). Their findings indicate that youth with disabilities experience several gaps in their sexuality education. They have limited knowledge of their sexual rights and also limited factual knowledge about HIV and the risks of contracting it. They further indicated no awareness of disability specific intervention programmes to address this and expressed the wish to be involved in

mainstream programmes instead, despite the fact this was uncommon at present. Importantly, participants reported contact with rehabilitation professionals from an early age, though this was limited in some more rural settings and did not generally address sexuality issues. The work conducted by Wazikili et al. allows the voices of South African disabled youth to be heard. Based on these voices, the authors make a number of recommendations to improve the provision of sexuality and HIV education to this group (C3). These include advising that rehabilitation professionals work closely with the parents of children with disabilities in order to deliver effective education. They also highlight the need for inclusive HIV educational programmes and challenge rehabilitation professionals to take the lead in their design and implementation. The authors comment on some of the limitations of the study, notably the inability to access participants that lived in particularly dangerous areas of the township and initial difficulties in establishing rapport and interview depth due to language barriers. Therefore, although the paper records the voices of South African youth with disabilities, we must be aware that there are still some that need to be heard more clearly.

Bibliography

The following bibliography of applied research pertinent to the project is divided into two sections, based on thematic content of each source: (A) attitudes toward the sexuality of persons with physical disabilities or (B) persons with physical disabilities' access to sexual and reproductive healthcare. In sources where both themes appear, classification has been made according to the dominant theme present (identified through close inspection of the abstract, keywords and/or main body of source).

Additionally, each section comprises two subsections, based on geographical region: (i) World and (ii) South Africa. These have been classified based on the country or region where the research has been conducted.

Prior to presenting the main bibliography, it is of interest to note that there are two review papers of the area:

- ❖ Di Giulio, Gina. "[Sexuality and people living with physical or developmental disabilities: a review of key issues](#)." *The Canadian Journal of Human Sexuality* 12, no. 1 (2003): 53-68.
- ❖ Milligan, Maureen S., and Neufeldt, Aldred H. "[The myth of asexuality: A survey of social and empirical evidence](#)." *Sexuality and Disability* 19, no. 2 (2001): 91-109.

Section A: Societal attitudes

Section A lists applied research which primarily investigates attitudes toward disabled sexuality. This includes empirical data on people's beliefs, emotions and experiences of the sexuality of persons with physical disabilities. The majority of studies investigate the attitudes of persons with physical disabilities themselves, often through qualitative methods design to elucidate the lived experiences of these individuals. Studies that gather data from non-disabled participants generally do so for the purposes of including a comparative/baseline sample; few expressly investigate non-disabled attitudes toward disabled sexuality. Research has also paid some attention to professional, and less commonly, parental attitudes toward disabled sexuality.

i): World

- ❖ Addlakha, Renu. "[How young people with disabilities conceptualize the body, sex and marriage in urban India: Four case studies](#)." *Sexuality and Disability* 25, no. 3 (2007): 111-123 (paying access)

Addlakhu's qualitative study of Indian youth with disabilities highlights some key issues (e.g., gender as important to sexual self-perception), in a largely under-researched domain.

- ❖ Aguilera, Raymond J. "[Disability and delight: Staring back at the devotee community](#)." *Sexuality and Disability* 18, no. 4 (2000): 255-261 (paying access)

Aguilera's qualitative study of devotees is a rare exploration of those for whom the disabled community are a sexual fetish. In particular, this paper challenges the view that people who are attracted to people with disabilities are "sick" or "bad".

- ❖ Akinci, Ayse C. "[The comfort levels of nurses during clinical experiences which include sexual topics.](#)" *Sexuality and Disability* 29, no. 3 (2011): 239-250 (paying access)

Akinci's descriptive study on the comfort levels of Turkish nurses (N = 141) with sexual topics finds that many (> 50%) are uncomfortable carrying out a range of duties (e.g., answering the sexuality questions of male patients).

- ❖ Akinci, Ayse C., Yildiz, Hicran, and Zengin, Neriman. "[The level of comfort among nursing students during sexual counseling to patients who have chronic medical conditions.](#)" *Sexuality and Disability* 29, no. 1 (2011): 11-20 (paying access)

Akinci et al.'s descriptive study on the comfort levels of Turkish nursing students (N = 161) during sexual counselling finds that less than half address sexual questions from patients comfortably. Akinci's work (see above) extends knowledge on professional attitudes to disabled sexuality to the Turkish context.

- ❖ Altuntug, Kamile, Ege, Emel, Akın, Belgin, Kal, H. Esra, and Sallı, Ali. "[An investigation of sexual/reproductive health issues in women with a physical disability.](#)" *Sexuality and Disability* 32, no. 2 (2014): 221-229 (paying access)

Altuntug et al.'s qualitative exploration of sexual and reproductive health in the Turkish context suggests that many experience sexual dysfunction, stemming from both physical and psychological factors.

- ❖ Andersson, Johanna. "[Physical disability and sexuality: A qualitative study on challenges and expectations connected to sexuality seen from the view of Tanzanian women living with physical disabilities.](#)" Bachelor Thesis (2010), 1-48 (open access)

Andersson's bachelor's thesis sheds light on the sexuality experiences of women with disabilities in an under-researched context (Tanzania). In common with the extant peer-reviewed literature (e.g., Bahner, 2012), she finds that women with disabilities face challenges to sexual expression at an individual and structural level.

- ❖ Balderston, Susie. "[Victimized again? intersectionality and injustice in disabled women's lives after hate crime and rape.](#)" *Gendered Perspectives on Conflict and Violence: Part A* 18 (2014): 17-51 (open access)

Balderston paper provides evidence which demonstrates that attitudes at the societal level legitimize sexual violence against women with disabilities in the UK. The findings further suggest micro-level strategies through which victimised women with disabilities can reconstruct their identities and challenge negative discourses at the societal level.

- ❖ Bahner, Julia. "[Legal rights or simply wishes? The struggle for sexual recognition of people with physical disabilities using personal assistance in Sweden.](#)" *Sexuality and Disability* 30, no. 3 (2012): 337-356 (paying access)

Bahner's qualitative exploration highlights the disparity between the stated aims (e.g., autonomy) of a personal assistance programme in Sweden and the lived experiences that persons with disabilities have of their sexuality. Like other extant research in the same context (e.g., Helmius, 1999) Bahner's work, demonstrates the gap between societal attitudes/aims and the experiences of persons with disabilities.

- ❖ Batty, Richard, McGrath, Laura, and Reavey, Paula. "[Embodying limb absence in the negotiation of sexual intimacy.](#)" *Sexualities*, 17, no. 5-6 (2014): 686-706 (paying access)

Batty and colleagues explore the way sexual identities are negotiated and managed among limb amputations. The use of a visual workshop highlights how participatory methodologies can provide a richer and more contextualised understanding of disabled sexuality.

- ❖ Beauregard, Line, and Noreau, Luc. "[Spouses of persons with spinal cord injury: Impact and coping.](#)" *British Journal of Social Work* (2009): 1-15 (paying access)

Beauregard and Noreau's work represents a rare qualitative exploration into how acquired physical disability (SCI) may impact spouses (see also Esmali et al., 2007, 2010).

- ❖ Beckwith, Alison, and Yau, Matthew K. "[Sexual recovery: experiences of women with spinal injury reconstructing a positive sexual identity.](#)" *Sexuality and Disability* 31, no. 4 (2013): 313-324 (paying access)

Beckwith and Yau build on the existing literature by investigating disabled sexuality within an Australia context, identifying a number of individual and structural barriers to sexual expression.

- ❖ Blackmore, Danielle E., Hart, Stacey L., Albani, Jenna J., and Mohr, David C. "[Improvements in partner support predict sexual satisfaction among individuals with multiple sclerosis.](#)" *Rehabilitation Psychology* 56, no. 2 (2011): 117-122 (open access)

Blackmore et al. show that both positive and negative partner support predicts the sexual satisfaction of persons with disabilities. The authors highlight the relevance of their findings to future intervention studies.

- ❖ Blum, Robert W., Resnick, Michael D., Nelson, Richard, and St Germaine, Anne. "[Family and peer issues among adolescents with spina bifida and cerebral palsy.](#)" *Pediatrics*, 88, no. 2 (1991): 280-285 (paying access)

While offering relatively pessimistic descriptive evidence as to the prevalence of dating (< 30%) among a sample of disabled teens (N = 162), this study nevertheless highlights that interest in intimacy is high (75%), thereby refuting myths of asexuality.

- ❖ Braathen, Stine H., and Kvam, Marit H. "[‘Can anything good come out of this mouth?’ Female experiences of disability in Malawi.](#)" *Disability & Society* 23, no. 5 (2008): 461-474 (paying access).

Braathen and Kvam's qualitative exploration of women with disabilities in Malawi, highlights a range of positive and negative experiences, shedding light on a little researched context.

- ❖ Browne, Jan, and Russell, Sarah. "[My home, your workplace: people with physical disability negotiate their sexual health without crossing professional boundaries.](#)" *Disability & Society* 20, no. 4 (2005): 375-388 (open access)

Data collected by Browne and Russell describes how Australian persons with physical disabilities negotiate sexual health issues without crossing client-carer boundaries.

- ❖ Brunnberg, Elinor M., Boström, Linden, and Berglund, Mats. "[Sexuality of 15/16-year-old girls and boys with and without modest disabilities.](#)" *Sexuality and Disability* 27, no. 3 (2009): 139-153 (open access)

In the Swedish context, Brunnberg et al. find that sexual debut is higher among disabled 15- 16 year olds, compared to non-disabled 15-16 year olds.

- ❖ Cardoso, Fernando L., Sacomori, Cinara, and Vieira, Mauro L. "[Validation of a scale for body and sexual self-esteem in athletes with disabilities.](#)" *Sexuality and Disability* 30, no. 1 (2012): 29-38 (open access)

The authors validate the scale for body and sexual self-esteem among a sample of Brazilian physically disabled athletes.

- ❖ Cheausuwantavee, Tavee. "[Sexual problems and attitudes toward the sexuality of persons with and without disabilities in Thailand.](#)" *Sexuality and Disability* 20, no. 2 (2002): 125-134 (paying access)

This descriptive comparative study suggests that persons with (N = 25) and without disabilities (N = 76) are mostly similar in their sexual attitudes (e.g., kinds of love they want).

- ❖ Cheng, Mariah M., and Udry, J. Richard. "[Sexual behaviors of physically disabled adolescents in the United States.](#)" *Journal of Adolescent Health* 31, no. 1 (2002): 48-58 (paying access)

Like other comparative studies (e.g., Cheausuwantavee, 2002) Cheng and Udry find similarities between physically disabled and non-disabled adolescents, notably in terms of their sexual experiences.

- ❖ Copel, Linda C. "[Partner abuse in physically disabled women: A proposed model for understanding intimate partner violence.](#)" *Perspectives in Psychiatric Care* 42, no. 2 (2006): 114-129 (Paying Access)

The findings of Copel's qualitative study on the experiences of abused women with disabilities were used to develop an alternative theoretical model of the abuse cycle.

- ❖ Corker, Mairian. "[Isn't that what girls do? -disabled young people construct \(homo\) sexuality in situated social practice.](#)" *Educational and Child Psychology* 18, no. 1 (2001): 89-107 (open access)

Corker uses narrative methods to explore how persons with disabilities identifying as non- heterosexual construct their identity in social and educational settings.

- ❖ Cramer, Elizabeth P., Gilson, Stephen, F. and Depoy, Elizabeth "[Women with disabilities and experiences of abuse.](#)" *Journal of Human Behavior in the Social Environment* 7, no 3-4 (2004): 183- 199 (paying access)

The authors explore intersectionality as a framework for understanding the partner victimisation experiences of non-White persons with disabilities. Their findings are illustrated through two case examples, and (the authors argue) demonstrate the usefulness of intersectionality for understanding abuse.

