

Experiences and Perceptions of Sexuality and HIV/AIDS among Young People with Physical Disabilities in a South African Township: a Case Study

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Abstract 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.

Keywords Physically disabled young people · Sexuality · Perceptions · HIV/AIDS · Experiences

In this paper the phrases ‘young people with physical disabilities’ and ‘disabled young people’ are used interchangeably.

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Introduction

This paper explores the experiences and perceptions of physically disabled young people and their parents in the context of Nyanga Township. The purpose is to identify the barriers that inhibit these young people from accessing information on sexuality and HIV/AIDS and services. The inhibiting factors will be highlighted by exploring the participants' experiences and perceptions of the socio-cultural issues that tend to increase their vulnerability to HIV/AIDS and how they respond to the same.

Context

Nyanga is one of the oldest and biggest 'Black Townships' in the Western Cape Metropolitan area in South Africa, predominantly inhabited by the Xhosa people. Initially, it was created to accommodate black migrant workers from the rural areas. Later it served to accommodate African people removed from 'District Six' near Table Mountain. It now accommodates a fluctuating population of some 60,000 people who moved from the Eastern Cape in search of a better life in the city and 1,600 of these are said to be disabled [1].

Nyanga is a community characterised by a social environment that offers few resources and little support for growing disabled young people. The high unemployment rate, estimated at 56% [1], and overcrowded living conditions where residents seek comfort from one another, are some of the factors leading to increased incidence of HIV/AIDS in South African Townships [2].

Nyanga has poor, makeshift housing ('shacks'), where movement between the 'shacks' is impossible for wheelchair users, a factor that contributes to their confinement to home. It shares one clinic with neighbouring Guguletu Township. Many people are involved in informal businesses or low-paid menial jobs. Young people with physical disabilities attend special schools, also in Guguletu and most get no opportunities for tertiary education, skills training or gainful employment. The shacks, which make up to 60% of Nyanga dwellings, do not provide privacy or adequate security for these young people.

The subject of disability in relation to sexuality and HIV/AIDS is prone to misperceptions and stereotyping. The recognition that young people with physical disabilities have a sexual life and that they are at risk of contracting HIV infection is a relatively new one [3] and is fraught with misperceptions. The stigma attached to having a disability means that disabled people are often ostracised in family, religious or political affairs of their community, consequently, they are socially excluded [4]. Helander [5], believes that many of the reasons behind the problems facing disabled people can be found in deeper rooted prejudices.

Researchers have called for an urgent need to examine the links between disability, sexuality and HIV/AIDS in order to inform policy and programmes for this target group [6]. Some studies have focused on experiences and perceptions of young people in general, in relation to HIV/AIDS [7, 8], but no specific study in this connection has been made on the young people with disabilities. There is very little research world wide on disabled people's needs regarding the prevention and mitigation of the AIDS epidemic [9, 10]. This is in spite of the fact that people with disabilities, especially women and girls, are among the most marginalised groups in society and equally affected by HIV/AIDS [11]. In addition, these groups are at greater risk of physical and sexual abuse and often denied their reproductive rights and have reduced opportunities for marriage. These factors

increase their likelihood of engaging in indiscriminate high-risk sexual activities, which increase their vulnerability to HIV/AIDS [