- ❖ Cramp, Jackie, Courtois, Frédérique, Connolly, Maureen, Cosby, Jarold, and Ditor, David. ["The Impact of urinary incontinence on sexual function and sexual satisfaction in women with spinal cord injury."](#) *Sexuality and Disability* 32, no. 3 (2014): 397-412 (paying access)

Cramp et al. build on previous work on the sexuality of persons with SCI (e.g., Julia & Othman, 2011) by focusing specifically on the experiences that women with disabilities have of urinary incontinence and their sexual satisfaction.

- ❖ Crawford, Danette, and Ostrove, Joan M. ["Representations of disability and the interpersonal relationships of women with disabilities."](#) *Women & Therapy* 26, no. 3-4 (2003): 179-194 (paying access)

Crawford and Ostrove explore how societal attitudes ("representations") of disability, shape the sexual experiences of women with disabilities, accessed through interviews.

- ❖ Deepak, Sunil. ["Male, female or disabled: Barriers to expression of sexuality"](#) Masters thesis, (2002): 1-84 (open access)

In this Master's thesis, Deepak identifies barriers to sexuality among an Italian sample of persons with disabilities. In common with the extant peer-reviewed literature (e.g., Helmius, 1999), he finds that persons with disabilities face barriers to sexual expression at the individual and structural level.

- ❖ Dune, Tinashe M. ["Understanding experiences of sexuality with cerebral palsy through sexual script theory."](#) *International Journal of Social Science Studies* 1, no. 1 (2012): 1-12 (open access)

Dune's work (see also below) uses sexual script theory to explore the sexuality experiences of people with cerebral palsy's through an interactional lens. The findings therefore help clarify how people with cerebral palsy negotiate and communicate about sexual preferences, desires and experiences.

- ❖ Dune, Tinashe M. ["You just don't see us": The influence of public schema on constructions of sexuality by people with cerebral palsy."](#) *World Journal of Social Science* 1, no. 1 (2013): 1-19 (open access)

This paper focuses explicitly on how public constructions of disabled sexuality influence the way that sexuality is negotiated among persons with disabilities.

- ❖ Dyer, Kerry, and das Nair, Roshan. ["Why don't healthcare professionals talk about sex? A systematic review of recent qualitative studies conducted in the United Kingdom."](#) *The Journal of Sexual Medicine* 10, no. 11 (2013): 2658-2670 (paying access)

Dyer and das Nair offer a systematic review of healthcare professionals' experiences of addressing the sexual health issues of service users. Findings offer a more comprehensive understanding of the perceived barriers in this area (e.g., worry about causing offence, personal discomfort), which can be used to guide future interventions.

- ❖ East, Lauri J., and Orchard, Treena R. "[‘Why can't I?': an exploration of sexuality and identity among Canadian youth living with physical disabilities.](#)" *Journal of Youth Studies* 17, no. 5 (2014): 559-576 (paying access)

The authors explore how a sample of Canadian youths with disabilities construct their sexual identities. In addition to addressing a gap in the literature and helping correct systematic misperceptions of disabled sexuality, the findings help legitimize the sexual and emotional needs of a sample of disabled youth.

- ❖ Esmali, Shaniff, Munro, Brenda and Gibson, Nancy. "[Couple's experience with multiple sclerosis in the context of their sexual relationship.](#)" *Sexuality and Disability* 25, no. 4 (2007): 163-177 (paying access)

Esmali's work (see also Esmali et al. 2010) aims to understand the lived experience of disability (multiple sclerosis; MS) on couples' sexuality, thus addressing an often neglected perspective in the literature. This paper focuses on experiences when the female partner is diagnosed with MS.

- ❖ Esmali, Shaniff, Huang, Jane, Lee, Isabel, and Maruska, Tanya. "[Couple's experiences when men are diagnosed with multiple sclerosis in the context of their sexual relationship.](#)" *Sexuality and Disability* 28, no. 1 (2010): 15-27. (paying access)

This paper focuses on experiences when the male partner is diagnosed with MS. Esmali's work (see also Esmali et al. 2007) offers practical guidance for clinicians (e.g., the need to recognise both partners' intimacy needs).

- ❖ Esmali, Shaniff, Darry, Kim, Walter, Ashlea, and Knupp, Heidi. "[Attitudes and perceptions towards disability and sexuality.](#)" *Disability and Rehabilitation* 32, no. 14 (2010): 1148-1155 (paying access)

The authors assess societal attitudes toward persons with disabilities by conducting a series of focus groups with different samples (e.g., general public, people with visible disabilities).

- ❖ Fritz, Heather A., Dillaway, Heather, and Lysack, Cathy L. "[‘Don't think paralysis takes away your womanhood': Sexual intimacy after spinal cord injury.](#)" *American Journal of Occupational Therapy*, 69, no. 2 (2015): 6902260030p1-6902260030p10 (open access)

Fritz et al. qualitatively explore the sexual and reproductive health experiences of women with spinal cord injuries (N = 20).

- ❖ Galvin, Rose D. "[Researching the disabled identity: Contextualising the identity transformations which accompany the onset of impairment.](#)" *Sociology of Health & Illness* 27, no. 3 (2005): 393-413 (paying access)

This study uses grounded theory to shed light on the processes that form the disabled identity, post-impairment on-set. Galvin finds that disabled sexuality is heavily influenced by the (negative) attitudes of others in society.

- ❖ **Guldin, Anne.** "[Self-claiming sexuality: mobility impaired people and American culture.](#)" **Sexuality and Disability 18, no. 4 (2000): 233-238 (paying access)**

Guldin interviewed a number of disabled participants (N = 7) to explore how they claim their sexuality. She found that dominant cultural notions of sexuality and disability were often simultaneously challenged and reinforced by participants.

- ❖ **Harrison, Tracie, Stuifbergen, Alexa, Adachi, Eishi, and Becker, Heather.** "[Marriage, impairment, and acceptance in persons with multiple sclerosis.](#)" **Western Journal of Nursing Research, 26, no. 3 (2004): 266-285 (paying access)**

Harrison et al. investigate the relationship between a number of marital (e.g., status, desire for) variables and self-acceptance of disability among a sample of people with multiple sclerosis. They identified a gender difference: for men, being married was associated with a greater acceptance of disability.

- ❖ **Hasan, Tanvir, Muhaddes, Tisa, Camellia, Suborna, Selim, Nasima and Rashid, Sabina F.** "[Prevalence and experiences of intimate partner violence against women with disabilities in Bangladesh: Results of an explanatory sequential mixed-method study.](#)" **Journal of Interpersonal Violence (2014) (paying access)**

Hasan et al. examine the prevalence, correlates and coping strategies in regard to intimate partner violence toward women with disabilities in Bangladesh (N = 226). Findings shed light on the problem of intimate partner violence toward persons with disabilities in an understudied context.

- ❖ **Hasson-Ohayon, Ilanit, Hertz, Ifat, Vilchinsky, Noa, and Kravetz, Schlomo.** "[Attitudes toward the sexuality of persons with physical versus psychiatric disabilities.](#)" **Rehabilitation Psychology 59, no. 2 (2014): 236-241 (open access)**

Using an experimental approach, the authors examine whether target involvement in a sexual relationship moderates attitudes toward people with physical vs. psychiatric disabilities. They found that involvement in a sexual relationship leads to positive attitudes if the person is physically disabled, but negative attitudes if the person has a psychiatric disability (see also Katz et al. 2000).

- ❖ **Hassouneh-Phillips, Dena, and McNeff, Elizabeth** "[I thought I was less worthy": Low sexual and body esteem and increased vulnerability to intimate partner abuse in women with physical disabilities.](#)" **Sexuality and Disability 23, no. 4 (2005): 227-240 (paying access)**

The authors qualitatively examine the link between low sexual and body esteem and intimate partner abuse in women with physical disabilities. A simple visual model is included for the purposes of aiding reader understanding.

- ❖ **Helmius, Gisela.** "[Disability, sexuality and sociosexual relationships in women's everyday life.](#)" **Scandinavian Journal of Disability Research, 1, no. 1 (1999): 50-63 (paying access)**

This paper explores sexual experiences of women with disabilities in the context of their daily life. One conclusion drawn is that issues of autonomy, independence and personal assistants in these women's everyday life are brought to a halt when they are related to private sexual life (see also: Bahner, 2012).

- ❖ Howland, Carol A., and Rintala, Diane H. "[Dating behaviors of women with physical disabilities.](#)" *Sexuality and Disability* 19, no. 1 (2001): 41-70 (paying access)

Howland and Rintala qualitatively explore dating behaviours among a sample of women with disabilities, a topic they suggest has been neglected by the literature. The authors identify constructs that may be critical to establishing dating behaviours (e.g., familial and peer response to disability; impairment on-set).

- ❖ Hunt, Brandon, Matthews, Connie, Milsom, Amy, and Lammel, Julie A. "[Lesbians with physical disabilities: A qualitative study of their experiences with counseling.](#)" *Journal of Counseling & Development* 84, no. 2 (2006): 163-173 (open access)

The authors interviewed 25 lesbians with physical disabilities about their counseling experiences.

- ❖ Hyland, Ann-Marie, and McGrath, Margaret. "[Sexuality and occupational therapy in Ireland—a case of ambivalence?](#)" *Disability and Rehabilitation* 35, no. 1 (2013): 73-80 (paying access)

A cross-sectional internet based survey was conducted among a convenience sample (N = 120) of occupational therapists working in Ireland. The authors found that sexuality although considered a legitimate area of practice was rarely addressed by occupational therapists, suggesting that additional training is needed among this group.

- ❖ Ikuomola, Adediran D. "[Socio-cultural conception of Albinism and sexuality challenges among Persons with Albinism \(PWA\) in South-West, Nigeria.](#)" *AFRREV IJAH: An International Journal of Arts and Humanities* 4, no. 2 (2015): 189-208 (open access)

Ikuomola reports a unique qualitative study, designed to explore how cultural Nigerian (Yoruba) myths influence the sexuality and relationships of persons with albinism. The study concludes that the socio-cultural conception of albinism and albinos as disabled and spiritual beings should be deconstructed to pave the way for effective expression of sexual relationships.

- ❖ Javier, Sarah J., Perrin, Paul B., Snipes, Daniel J., Olivera, Silvia L., Perdomo, Jose L., Arango, Jose A., and Arango-Lasprilla, Juan-Carlos. "[The influence of health related quality of life on sexual desire in individuals with spinal cord injury from Colombia, South America.](#)" *Sexuality and Disability* 31, no. 4 (2013): 325-335. (paying access)

This study compared the sexual desire of Colombian individuals with spinal cord injuries (N = 40) to a non-disabled control group (N = 42) and examined the relationship between health related quality of life and sexual desire in each group. Like other studies conducted in different contexts (e.g., Cheng & Udry, 2002) the findings show that sexuality is just as important for persons with disabilities as it is for the non- disabled.

- ❖ Jemtå, Lena, Fugl-Meyer, Kerstin S., and Öberg, Katerina. "[On intimacy, sexual activities and exposure to sexual abuse among children and adolescents with mobility impairment.](#)" *Acta paediatrica* 97, no. 5 (2008): 641-646 (paying access)

Data collected by Jemtå et al. describes experiences of intimacy, sexual activity, and abuse among children and adolescents with mobility impairments. The authors call for specialized sexual health care services to protect the sexual rights of this group.

- ❖ Julia, P. E., and Othman, A. S. "[Barriers to sexual activity: counselling spinal cord injured women in Malaysia.](#)" *Spinal Cord* 49, no. 7 (2011): 791-794 (open access)

The authors investigate barriers to sexual activity among women with spinal cord injuries within an under-researched setting (Malaysia).

- ❖ Juergens, Maria H., Smedema, Susan M., and Berven, Norman L. "[Willingness of graduate students in rehabilitation counseling to discuss sexuality with clients.](#)" *Rehabilitation Counseling Bulletin* 53, no. 1 (2009): 34-43 (paying access)

The authors test simultaneously a number of established predictors (e.g., knowledge, education) of rehabilitation professionals' willingness to discuss sexual issues with clients.

- ❖ Kaiser, Anita, Reid, D., and Boschen, Kathryn A. "[Experiences of parents with spinal cord injury.](#)" *Sexuality and Disability* 30, no. 2 (2012): 123-137 (paying access)

Kaiser et al. extend knowledge of the sexuality of persons with spinal cord injuries by examining it from the perspective of a group of their parents.

- ❖ Karlen, Arno. "[Positive sexual effects of chronic illness: case studies of women with lupus \(SLE\).](#)" *Sexuality and Disability* 20, no. 3 (2002): 191-208 (paying access)

Through case studies of women with lupus, Karlen draws attention to the positive sexual effects that disability can have (e.g., improved sexual relationships), noting that this runs counterintuitive to much of the extant medical literature.

- ❖ Kassah, Bente L. L., Kassah, Alexander K., and Agbota, Tete K., "[Abuse of physically disabled women in Ghana: its emotional consequences and coping strategies.](#)" *Disability and Rehabilitation* 36, no. 8 (2014): 665-671 (paying access)

The authors explore experiences of abuse among women with disabilities in Ghana using interviews. They conclude that women with disabilities in Ghana still face various forms of abuse because of cultural beliefs and norms and call for awareness programmes at the societal level.

- ❖ Kattari, Shanna K. "[Sexual experiences of adults with physical disabilities: Negotiating with sexual partners.](#)" *Sexuality and Disability* 32, no. 4 (2014): 499-513 (paying access)

Like the work of Dune (2013, 2014), Kattari explores how persons with physical disabilities negotiate their sexual identities with partners.

- ❖ Kattari, Shanna K. "[Getting It": Identity and sexual communication for sexual and gender minorities with physical disabilities.](#)" *Sexuality & Culture* 19, no. 4 (2015): 882-899 (paying access)

In this paper, Kattari uses a subsample of data from her previous work (Kattari, 2014), to explore how sexual and gender minorities with disabilities negotiate their sexual identities.

- ❖ Katz, Shlomo, Shemesh, Tami, and Bizman, Aharon. "[Attitudes of university students toward the sexuality of persons with mental retardation and persons with paraplegia.](#)"

British Journal of Developmental Disabilities 46, no. 2; ISSU 91 (2000): 109-117 (open access)

Katz et al. compare attitudes toward persons with physical and intellectual disabilities among university students. They find that although attitudes to both groups were generally negative, persons with physical disabilities were viewed more positively in a number of areas, including control over their sex drive and sexual responsibilities.

- ❖ Kazukauskas, Kelly A., and Lam, Chow S. "[Importance of addressing sexuality in Certified Rehabilitation Counselor practice.](#)" **Rehabilitation Education 23, no. 2 (2009): 127-139 (paying access)**

This study investigated rehabilitation professionals' (N = 199) beliefs about the importance of addressing sexuality issues during rehabilitation using a survey. Results suggest that additional training in disability and sexuality issues is needed.

- ❖ Kazukauskas, Kelly A., and Lam, Chow S. "[Disability and sexuality: Knowledge, attitudes, and level of comfort among certified rehabilitation counselors.](#)" **Rehabilitation Counseling Bulletin 54, no. 1 (2010): 15-25 (paying access)**

This study investigated whether rehabilitation professionals' (N = 199) levels of comfort could be predicted by their sexuality attitudes and knowledge. Both sexuality attitudes and knowledge contributed to comfort levels, leading the authors to call for increased training in these areas.

- ❖ Kedde, Harald, and van Berlo, Willy. "[Sexual satisfaction and sexual self-images of people with physical disabilities in the Netherlands.](#)" **Sexuality and Disability 24, no. 1 (2006): 53-68 (open access)**

The authors assessed the association between sexual satisfaction and various demographic variables (e.g., relationship status) among persons with physical disabilities. Findings suggest some gender differences (e.g., men with late onset impairment experience more difficulties; see also: Harrison et al., 2004).

- ❖ Koç, Zeliha, and Saglam, Zeynep. "[Determining the correlation between sexual satisfaction and loneliness levels in patients with hemodialysis in a Muslim community.](#)" **Sexuality and Disability 31, no. 1 (2013): 13-29 (paying access)**

This correlational study (N = 131) finds that low sexual satisfaction is associated with loneliness among a sample of Muslim hemodialysis patients.

- ❖ Koch, Tina, Kralik, Debbie, and Eastwood, Sue. "[Constructions of sexuality for women living with multiple sclerosis.](#)" **Journal of Advanced Nursing 3, 9, no. 2 (2002): 137-145 (paying access)**

In an effort to gain a greater understanding of the topic, Koch and Kralik explore how 12 women with multiple sclerosis construct their sexuality. The authors find that sexuality is seen as an everyday experience for women with disabilities, echoing previous work (e.g., Helmius, 1999).

- ❖ Kolzet, J., Quinn, H., Zemon, V., Tyry, T., Marrie, R. A., Foley, F. W., and Flood, S. "[Predictors of body image related sexual dysfunction in men and women with multiple sclerosis.](#)" *Sexuality and Disability* 33, no. 1 (2015): 63-73 (open access)

Kolzet et al. focus on body image as a predictor of sexual dysfunction and its correlates among a sample of persons with multiple sclerosis.

- ❖ Kraaiaat, Floris W., Bakker, Anneke H., Janssen, Erick., and Bijlsma, Johannes W. J. "[Intrusiveness of rheumatoid arthritis on sexuality in male and female patients living with a spouse.](#)" *Arthritis Care and Research* 9, no. 2 (1996): 120-125 (open Access)

Kraaiaat et al. examine predictors of sexuality (e.g., pain, depression) among a sample of persons with rheumatoid arthritis.

- ❖ Kvam, Marit H., and Braathen, Stine H. "[“I thought... maybe this is my chance”: Sexual abuse against girls and women with disabilities in Malawi.](#)" *Sexual Abuse: A Journal of Research and Treatment* 20, no. 1 (2008): 5-24 (open access)

Kvam and Braathen utilise semi-structured interviews to uncover stories of sexual abuse experienced by women with disabilities in Malawi. The authors suggest the project is the first of its kind in Malawi and therefore sheds light on an area where previous knowledge is very limited (see also Braathen & Kvam, 2008).

- ❖ Lease, Suzanne H., Cohen, Jaime E., and Dahlbeck, David T. "[Body and sexual esteem as mediators of the physical disability-interpersonal competencies relation.](#)" *Rehabilitation Psychology* 52, no. 4 (2007): 399-408 (paying access)

The authors examine whether body and sexual esteem mediate the associations between sexual satisfaction, perceived disability severity, and social perceptions of the disability and interpersonal competencies. Findings indicate the importance of perceived attractiveness to others in mediating the negative relations between impact of the disability and interpersonal competencies.

- ❖ Leibowitz, Ruth Q., and Stanton, Annette L. "[Sexuality after spinal cord injury: A conceptual model based on women's narratives.](#)" *Rehabilitation Psychology* 52, no. 1 (2007): 44-55 (paying access)

Leibowitz and Stanton investigate how women (N = 24) experience and conceptualize their sexuality after traumatic spinal cord injury by accessing their narratives. Through these narratives, a conceptual model of sexuality is proposed.

- ❖ Li, Candy M., and Yau, Matthew K. "[Sexual issues and concerns: tales of Chinese women with spinal cord impairments.](#)" *Sexuality and Disability* 24, no. 1 (2006): 1-26 (paying access)

Li and Yau attempt to gain insight into the sexuality of women (N = 10) with spinal cord injuries through in-depth interviews. They shed light on the experiences of women with disabilities within an under-researched context.

- ❖ Liddiard, Kirsty. "[‘I never felt like she was just doing it for the money’: Disabled men’s intimate \(gendered\) realities of purchasing sexual pleasure and intimacy.](#)" *Sexualities* 17, no. 7 (2014): 837- 855 (paying access)

Liddiard draws upon the sexual stories of heterosexual men with disabilities in order to explore their embodied realities of purchasing of sex, pleasure and intimacy from non- disabled female sex workers. The paper contributes knowledge to an area where scholarship enquiry is limited; i.e. the intersection between disability and commercial sex.

- ❖ Lindemann, Kurt. "[Masculinity, disability, and access-ability: Ethnography as alternative practice in the study of disabled sexualities.](#)" *Southern Communication Journal* 75, no. 4 (2010): 433-451 (paying access)

Lindemann draws on over 100 hours of ethnographic fieldwork to illustrate how the performances of wheelchair rugby players construct disabled sexualities in the context of sport participation.

- ❖ Linton, Simi S. "[Sexual satisfaction in males following spinal cord injury as a function of locus of control.](#)" *Rehabilitation Psychology* 35, no. 1 (1990): 19-27 (paying access)

Among 118 men with physical disabilities, Linton finds that greater internal locus of control is positively associated with sexual satisfaction.

- ❖ Linton, Kristen F., and Rueda, Heidi A. "[Dating and sexuality among minority adolescents with disabilities: An application of sociocultural theory.](#)" *Journal of Human Behavior in the Social Environment* 25, no. 2 (2015): 77-89 (paying access)

The authors apply Vygotsky’s sociocultural theory in order to better understand the sexuality of minority adolescents with disabilities. Participants were social workers (N = 13) and provided their dialogues on the subject through in-depth interviews.

- ❖ MacDougall, J. C., and Morin, S. "[Sexual attitudes and self-reported behavior of congenitally disabled adults.](#)" *Canadian Journal of Behavioural Science* 11, no. 3 (1979): 189-204 (paying access)

MacDougall and Morin investigate the sexual attitudes of adults with physical disability, ranging from their interest in pornography to their own sexual experiences and habits.

- ❖ Man, Michelle, Rojahn, Johannes, Chrosniak, Linda, and Sanford, James. "[College students’ romantic attraction toward peers with physical disabilities.](#)" *Journal of Developmental and Physical Disabilities* 18, no. 1 (2006): 35-44 (open access)

Man et al. assess experimentally how romantically attractive non-disabled people (university students) find persons with physical disabilities, through the presentation of profiles of different individuals. They find that the presence of disability did not influence romantic attractiveness ratings.

- ❖ Marini, Irmo, Chan, Roy, Feist, Amber, and Flores-Torres, Leila. "[Student attitudes toward intimacy with persons who are wheelchair users.](#)" *Rehabilitation Research, Policy, and Education* 25, no. 1-2 (2011): 15-25 (paying access)

Marini et al. explored whether non-disabled students (N = 408) would be attracted to having an intimate relationship with a wheelchair user if participants were able to first read a profile of them. They found that romantic attraction was moderated by several variables (e.g., gender, prior contact with persons who have physical disabilities).

- ❖ Marini, Irmo, Wang, X., Etzbach, Colleen A., and Del Castillo, Alinka. "[Ethnic, gender, and contact differences in intimacy attitudes toward wheelchair users.](#)" *Rehabilitation Counseling Bulletin* (2012) (paying access)

Student attitudes (N = 810) toward having a relationship with a wheelchair user were explored, using a similar design to Marini et al. (2011). Overall, Marini's work sheds light on the misgivings that non-disabled people may have about dating persons with physical disabilities.

- ❖ Mathias, Zoë, and Harcourt, Diana. "[Dating and intimate relationships of women with below-knee amputation: an exploratory study.](#)" *Disability and Rehabilitation* 36, no. 5 (2014): 395-402 (paying access)

The authors explore experiences of dating and intimate relationships amongst women who use a below-knee prosthesis. The authors argue their findings highlight the need for researchers and clinicians to give more attention to these important aspects of amputees' lives.

- ❖ Mayers, Kathleen S., and Heller, Jessica A. "[Sexuality and the late stage Huntington's disease patient.](#)" *Sexuality and Disability* 21, no. 2 (2003): 91-105 (paying access)

This study assesses sexual interests, needs related to sexuality, and intimacy issues in severely impaired, late stage Huntington's disease patients through use of structured interviews. The authors offer suggestions for caregivers, based on their findings (e.g., proving sexually orientated videos).

- ❖ McCabe, Marita P. "[Sexual knowledge, experience and feelings among people with disability.](#)" *Sexuality and Disability* 17, no. 2 (1999): 157-170 (paying access)

This study evaluates the sexual knowledge, experience, feelings and needs of persons with a physical disability, and compared them to people from the general population. Like many other comparative studies (e.g., Cheng & Udry, 2002), they find similarities between the two groups.

- ❖ McCabe, Marita P., and McDonald, Elizabeth. "[Perceptions of relationship and sexual satisfaction among people with multiple sclerosis and their partners.](#)" *Sexuality and Disability* 25, no. 4 (2007): 179-188 (paying access)

McCabe & McDonald evaluate relationships and sexuality among persons with multiple sclerosis (MS) and their partners (see also Esmali et al. 2007). They found that partners of persons with MS were more likely than persons with MS to feel that MS had a negative impact on the physical and emotional support in their relationship.

- ❖ McCabe, Marita P., Cummins, Robert A., and Deeks, Amada A., "[Sexuality and quality of life among people with physical disability](#)." *Sexuality and Disability* 18, no. 2 (2000): 115-123 (paying access)

McCabe et al. evaluate the association between the sexuality and quality of life of persons with a congenital physical disability (N = 60) using the Sexual Knowledge, Experience and Needs Scale.

- ❖ McCabe, Marita P., and Taleporos, George. "[Sexual esteem, sexual satisfaction, and sexual behavior among people with physical disability](#)." *Archives of Sexual Behavior* 32, no. 4 (2003): 359-369 (open access)

This study investigates the association between the severity and duration of physical disability and sexual esteem, sexual depression, sexual satisfaction, and the frequency of sexual behaviour, using a particularly large sample of (N = 1, 196). Persons with physical disabilities generally reported more negative feelings and less sexual experiences than did persons without disabilities.

- ❖ McLaughlin, John, and Cregan, Alison. "[Sexuality in stroke care: a neglected quality of life issue in stroke rehabilitation? A pilot study](#)." *Sexuality and Disability* 23, no. 4 (2005): 213-226 (open access)

McLaughlin and Cregan explore the experiences that rehabilitation professionals have of addressing sexuality issues, an area where they note there is a paucity of literature. The findings suggest that all rehabilitation professionals need to become more knowledgeable about sexuality issues in stroke care and could benefit from further education and training in comprehensive sexual health care.

- ❖ Mendes, A. K., Cardoso, F. L., and Savall, A. C. R.. "[Sexual satisfaction in people with spinal cord injury](#)." *Sexuality and Disability* 26, no. 3 (2008): 137-147 (open access)

Mendes et al. compare the sexual satisfaction of persons with spinal cord injuries pre- and post-lesion and a non-disabled comparison group. The findings suggest there are changes in the sexual satisfaction of men, arising from the difficulty in maintaining a sex life similar to that experienced pre-lesion.

- ❖ Meyerson, Lee. "[The sexual revolution: Has it embraced the disabled co-ed?](#)." *Rehabilitation Psychology* 24, no. 4 (1977): 221-224. (paying access)

This early study on the topic of attitudes toward disabled sexuality recruited a small group of non-disabled students (N = 20) and asked about their attitudes to the sex lives of their disabled peers.

- ❖ Milligan, Maureen S., and Neufeldt, Aldred H. "[Postinjury marriage to men with spinal cord injury: Women's perspectives on making a commitment](#)." *Sexuality and Disability* 16, no. 2 (1998): 117-132 (paying access)

The authors explore the little researched area of examined why able-bodied women might choose to marry men with a significant, permanent physical impairment. They use the findings to construct a preliminary model of relationship development.

- ❖ Moin, Victor, Duvdevany, Ilana, and Mazor, Daniela. "[Sexual identity, body image and life satisfaction among women with and without physical disability.](#)" *Sexuality and Disability* 27, no. 2 (2009): 83-95 (paying access)

The authors examine the association between sexual identity, body image and life satisfaction among women with and without physical disability. The results illustrated similarities between the two groups (see also Javier et al. 2013) but also some differences, notably that women with physical disabilities experienced less sexual and life satisfaction, and more negative body image.

- ❖ Motalingoane-Khau, Mathabo. "[I never thought they do it too!': Sexuality and disabled body.](#)" African Regional Sexuality Centre (ARSC). 2006 (open access)

This piece of research conducted for the African Regional Sexuality Resource Center explores the sexuality of youth with physical disabilities in Lesotho, thus shedding light on an under- researched context.

- ❖ Mullan, Patricia B., and Cole, Sandra, S. "[Health care providers' perceptions of the vulnerability of persons with disabilities: Sociological frameworks and empirical analyses.](#)" *Sexuality and Disability* 9, no. 3 (1991): 221-241 (open access)

Mullan et al. investigate health care providers' perceptions about their professional responsibility for persons with disabilities. Their analyses indicated that these professionals perceived that different categories of disability pose different risk of sexual exploitation.

- ❖ Murray, Craig D., and Harrison, B. "[The meaning and experience of being a stroke survivor: an interpretative phenomenological analysis.](#)" *Disability & Rehabilitation* 26, no. 13 (2004): 808-816 (paying access)

Murray and Harrison investigate the meaning and experience of being a stroke survivor using Interpretative Phenomenological Analysis. The authors call for post-stroke counselling regarding romantic and sexual relationships, as well as the need for health professionals to address issues such as social withdrawal.

- ❖ Nario-Redmond, Michelle R. "[Cultural stereotypes of disabled and non-disabled men and women: Consensus for global category representations and diagnostic domains.](#)" *British Journal of Social Psychology* 49, no. 3 (2010): 471-488 (open access)

Using a free-response methodology, Nario-Redmond contrasted stereotypes of men and women with disabilities against that of non-disabled men and women. Her results indicate the existence of global disability stereotypes applied to persons with disabilities, such as "dependent", "incompetent" and "asexual" (see also Esmali et al. 2010).

- ❖ Nosek, Margaret A., Howland, Carol A., Young, Mary E., Georgiou, Doris, Rintala, D. H., Foley, C. C., Bennett, J. L., and Smith, Q. "[Wellness models and sexuality among women with physical disabilities.](#)" *Journal of Applied Rehabilitation Counseling* 25 (1994): 50-58 (paying access)

Nosek et al. adopt a wellness perspective in order to identify domains of sexuality among women with physical disabilities. They use their findings to identify 5 domains, comparing them to physical, psychological, spiritual, developmental, and sociocultural aspects of wellness.

- ❖ Nosek, Margaret A., Foley, Catherine C., Hughes, Rosemary B. and Howland, Carol A. "[Vulnerabilities for abuse among women with disabilities](#)." *Sexuality and Disability* 19, no. 3 (2001): 177-189 (paying access)

The authors use qualitative methods to identify forms of emotional, physical and sexual abuse that are directly related to disability. They suggest that the findings reveal the need to for the development of disability-sensitive abuse screening instruments and interventions to help women with disabilities recognise abuse.

- ❖ Oksel, Esra, and Gündüzoğlu Nazmiye, C. "[Investigation of life experiences of women with scleroderma](#)." *Sexuality and Disability* 32, no. 1 (2014): 15-21 (paying access)

Oksel and Gündüzoğlu explore the lived experiences of women with scleroderma. The authors find that the disruption of sexual life was the predominant theme within the data.

- ❖ Olaleye, Adeniyi O., Anoemuah, Olayinka A., Ladipo, Oladapo A., Delano, Grace E., and Idowu, Grace F. "[Sexual behaviours and reproductive health knowledge among in-school young people with disabilities in Ibadan, Nigeria](#)." *Health Education* 107, no. 2 (2007): 208-218 (paying access)

The paper investigates sexual behaviours and reproductive health knowledge among young persons with disabilities in Nigeria, using structured questionnaires. The findings show that there is an urgent need to develop specific programs for young persons with disabilities, especially for those in schools, to address knowledge and behaviour issues regarding reproductive health and HIV/AIDS.

- ❖ O'Toole, Corbett J., and Doe, Tanis. "[Sexuality and disabled parents with disabled children](#)." *Sexuality and Disability* 20, no. 1 (2002): 89-101.

O'Toole and Doe use participatory ethnography to present stories from parents with disabilities, suggesting that their empirical data offers a radical reconceptualisation of a little studied topic.

- ❖ Parchomiuk, Monika. "[Specialists and sexuality of individuals with disability](#)." *Sexuality and Disability* 30, no. 4 (2012): 407-419 (paying access)

Parchomiuk investigates specialists' attitudes towards the sexuality of persons with intellectual and physical disabilities. The findings suggest that specialists' view most aspects of the sexuality of persons with physical disabilities more positively than persons with intellectual disabilities.

- ❖ Parker, Gillian. "[Disability, caring and marriage: The experience of younger couples when a partner is disabled after marriage](#)." *British Journal of Social Work* 23, no. 6 (1993): 565-580 (paying access)

Parker qualitatively explores the experiences of couples where one partner is disabled (see also Esmali et al. 2007, 2010). Findings suggest that married couples are left virtually unsupported, both practically and emotionally, at times when their relationship may be under considerable strain.

- ❖ Parker, Malorie G., and Matthew Yau, K. "[Sexuality, identity and women with spinal cord injury](#)." *Sexuality and Disability* 30, no. 1 (2012): 15-27 (paying access)

This qualitative study investigates the lived experience of post-injury sexuality among women with spinal cord injuries (Li & Yau, 2006). The authors draw a number of practical conclusions for health professionals (e.g., that they must have an adequate understanding of how disability may impact sexuality in order to assist clients).

- ❖ Parritt, Simon, and O'Callaghan, Jean. "[Splitting the difference: An exploratory study of therapists' work with sexuality, relationships and disability](#)." *Sexual and Relationship Therapy* 15, no. 2 (2000): 151-169 (paying access)

This study explores sexual and marital therapists' experience of working with physically disabled clients, using Grounded Theory. Despite extensive experience, they found that disabled clients evoked stronger responses than other clients.

- ❖ Pearson, Veronica, and Klook, Andrew. "[Sexual behaviour following paraplegia: an exploratory study in Hong Kong](#)." *Disability, Handicap & Society* 4, no. 3 (1989): 285-295 (paying access)

Pearson and Klook investigate the sexual behaviour of paraplegics in Hong Kong, contributing knowledge to an understudied context.

- ❖ Peta, Christine, McKenzie, Judith, and Kathard, Harsha. "[Voices from the periphery: A narrative study of the experiences of sexuality of disabled women in Zimbabwe](#)." *Agenda* 29, no. 2 (2015): 66-76 (paying access)

Peta et al. use a single case study to illuminate the intersectional nature of a disabled Zimbabwean woman's sexuality experiences. Findings suggest these experiences are located between gender, culture, disability and sexuality.

- ❖ Pfaffenberger, N., Gutweniger, S., Kopp, M., Seeber, B., Stürz, K., Berger, T., and Günther, V. "[Impaired body image in patients with multiple sclerosis](#)." *Acta Neurologica Scandinavica* 124, no. 3 (2011): 165-170 (paying access)

The authors compare body image perceptions between multiple sclerosis patients and able-bodied controls. Findings highlight the importance in taking gender-specific issues into account when addressing the body image problems of persons with disabilities.

- ❖ Prilleltensky, Ora. "[A ramp to motherhood: the experiences of mothers with physical disabilities](#)." *Sexuality and Disability* 21, no. 1 (2003): 21-47.

This paper describes a qualitative study on the experiences of mothers with physical disabilities, accessed through focus groups.

- ❖ Rich, Karen. "[“My body came between us”: Accounts of partner-abused women with physical disabilities.](#)" *Journal of Women and Social Work* 29, no. 4 (2014): 418-433 (paying access)

Rich accesses accounts of women with physical disabilities (N =19) who have experienced intimate partner violence. Results indicate that partner-abused women view themselves as possessing stereotypically feminine identities.

- ❖ Richards, Eleanor, Tepper, Mitchell, Whipple, Beverly, and Komisaruk, Barry R. "[Women with complete spinal cord injury: a phenomenological study of sexuality and relationship experiences.](#)" *Sexuality and Disability* 15, no. 4 (1997): 271-283.

This phenomenological study examines the sexuality and relationship "lived experiences" of spinal cord injured women (N = 15).

- ❖ Robillard, Kristen, and Fichten, Catherine S. "[Attributions about sexuality and romantic involvement of physically disabled college students: An empirical study.](#)" *Sexuality and Disability* 6, no. 3-4 (1983): 197-212 (open access)

Robillard and Fichten investigate the attributions of able-bodied college students (N = 99) about the sexuality of students with physical disabilities (see also Meyerson, 1977).

- ❖ Rogers, Paul, Titterington, Leigh, and Davies, Michelle. "[Attributions of blame and credibility in a hypothetical child sexual abuse case: Roles of victim disability, victim resistance and respondent gender.](#)" *International Journal of Disability, Development and Education* 56, no. 3 (2009): 205-228 (open access)

This study examines the effect of victim disability (physical vs. intellectual vs. none), victim resistance (physical vs. verbal vs. none) and respondent gender (male vs. female) on attributions of blame and credibility in a hypothetical case of child sexual abuse. Results emphasise the importance of these factors in influencing attribution in child sex abuse cases.

- ❖ Rojahn, Johannes, Komelasky, Kristi G. and Man, M. "[Implicit attitudes and explicit ratings of romantic attraction of college students toward opposite-sex peers with physical disabilities.](#)" *Journal of Developmental and Physical Disabilities* 20, no. 4 (2008): 389-397 (open access)

This study is a replication and extension of Man et al. (2006). Specifically, Rojahn et al. also measure implicit attitudes, finding a clear preference for physical health over disability, despite no stated preference in explicit attitudes.

- ❖ Rolland, John S. "[In sickness and in health: the impact of illness on couples' relationship.](#)" *Journal of Marital and Family Therapy* 20 (1994): 327-327 (open access)

Rolland explores key issues in intimacy and communication among couples' where one partner is ill. Findings are used to outline treatment priorities for couples (e.g., about how to manage adversity).

- ❖ Sahay, Rashmi D., Haynes, Erin N., Rao, M. B., and Pirko, Istvan. "[Assessment of sexual satisfaction in relation to potential sexual problems in women with multiple sclerosis: A pilot study](#)." *Sexuality and Disability* 30, no. 2 (2012): 227-236 (open access)

The study examined levels of sexual satisfaction in relation to changes in sexual functioning among women with multiple sclerosis (N = 160). Results indicate that frequency of sexual activity and sexual desire ranked highest for having an impact on overall sex life.

- ❖ Sakellariou, Dikaïos. "[If not the disability, then what? Barriers to reclaiming sexuality following spinal cord injury](#)." *Sexuality and Disability* 24, no. 2 (2006): 101-111 (paying access)

Sakellariou qualitatively explores barriers to reclaiming sexuality among men with spinal cord injuries using unstructured interviews. Based on the findings, the author suggests that changes in education as well as the removal of physical barriers may positively influence societal attitudes toward disabled sexuality.

- ❖ Sakellariou, Dikaïos. "[Sexuality and disability: a discussion on care of the self](#)." *Sexuality and Disability* 30, no. 2 (2012): 187 (open access)

Sakellariou uses the same data from his 2006 paper to illustrate the importance of care of the self (e.g., life choices, use of technologies) to disabled sexuality.

- ❖ Sakellariou, Dikaïos, and Algado, Salvador S. "[Sexuality and disability: A case of occupational injustice](#)." *The British Journal of Occupational Therapy* 69, no. 2 (2006): 69-76 (open access)

The authors analyse sexual (dis)satisfaction among persons with disabilities in terms of occupational injustice, using in-depth unstructured interviews. They argue that occupational therapists should embrace occupational justice as the main purpose of the profession and include issues of sexuality in their agenda.

- ❖ Sanders, Audrey S., Foley, Frederick W., LaRocca, Nicholas G., and Zemon, V. "[The multiple sclerosis intimacy and sexuality questionnaire-19 \(MSISQ-19\)](#)." *Sexuality and Disability* 18, no. 1 (2000): 3-26 (paying access)

In this paper, A. S. Sanders et al. undertake the development and validation of a scale to assess sexuality and intimacy among persons with multiple sclerosis.

- ❖ Sanders, Teela. "[The politics of sexual citizenship: commercial sex and disability](#)." *Disability & Society* 22, no. 5 (2007): 439-455 (paying access)

Research conducted by T. Sanders brings together work on disabled sexuality and sex work. Her empirical data is derived from interviews with both men with disabilities (Study 1) and sex workers (Study 2).

- ❖ Schlesinger, Lynn. "[Chronic pain, intimacy, and sexuality: A qualitative study of women who live with pain](#)." *Journal of Sex Research* 33, no. 3 (1996): 249-256 (paying access)

Schlesinger examines experiences of pain, intimacy and sexuality through phenomenological interviews with a sample of women with disabilities (N = 17).

- ❖ Schrader, Erin. "[Sexual esteem, perceptions of pregnancy, and maternal confidence in women with and without physical disabilities.](#)" PhD Thesis (2014): 1-162 (open access)

Schrader's Ph.D. thesis explores sexual esteem, perceptions of pregnancy, and maternal confidence in women with and without physical disabilities (N = 154). Like peer-reviewed comparative material (e.g., Shandra et al. 2014), the study highlights differences and similarities among women with and without disabilities.

- ❖ Shakespeare, Tom. "[The sexual politics of disabled masculinity.](#)" *Sexuality and Disability* 17, no. 1 (1999): 53-64. (paying access)

Shakespeare reveals the complicated landscape of disabled masculinity through semi-structured interviews with 21 men with disabilities.

- ❖ Shandra, Carrie L., Hogan, Dennis P., and Short, Susan, E. "[Planning for motherhood: Fertility attitudes, desires and intentions among women with disabilities.](#)" *Perspectives on Sexual and Reproductive Health* 46, no. 4 (2014): 203-210 (open access)

In this comparative study, Shandra et al. find that women with and without disabilities hold similar attitudes toward motherhood. The authors call for a deeper understanding of the reproductive needs of women with disabilities.

- ❖ Shuttleworth, Russell P. "[The search for sexual intimacy for men with cerebral palsy.](#)" *Sexuality and Disability* 18, no. 4 (2000): 263-282 (open access)

Shuttleworth qualitatively explores the sexuality experiences of 14 men with cerebral palsy, noting that, despite some challenges, most had experienced long-term sexual relationships.

- ❖ Simkhada, Padam P., Shyangdan, Deepson, van Teijlingen, Edwin R., Kadel, Santosh, Stephen, Jane, and Gurung, Tara. "[Women's knowledge of and attitude towards disability in rural Nepal.](#)" *Disability and Rehabilitation* 35, no. 7 (2013): 606-613 (paying access)

This paper explores knowledge and attitudes towards persons with disabilities among rural women (N = 418) in Nepal, shedding light on this under researched context.

- ❖ Slater, Jenny. "[Constructions, perceptions and expectations of being disabled and young. A critical disability perspective.](#)" PhD Thesis (2013): 1-301 (open access)

Slater's Ph.D. thesis investigates the intersections between disability and youth, including in terms of sexuality, from a critical perspective.

- ❖ Taleporos, George, and McCabe, Marita P. "[Body image and physical disability—personal perspectives.](#)" *Social Science & Medicine* 54, no. 6 (2002): 971-980 (paying access)

Taleporos & McCabe investigate the body image concerns of persons with physical disabilities in Australia. Findings elucidate the impact of the (social) environment on body image and how body image may improve over time.

- ❖ Taleporos, George, and McCabe, Marita P. "[Relationships, sexuality and adjustment among people with physical disability](#)." *Sexual and Relationship Therapy* 18, no. 1 (2003): 25-43 (paying access)

This comparative study compares the sexual lives of persons with and without physical disabilities, using a particularly large sample (N = 1196). Results highlighted some disadvantages for persons with physical disadvantages (e.g., lower sexual wellbeing).

- ❖ Taleporos, George, and McCabe, Marita P. "[The relationship between the severity and duration of physical disability and body esteem](#)." *Psychology & Health* 20, no. 5 (2005): 637-650 (paying access)

Using the same large sample as Taleporos & McCabe (2003), the authors investigate the relationships between impairment severity, duration & body image. Findings suggest that those with severe disabilities may be particularly vulnerable to problems associated with their body esteem.

- ❖ Taylor, Bridget. "[Experiences of sexuality and intimacy in terminal illness: A phenomenological study](#)." *Palliative Medicine* 28, no 5 (2014): 438-447 (paying access)

Taylor aims to understand the experiences of sexuality and intimacy of persons living with a terminal illness, through interpretative phenomenological analysis. Findings emphasise that patients' sexuality needs should be discussed with providers as part of holistic end of life care.

- ❖ Tepper, Mitchell S. "[Letting go of restrictive notions of manhood: Male sexuality, disability and chronic illness](#)." *Sexuality and Disability* 17, no. 1 (1999): 37-52 (paying access)

Tepper offers a first person account of disability and (male) sexuality, by disseminating his autobiographical experiences.

- ❖ Tervo, Raymond C., Palmer, Glen, Redinius, Pat. "[Health professional student attitudes towards people with disability](#)." *Clinical Rehabilitation* 18, no. 8 (2004): 908-915 (paying access)

In this cross-sectional study, Tervo et al. find that student health professionals hold less positive attitudes toward disability than is normal.

- ❖ Umoren, Anietie M., and Adejumo, Adebayo A. "[Role of sexual risk behaviors and sexual attitude in perceived HIV vulnerability among youths with disabilities in two Nigerian cities](#)." *Sexuality and Disability* 32, no. 3 (2014): 323-334 (paying access)

Umoren et al. investigate sexual attitudes and risk behaviour among able-bodied and disabled youths in Nigeria. The authors argue that health care planners should consider sexual risk behavior in improving perceived HIV-vulnerability in both impaired and able-bodied populations.

- ❖ Valvano, Abbey K., West, Lindsey M., Wilson, Christina K., Macapagal, Kathryn R., Penwell-Waines, Lauren M., Waller, Jennifer, L., and Stepleman, Lara M. "[Health professions students' perceptions of sexuality in patients with physical disability.](#)" *Sexuality and Disability* 32, no. 3 (2014): 413-427 (paying access)

Valvano et al. investigate healthcare students' experiences and training of addressing the sexual needs of physically disabled clients. The authors suggest implementing a more comprehensive sexual health curriculum into training programmes.

- ❖ Van der Stege, Heleen A., Hilberink, Sander R., Visser, Adriaan P., and Van Staa, AnneLoes. "[Motivational factors in discussing sexual health with young people with chronic conditions or disabilities.](#)" *Sex Education* 14, no. 6 (2014): 635-651 (paying access)

Van der Stege et al. assess professionals' (N =336) intentions to use a board game (SeCZ TaLK) to facilitate discussion about sexual health among youth with chronic disabilities (see also Van der Stege et al. 2010). Motivation and practitioner competency were identified as determinants of behavioural intentions.

- ❖ Van Rooy, Gert, and Mufune, Pempelani. "[Experiences and perceptions of HIV/AIDS and sex among people with disabilities in Windhoek, Namibia.](#)" *Sexuality and Disability* 32, no. 3 (2014): 311-321 (paying access)

Van Rooy & Mufane explore sexual and HIV perceptions among persons with disabilities in Namibia, using focus groups and interviews. The study highlights the difficulties and differences in healthcare that persons with disabilities face within an understudied context.

- ❖ Vansteenwegen, Alfons, Jans, I., and Revell, Arlynn T., "[Sexual experience of women with a physical disability: a comparative study.](#)" *Sexuality and Disability* 21, no. 4 (2003): 283-290 (paying access)

This comparative study compares the sexual desires and experiences of disabled and non- persons with disabilities. Results suggest some similarities (e.g., in terms of sexual desires) and differences (e.g., less sexual knowledge and experience) among the disabled group.

- ❖ Verschuren, Jesse E. A., Geertzen, Jan H. B., Enzlin, Paul, Dijkstra, Pieter U., Dekker, Rienk, and van der Sluis, Corry D. "[Addressing sexuality as standard care in people with an upper limb deficiency: taboo or necessary topic?.](#)" *Sexuality and Disability* 31, no. 2 (2013): 167-177 (open access)

and

- ❖ Verschuren, Jesse E. A., Enzlin, Paul, Geertzen, Jan H. B., Dijkstra, Pieter U., and Dekker, Rienk. "[Sexuality in people with a lower limb amputation: a topic too hot to handle?.](#)" *Disability and Rehabilitation* 35, no. 20 (2013): 1698-1704 (open access)

Using a cross-sectional survey, Verschuren et al. investigated how the sexuality of amputees is discussed in healthcare departments. Findings suggest that this topic is rarely discussed in a systematic way and therefore, that the competence and comfort of professionals in this area needs to increase.

- ❖ Vilchinsky, Noa, Findler, Liora, and Werner, Shirli. "[Attitudes toward people with disabilities: The perspective of attachment theory](#)." *Rehabilitation Psychology*, 55, no. 3 (2010): 298-306 (open access)

The authors investigate disability attitudes from the theoretical perspective of attachment theory. Results suggest that attachment style does indeed influence disability attitudes, thus providing a new perspective by which attitudes can be examined.

- ❖ Vilchinsky, Noa, Werner, Shirli, and Findler, Liora. "[Gender and attitudes toward people using wheelchairs: A multidimensional perspective](#)." *Rehabilitation Counseling Bulletin* 53, no 3 (2010): 163-174 (open access)

Vilchinsky et al. find that observer gender influences disability attitudes but that target gender does not, providing experimental evidence of societal perception of the disabled as asexual.

- ❖ Walter, Laurie J., Nosek, Margaret A., and Langdon, Karen. "[Understanding of sexuality and reproductive health among women with and without physical disabilities](#)." *Sexuality and Disability* 19, no. 3 (2001): 167-176 (paying access)

This study compares the reproductive health knowledge of women with and without disabilities. Results highlight the need for healthcare professionals to respond to the special requirements of women with disabilities.

- ❖ Walters, Andrew S., and Williamson, Gail M. "[Sexual satisfaction predicts quality of life: A study of adult amputees](#)." *Sexuality and Disability* 16, no. 2 (1998): 103-115 (paying access)

A.S. Walters et al. investigate the relationship between sexual satisfaction and quality of life in the context of amputees. Results indicate that sexual satisfaction is positively predictive of quality of life.

- ❖ Were, Rosh A., Kioli, Felix N., and Kurgat, Sussy G. "[Sexuality and the youth with disabilities in Kenya](#)." *American Journal of Sociological Research* 2, no. 4 (2012): 72-77 (open access)

Were et al. explore the sexuality of youth with disabilities in Kenya, using a combination of interview, focus group and conversational data. The authors call for the empowerment of disabled youth in Kenya through transforming extant policies and practices related to sexual healthcare

- ❖ West, Lindsey M., Stepleman, Lara M., Wilson, Christina K., Campbell, Jeff, Villarosa, Margo, Bodie, Brittany, and Decker, Matthew. "[It's supposed to be personal: Personal and educational factors associated with sexual health attitudes, knowledge, comfort and skill in health profession students](#)." *American Journal of Sexuality Education* 7, no. 4 (2012): 329-354 (paying access)

This study investigated personal factors (e.g., gender, spirituality) and educational factors (e.g., quality of education) as predictors of knowledge, comfort and competency in dealing with disabled sexuality among student health professionals (N = 486).

- ❖ Westgren, Ninni, and Levi, Richard. "[Sexuality after injury: interviews with women after traumatic spinal cord injury](#)." *Sexuality and Disability* 17, no. 4 (1999): 309-319 (paying access)

Westgren and Levi elucidate the sexuality experiences of women with spinal cord injuries, through a series of semi-structured interviews. Results suggest a strong influence of pre-injury sexual behaviour on post-injury adaptation.

- ❖ Whitney, Chelsea. "[Intersections in identity–identity development among queer women with disabilities](#)." *Sexuality and Disability* 24, no. 1 (2006): 39-52 (paying access)

Whitney examines how queer women with disabilities construct their identities through the use of semi-structured interviews.

- ❖ Wiegerink, Diana J. H. G., Stam, Henk J., Ketelaar, Marjolijn, Cohen-Kettenis, Peggy T., and Roebroek, Marji E. "[Personal and environmental factors contributing to participation in romantic relationships and sexual activity of young adults with cerebral palsy](#)." *Disability and Rehabilitation* 34, no. 17 (2012): 1481-1487 (paying access)

Wiegerink et al. examine personal and situational predictors of romantic relationships and sexual activity among youth with cerebral palsy. Findings emphasise that self-efficacy, self-esteem and sexual esteem are facilitators of romantic relationships and sexual encounters.

- ❖ Wijesinghe, R. S., Wickremasinghe, A. R., Ekanayake, Sriyani, and Perera, M. S. A. "[Physical disability and psychosocial impact due to chronic filarial lymphoedema in Sri Lanka](#)." *Filaria Journal* 6, no. 1 (2007): 1-8 (open access)

This descriptive study sheds light on the psychosocial impact of chronic lymphoedema on patients in a district of Sri Lanka.

- ❖ Wolfe, Pamela S. "[The influence of personal values on issues of sexuality and disability](#)." *Sexuality and Disability* 15, no. 2 (1997): 69-90.

Wolfe investigates the attitudes of healthcare professionals (N = 98) toward the sexuality of persons with disabilities. She finds that attitudes are generally more conservative toward those who have severe disabilities.

- ❖ Yoshida, K. K., Li, A., and Odette, F. "[Cross-cultural views of disability and sexuality: Experiences of a group of ethno-racial women with physical disabilities](#)." *Sexuality and Disability* 17, no. 4 (1999): 321- 337 (paying access)

Yoshida, Li and Odette investigate the experiences of ethnic minority women with disabilities through focus groups. They note that while commonalities exist between ethnic minority women with disabilities and women with disabilities in general, the former also experience additional barriers.

- ❖ **Zaviršek, Darja.** "[Pictures and silences: memories of sexual abuse of disabled people.](#)" **International Journal of Social Welfare** 11, no. 4 (2002): 270-285 (paying access)

Zaviršek presents the first person accounts of Slovenian women with disabilities who were subjected to sexual abuse in order to highlight the structural causes of this abuse (e.g., societal perception that women with disabilities are asexual).

ii): South Africa

Research conducted on attitudes toward the sexuality of persons with physical disabilities in South Africa tends to have some key differences to work conducted elsewhere. The most obvious of these is an increased focus on attitudes toward and knowledge of HIV, among persons with disabilities, their parents and educators. Attention is also paid to how traditional cultural beliefs about both disability and gender may shape sexuality attitudes.

- ❖ **Barry, Shelly.** "[Disability and desire: journey of a filmmaker.](#)" **Feminist Africa 6: Subaltern Sexualities** (2006): 65-67 (open access)

Barry recounts her autobiographical experiences of becoming disabled in South Africa.

- ❖ **Basson, Melanie.** "[An investigation of disabled women's perceptions of HIV and AIDS and aspects of sex and sexuality in three South African provinces.](#)" PhD Thesis, (2010): 1-97 (open access)

Basson qualitatively explores the lives of 17 South African women with disabilities in the context of their sexuality and HIV perceptions. The study sheds light on an under-researched area, identifying, notably, that nearly all the women had experienced sexual abuse.

- ❖ **Chappell, Paul.** "[Secret languages of sex: disabled youth's experiences of sexual and HIV communication with their parents/caregivers in KwaZulu-Natal, South Africa.](#)" **Sex Education** (2015): 1-13 (paying access)

See Reading Note 1 p.16

- ❖ **Chappell, Paul, Rule, Peter, Dlamini, Mfana, and Nkala, Nompilo.** "[Troubling power dynamics: Youth with disabilities as co-researchers in sexuality research in South Africa.](#)" **Childhood** 21, no. 3 (2014): 385-399 (Paying Access)

See Reading Note 2 p.17

- ❖ **Chirawu, Petronella, Hanass-Hancock, Jill, Aderemi, Toyin, J., de Reus, Liset, and Henken, Anne S.** "[Protect or enable? Teachers' beliefs and practices regarding provision of sexuality education to learners with disability in KwaZulu-Natal, South Africa.](#)" **Sexuality and Disability** 32, no. 3 (2014): 259- 277 (open access)

See Reading Note 3 p.18

- ❖ Hanass-Hancock, Jill. "[Interweaving conceptualizations of gender and disability in the context of vulnerability to HIV/AIDS in KwaZulu-Natal, South Africa](#)." *Sexuality and Disability* 27, no. 1 (2009): 35-47 (paying access)

See Reading Note 5 p.22

- ❖ Hanass-Hancock, Jill, Henken, Sophie, Pretorius, Leandri, de Reus, Liset, and van Brakel, Wim. "[The cross-cultural validation to measure the needs and practices of educators who teach sexuality education to learners with a disability in South Africa](#)." *Sexuality and Disability* 32, no. 3 (2014): 279- 298 (open access)

Using data collected as part of a larger project (see Chirawu et al., 2014; de Reus et al., 2015), the authors develop a measure to assess the needs and practices of educators who deliver sexuality education to learners with disabilities.

- ❖ Louw, Julia S., Kosciulek, John, and Chen, Roy K. "[Investigating educators' views of sexuality, HIV and AIDS education in working with students with disabilities in South African schools](#)." *Journal of Applied Rehabilitation Counseling* 45, no. 2 (2014): 9-17 (paying access)

See Reading Note 6 p.24

- ❖ Maart, Soraya, and Jelsma, Jennifer. "The sexual behaviour of physically disabled adolescents." *Disability and Rehabilitation* 32, no. 6 (2010): 438-443 (paying access)

Maart and Jelsma examine the sexual behaviour of physically disabled adolescents (N = 91) in Cape Town. They found evidence that disabled adolescents are indulging in risky sexual behaviours (e.g., not using protection) and argue that this group must not be excluded from mainstream health promotion activities.

- ❖ McKenzie, Judith A. "[Disabled people in rural South Africa talk about sexuality](#)." *Culture, Health & Sexuality* 15, no. 3 (2013): 372-386 (paying access)

See Reading Note 7 p.25

- ❖ McKenzie, Judith A., and Swartz, Leslie. "[The shaping of sexuality in children with disabilities: A Q methodological study](#)." *Sexuality and Disability* 29, no. 4 (2011): 363-376 (open access)

Reasoning that sexuality is shape by childhood, McKenzie and Swartz investigate stigma and abuse among disabled children in South Africa. The authors find that a healthy development of sexuality among this population may be limited by high levels of stigma that they experience.

- ❖ Potgieter, Cheryl-Ann, and Khan, Gadija. "[Sexual self-esteem and body image of South African spinal cord injured adolescents](#)." *Sexuality and Disability* 23, no. 1 (2005): 1-20 (paying access)

See Reading Note 9 p.28

- ❖ Rohleder, Poul, Eide, Arne H., Swartz, Leslie, Ranchod, Chitra, Schneider, Margie, and Schür, Clare. "[Gender differences in HIV knowledge and unsafe sexual behaviours among persons with disabilities in South Africa](#)." *Disability and Rehabilitation* 34, no. 7 (2012): 605-610 (paying access)

See Reading Note 10 p.29

- ❖ Wazakili, Margaret, Mpofu, Ratie, and Devlieger, Patrick. "[Experiences and perceptions of sexuality and HIV/AIDS among young people with physical disabilities in a South African township: a case study](#)." *Sexuality and Disability* 24, no. 2 (2006): 77-88 (open access)

See Reading Note 11 p.31

- ❖ Willems, Melanie. "[HIV/AIDS and persons with disabilities](#)." *Masters Thesis* (2011): 1-92 (open access)

This Masters' thesis investigates the impact of HIV among persons with disabilities in South Africa, using a survey (N = 74). Findings indicate that the majority of respondents considered HIV to be a relevant issue, however other findings, such as "it is not clear if disabled people are at risk of HIV", are at odds with peer-reviewed work (e.g., Hanass-Hancock, 2009).

- ❖ Wogqoyi, Mirriam N. "[Knowledge, attitudes and practices of parents/guardians of children with disabilities on abuse of children with disabilities, in the Willowvale area, Eastern Cape Province, South Africa](#)." *PhD Thesis* (2012): 1-109 (open access)

Wogqoyi employs mixed methods to investigate the prevalence of abuse among children in an area of Eastern Cape. Parents/caregivers indicated low levels of knowledge of the definitional aspects of abuse, but were aware of its occurrence among children with disabilities (including sexual abuse).

Section B: Access to sexual and reproductive healthcare

Section B lists applied research which primarily investigates access toward sexual and reproductive healthcare. This includes empirical data on people's beliefs and experiences of healthcare services, as well as studies that seek to identify barriers and facilitators of access. Several studies test interventions to improve access, by either targeting the experiences of persons with disabilities, or the experiences that professionals have in delivering sexuality education. A few notable papers review sexual and reproductive healthcare access within different areas of Africa (e.g., countries, regions), although the methodologies used in each case differ (e.g., interviews; meta- analyses). Studies also tend to focus on the first-person experiences that persons with physical disabilities face when accessing healthcare services.

i): World

- ❖ Aderemi, Toyin J., Mac-Seing, Muriel, Woreta, Seblewangel A., and Mati, Komi A. "[Predictors of voluntary HIV counselling and testing services utilization among people with disabilities in Addis Ababa, Ethiopia.](#)" *AIDS care* 26, no. 12 (2014): 1461-1466 (paying access)

Aderemi et al. investigate predictors of HIV counselling among persons with disabilities (N = 411) in Ethiopia. Testing prevalence was 53.2% and knowledge, cohabitation with a spouse and religiosity were identified as positive predictors of testing.

- ❖ Ahumuza, Sharon E., Matovu, Joseph, Ddamulira, John, and Muhanguzi, Florence. "[Challenges in accessing sexual and reproductive health services by people with physical disabilities in Kampala, Uganda.](#)" *Reproductive Health* 11, no. 1 (2014): 59 (paying access)

The authors qualitatively investigate barriers to persons with disabilities accessing healthcare services in Uganda, using interviews. Findings identify such as barriers as negative attitudes, long queues at facilities, high costs and inaccessible buildings. The authors suggest this highlights the need to provide disability friendly services at these facilities (see also Anderson & Kitchin, 2000).

- ❖ Alexander, Ronald W., Bradley, Laurence A., Alarcón, Graciela S., Triana-Alexander, M., Aaron, Leslie A., Alberts, Kristin R., Martin, Michelle Y., Stewart, Katharine, E. "[Sexual and physical abuse in women with fibromyalgia: association with outpatient health care utilization and pain medication usage.](#)" *Arthritis & Rheumatism* 11, no. 2 (1998): 102-115 (paying access)

The authors investigate the prevalence of abuse among outpatient women with disabilities (N = 75) and its link with healthcare utilization and pain medication usage. 35 patients reported sexual abuse and abuse history was linked to greater healthcare usage and greater pain medication usage.

- ❖ Anderson, Paul, and Kitchin, Rob. "[Disability, space and sexuality: access to family planning services.](#)" *Social Science & Medicine*, 51, (2000): 1163-1173 (open access)

Anderson and Kitchin investigate access to family planning clinics among persons with disabilities in Northern Ireland. They identify a number of barriers to access (e.g., physical structures, attitudes) that suggests there exists a "culture of exclusion" of the disabled from healthcare.

- ❖ Berman, Helene, Harris, Dorothy, Enright, Rick, Gilpin, Michelle, Cathers, Tamzin, and Bukovy, Gloria. "[Sexuality and the adolescent with a physical disability: understandings and misunderstandings.](#)" *Issues in Comprehensive Pediatric Nursing* 22, no. 4 (1999): 183-196 (paying access)

This descriptive study investigates sexual knowledge and beliefs among a small sample of physically disabled adolescents (N = 29).

- ❖ Bitzer, Johannes, Platano, Giacomo, Tschudin, S. and Alder, Judith. "[Sexual Counseling for women in the context of physical diseases—A teaching model for physicians.](#)" *The Journal of Sexual Medicine* 4, no. 1 (2007): 29-37 (paying access)

Bitzer et al. develop a psychometric tool to help physicians assess sexual problems and issues among women with chronic health conditions.

- ❖ Booth, Susan, Kendall, Melissa, Fronek, Patricia, Miller, Deborah, and Geraghty, Timothy. "[Training the interdisciplinary team in sexuality rehabilitation following spinal cord injury: a needs assessment.](#)" *Sexuality and Disability* 21, no. 4 (2003): 249-261 (paying access)

This paper reports on a needs assessment conducted with spinal rehabilitation professionals (N = 90). Results highlight a number of areas for future focus, such as the promotion of staff comfort.

- ❖ Christopherson, Jeannine M., Moore, Katherine, Foley, Frederick W., and Warren, Kenneth G. "[A comparison of written materials vs. materials and counselling for women with sexual dysfunction and multiple sclerosis.](#)" *Journal of Clinical Nursing* 15, no. 6 (2006): 742-750 (open access)

Christopherson et al. experimentally assess the added value of counselling when combined with written materials concerning sexual dysfunction in multiple sclerosis patients. Both groups experienced reduced sexual dysfunction post-intervention, suggesting that nurses need not apply in-depth specialised knowledge to improve quality of life.

- ❖ Collins, Carol. "[Reproductive technologies for women with physical disabilities.](#)" *Sexuality and Disability* 17, no. 4 (1999): 299-307 (paying access)

The paper presents a biographical interview with a disabled participant about her experience of reproductive technologies.

- ❖ De Beaudrap, Pierre, Mac-Seing, Pierre, and Pasquier, Estelle. "[Disability and HIV: a systematic review and a meta-analysis of the risk of HIV infection among adults with disabilities in Sub-Saharan Africa.](#)" *AIDS care* 26, no. 12 (2014): 1467-1476 (open access)

De Beaudrap et al's meta-analysis provides strong empirical evidence that persons with disabilities do not have a decreased risk of HIV infection, in particular highlighting that women with disabilities are most likely to be affected by the disease.

- ❖ De Beaudrap Pierre, Pasquier Estelle, Tchoumkeu Alice, Touko, Adonis, Essomba, Frida, Brus, Aude, du Loû, Annabel D., Aderemi, Toyin J., Hanass-Hancock, J., Eide, Aide H., Mont, Daniel, Mac-Seing, Muriel, Beninguisse, Gervais. "[HandiVIH: A population-based survey to understand the vulnerability of people with disabilities to HIV and other sexual and reproductive health problems in Cameroon: protocol and methodological considerations](#)". *BMJ Open* 6 (2016):e008934 (paying access)

De Beaudrap et al. employ a mixed methodological design in order to better understand the vulnerabilities that persons with disabilities in Cameroon may experience toward HIV. The authors suggest that their methodology may contribute to the development of good practice when conducting future quantitative surveys with persons with disabilities.

- ❖ Haboubi, N. H. J., and Lincoln, N. "[Views of health professionals on discussing sexual issues with patients.](#)" *Disability and Rehabilitation* 25, no. 6 (2003): 291-296 (paying access)

Haboubi and Lincoln assess health professionals' (N = 813) views toward delivering sexual healthcare to persons with disabilities. Findings indicated gaps in professionals' knowledge and training, suggesting that further sexuality training should be implemented.

- ❖ Hess, Marika J., Hough, Sigmund, and Tammaro, Elizabeth. "[The experience of four individuals with paraplegia enrolled in an outpatient interdisciplinary sexuality program.](#)" *Sexuality and Disability* 25, no. 4 (2007): 189-195 (paying access)

Hess et al. focus on the rehabilitation experiences of four males with spinal cord injuries, finding that each client had found the healthcare process relatively positive.

- ❖ Higgins, Agnes, Sharek, Danika, Nolan, Maeve, Sheerin, Barbara, Flanagan, Paul, Slaicuinaite, Sniguole, McDonnell, Sinead, and Walsh, Heather. "[Mixed methods evaluation of an interdisciplinary sexuality education programme for staff working with people who have an acquired physical disability.](#)" *Journal of Advanced Nursing* 68, no. 11 (2012): 2559-2569 (paying access)

Higgins et al. evaluate the effectiveness of a 1 day sexuality education programme for personnel working with persons with disabilities, using a pre- vs. post-test. Results suggest the programme was effective at promoting knowledge, skill and comfort among healthcare professionals.

- ❖ Hilberink, Sander R., Kruijver, Egbert, Wiegerink, Diana J. H. G. and Vliet Vlieland, Thea P. M. "[A pilot implementation of an intervention to promote sexual health in adolescents and young adults in rehabilitation.](#)" *Sexuality and Disability* 31, no. 4 (2013): 373-392 (paying access)

This study evaluates the pilot implementation of a group program for young adults with physical disabilities.

- ❖ Hough, Sigmund, Stone, Melissa T. and Buse, Dawn C. "[Dating and relationship psychoeducational group for veterans with spinal cord injury/dysfunction: A historical account of an initial clinical course.](#)" *Sexuality and Disability* 31, no. 4 (2013): 337-359 (paying access)

This study addresses a gap in the literature, by testing a group skill model of dating and relationships to individuals with spinal cord injuries.

- ❖ Kedde, H., Van De Wiel, H. B. M., Weijmar Schultz, W. C. M., Vanwesenbeek, W. M. A., and Bender, J. L. "[Efficacy of sexological healthcare for people with chronic diseases and physical disabilities.](#)" *Journal of Sex & Marital Therapy* 36, no. 3 (2010): 282-294 (open access)

This authors evaluate the efficacy of psychosexual therapy for persons with physical impairments. Although based on a small sample, the findings indicate some of benefits of psychosexual therapy.

- ❖ Kemp, Nancy T., and Mallinckrodt, Brent. "[Impact of professional training on case conceptualization of clients with a disability.](#)" *Professional Psychology: Research and Practice* 27, no. 4 (1996): 378-385 (paying access)

Kemp & Mallinckrodt experimentally assess the impact of disability status on the way that clients are viewed.

- ❖ Kendall, Melissa, Booth, Susan, Fronek, Patricia, Miller, Deborah, and Geraghty, Timothy. "[The development of a scale to assess the training needs of professionals in providing sexuality rehabilitation following spinal cord injury.](#)" *Sexuality and Disability* 21, no. 1 (2003): 49-64 (paying access)

Kendall et al. develop a scale to assess the training needs of rehabilitation professionals addressing clients' sexuality needs.

- ❖ Lee, Eun-Kyoung O., and Oh, Heykyung. "[A wise wife and good mother: reproductive health and maternity among women with disability in South Korea.](#)" *Sexuality and Disability* 23, no. 3 (2005): 121-144 (paying access)

Lee & Oh investigate the experiences and needs of mothers with disabilities in South Korea, shedding light on an under-researched context. The study highlights a wide range of barriers (e.g., lack of competence of healthcare professionals) that these women face.

- ❖ Leibowitz, Ruth Q. "[Sexual rehabilitation services after spinal cord injury: what do women want?](#)" *Sexuality and Disability* 23, no. 2 (2005): 81-107 (open access)

Leibowitz explores the experiences and concerns of women with disabilities related to sexual rehabilitation (N = 24), using semi-structured interviews. Results highlight the value of participant feedback on the conduct and competence of healthcare professionals.

- ❖ McCabe, Janet, and Holmes, Dave. "[Nursing, sexual health and youth with disabilities: a critical ethnography.](#)" *Journal of Advanced Nursing* 70, no. 1 (2014): 77-86 (open access)

The authors conduct a critical ethnography study investigating the experiences of nurses that provide sexual healthcare to adolescents with disabilities. They identify some barriers (e.g., institutional space), which the authors argue facilities need to take steps to address.

- ❖ Northcott, Rebekah, and Chard, Gill. "[Sexual aspects of rehabilitation: The client's perspective.](#)" *The British Journal of Occupational Therapy* 63, no. 9 (2000): 412-418 (open access)

This study qualitatively explores the experiences with sexual rehabilitation that persons with disabilities have. Like other studies (e.g., Haboubi & Lincoln, 2003), findings point to extant training needs in this area.

- ❖ O'Dea, Shane M., Shuttleworth, Russell P., and Wedgwood, Nikki. "[Disability, doctors and sexuality: Do healthcare providers influence the sexual wellbeing of people living with a neuromuscular disorder?](#)" *Sexuality and Disability* 30, no. 2 (2012): 171-185 (open access)

O'Dea et al. compare sexuality experiences and expression between persons with neuromuscular disorders and persons without disabilities. The study also investigates sexual expression as a predictor of patient quality

of life. A positive relationship was identified between the two, which was strongest among the persons with neuro-muscular disorders.

- ❖ **Oladunni, Taiwo M.** "[Sexual behavior and practices among adolescents with disabilities in Southwest Nigeria](#)." *Sexuality and Disability* 30, no. 3 (2012): 289-299 (paying access)

Oladunni investigates sexual behaviour and practices among youth with disabilities in Nigeria (N = 140). Findings indicate that although over half had engaged in sexual intercourse, they had little access to HIV testing and counselling, mirroring problems in different contexts, particularly African (e.g., Ethiopia; Aderemi et al., 2014).

- ❖ **Pebdani, Roxanna N., Johnson, Kurt L., and Amtmann, Dagmar.** "[Personal experiences of pregnancy and fertility in individuals with spinal cord injury](#)." *Sexuality and Disability* 32, no. 1 (2014): 65-74 (paying access)

Pebdani et al. investigate the barriers facing women who have spinal cord injuries (N = 253) and pursue pregnancy and motherhood.

- ❖ **Pendergrass, Stephanie, Nosek, Margaret A., and Holcomb, J. David.** "[Design and evaluation of an internet site to educate women with disabilities on reproductive health care](#)." *Sexuality and Disability* 19, no. 1 (2001): 71-83 (paying access)

Pendergrass et al. conduct a pilot study to evaluate whether an internet site can sufficiently educate women with disabilities on reproductive healthcare. Findings indicate both that women with disabilities possess gaps in their knowledge of reproductive healthcare and that the internet site was effective at addressing these gaps.

- ❖ **Porat, Omer, Heruti, R., Navon-Porat, Hagit, and Hardoff, Daniel.** "[Counseling young people with physical disabilities regarding relationships and sexuality issues: Utilization of a novel service](#)." *Sexuality and Disability* 30, no. 3 (2012): 311-317 (paying access)

Porat et al. evaluate a service designed to provide sexual counselling to youth with disabilities. The authors identify that usage of the service was hampered by a lack of suitable transportation, highlighting the need to consider accessible transportation as part of sexual healthcare services.

- ❖ **Post, Marcel W. M., Gianotten, Woet L., Heijnen, Lily, Hille, Lambers, Erick J. H. R., and Willems, Mia.** "[Sexological competence of different rehabilitation disciplines and effects of a discipline-specific sexological training](#)." *Sexuality and Disability* 26, no. 1 (2008): 3-14 (open access)

Post et al. evaluate an intervention designed to increase the competence of professionals who deal with sexual rehabilitation. Additionally, they compare competence of professionals across different healthcare disciplines.

- ❖ Rueda, Heidi A., Linton, Kristin F., and Williams, Lela R. "[School social workers' needs in supporting adolescents with disabilities toward dating and sexual health: A qualitative study.](#)" *Children & Schools* 36, no. 2 (2014): 79-90 (open access)

Rueda et al. qualitatively investigate the needs of social workers who support adolescents with disabilities in relation to dating and sexual health. The authors suggest that challenges exist at both the school level (e.g., need for school-based education programmes) and within the broader environment (e.g., unhealthy cultural depictions of sex).

- ❖ Sawyer, Susan M., and Roberts, Kathryn V. "[Sexual and reproductive health in young people with spina bifida.](#)" *Developmental Medicine & Child Neurology* 41, no. 10 (1999): 671-675 (open access)

This study investigates the sexual and reproductive health experiences and attitudes among youth who have spina bifida. Similar to other studies that have investigated sexuality among persons with disabilities (e.g., Oladunni, 2012) a large percentage of respondents (60%) were in intimate relationships, but almost all (95%) thought they possessed inadequate sexual knowledge.

- ❖ Seburg, Elisabeth M., McMorris, Barbara J., Garwick, Ann W., and Scal, Peter B. "[Disability and discussions of health-related behaviors between youth and health care providers.](#)" *Journal of Adolescent Health* 57 (2015): 81-86 (paying access)

Seburg et al. compare the likelihood of discussing health-related behaviours (including sexual and reproductive healthcare) between youth with disabilities and healthcare providers. The authors emphasise the importance of healthcare providers viewing the needs of youth with disabilities similarly to those without disabilities.

- ❖ Seidel, Anja, Wienholz, Sabine, Michel, Marion, Lupp, Melanie, and Riedel-Heller, Steffi G., "[Sexual knowledge among adolescents with physical handicaps: A systematic review.](#)" *Sexuality and Disability* 32, no. 3 (2014): 429-441 (paying access)

Seidel conduct a systematic review to assess how sexuality is provided for physically disabled adolescents, encompassing nine papers. While it was discovered that adolescents generally receive sexual education in schools, very little of this information was impairment-specific, highlighting the need to include more specialised, as well as general, material.

- ❖ Smith, E., Murray, S. F., Yousafzai, A. K., and Kasonka, L. "[Barriers to accessing safe motherhood and reproductive health services: the situation of women with disabilities in Lusaka, Zambia.](#)" *Disability and Rehabilitation* 26, no. 2 (2004): 121-127 (paying access)

Smith et al. assess how well services in Lusaka, Zambia, can provide sexual and reproductive healthcare to women with disabilities. Findings identified several barriers to effective healthcare, in common with several other papers conducted within different countries in Africa (e.g., Ahumuzu et al. 2014; Oladunni, 2012).

- ❖ Sorsa, Solomon. "[Health problems of children with disabilities with special reference to HIV/AIDS in Southern Ethiopia.](#)" *Ethiopian Journal of Health Development* 27, no. 2 (2013): 94-103 (open access)

Sorsa investigates health problems among children with disabilities in Ethiopia, identifying, among others, that their access to HIV treatment is restricted and they are vulnerable to sexual abuse.

- ❖ Stein, Joel, Hillinger, Marni, Clancy, Cait, and Bishop, Lauri. "[Sexuality after stroke: patient counseling preferences.](#)" *Disability and Rehabilitation* 35, no. 21 (2013): 1842-1847 (paying access)

The authors examine patient (N = 268) counselling preferences post-stroke. They note that patient preferences for the timing of counselling vary, creating challenges for optimizing this type of care.

- ❖ Stevens, S. Elizabeth, Steele, Catherine A., Jutai, Jeffrey W., Kalnins, Ilze V., Bortolussi, Joseph A. and Biggar, W. Douglas. "[Adolescents with physical disabilities: some psychosocial aspects of health.](#)" *Journal of Adolescent Health* 19, no. 2 (1996): 157-164 (open access)

Stevens et al. investigate psychosocial risks to health among adolescents with disabilities, identifying gaps in their knowledge of sexuality, similar to other work with persons with disabilities (e.g., Pendergrass et al. 2001).

- ❖ Tanabe, Mihoko, Nagujjah, Yusrah, Rimal, Nirmah, Bukania, Florah, and Krause, Sandra. "[Intersecting sexual and reproductive health and disability in humanitarian settings: risks, needs, and capacities of refugees with disabilities in Kenya, Nepal, and Uganda.](#)" *Sexuality and Disability* 33, no. 4 (2015): 411- 427 (open access)

Tanabe et al. conduct a participatory research project with refugees who have disabilities across three developing countries. The authors suggest that their findings speak to the need to recognise the sexual and reproductive health rights of disabled refugees.

- ❖ Thomas, Carol. "[Medicine, gender, and disability: disabled women's health care encounters.](#)" *Health Care for Women International* 22, no. 3 (2001): 245-262 (paying access)

Thomas investigates the healthcare encounters of women with disabilities by collecting women's narratives (N = 68) and conducting in-depth interviews (N = 17).

- ❖ Van der Stege, Heleen A., van Staa, AnneLoes, Hilberink, Sander R., and Visser, Adriaan, Ph. "[Using the new board game SeCZ TaLK to stimulate the communication on sexual health for adolescents with chronic conditions.](#)" *Patient Education and Counseling* 81, no. 3 (2010): 324-331 (paying access)

Van der Stege et al. assess effectiveness of an intervention (SeCZ TaLK) to facilitate discussion about sexual health among young with chronic disabilities (N = 85). Results indicate that the majority of youth found the tool useful in promoting discussion.

- ❖ Wiegerink, Diana, Roebroek, Marij, Bender, Jim, Stam, Henk, and Cohen-Kettenis, Peggy. "[Sexuality of young adults with cerebral palsy: experienced limitations and needs.](#)" *Sexuality and Disability* 29, no. 2 (2011): 119-128 (open access)

The authors report a descriptive study investigating the sexual problems of a sample of young adults with cerebral palsy (N = 74).

- ❖ Xenakis, Nancy, and Goldberg, Judith. "[The Young Women's Program: A health and wellness model to empower adolescents with physical disabilities.](#)" *Disability and Health Journal* 3, no. 2 (2010): 125- 129 (paying access)

Xenakis et al. evaluate the efficacy of a programme to promote healthy lifestyles (including sexuality) among women with disabilities. Findings suggest response to the programme was generally favourable.

- ❖ Yousafzai, A. K., Edwards, K., D'Allesandro, C., and Lindström, L. "[HIV/AIDS information and services: the situation experienced by adolescents with disabilities in Rwanda and Uganda.](#)" *Disability and Rehabilitation* 27, no. 22 (2005): 1357-1363 (open access)

Like other studies in the area (Oladunni, 2012; Smith et al. 2004), Yousafzai et al. report work that illustrates that the HIV epidemic among persons with disabilities is a neglected area.

ii) South Africa

- ❖ De Reus, Liset, Hanass-Hancock, Jill, Henken, Sophie, and van Brakel, Wim. "[Challenges in providing HIV and sexuality education to learners with disabilities in South Africa: the voice of educators.](#)" *Sex Education* 15, no 4 (2015): 1-15 (paying access)

See Reading Note 4 p.20

- ❖ Mavuso, Sibusisiwe S., and Maharaj, Pranitha. "[Access to sexual and reproductive health services: Experiences and perspectives of persons with disabilities in Durban, South Africa.](#)" *Agenda* 29, no. 2 (2015): 79-88 (paying access)

See Reading Note 8 p.26

- ❖ Njoki, Emmah. "[Health promotion needs of youth with physical disabilities with specific reference to spinal cord injury in the Western Cape--South Africa.](#)" Masters Thesis, 2004, 1-121 (open access)

Although this Master's thesis is focused on the general health needs of youth with physical disabilities in Durban, Njoki finds that individuals desire more information about sexuality issues. This agrees with extant peer-reviewed work (e.g., Mavuso & Maharaj, 2015).

- ❖ Wazakili, Margaret, Mpofu, Ratie, and Devlieger, Patrick. "[Should issues of sexuality and HIV and AIDS be a rehabilitation concern? The voices of young South Africans with physical disabilities.](#)" *Disability and Rehabilitation* 31, no. 1 (2009): 32-41 (paying access)

See Reading Note 12 p.32

The present document was conducted as part of the applied research “The myth of asexuality? Disability stigma as a barrier to sexual relationships in South Africa” led by the University of East London, in partnership with the Southern African Federation of the Disabled, SINTEF Technology and Society and Stellenbosch University. It was funded by FIRA’s (International Foundation of Applied Research on Disabilities) call for projects in 2014.

The goal of this literature review is to report on existing knowledge about applied research on the theme of the myth of asexuality in South Africa. It resulted in the selection of relevant research papers which were each categorised using a set of predetermined criteria. Of these research papers 12 were selected as being particularly relevant or interesting because of their potential for being applied with practical effect, especially with persons with disabilities and their own organisations.

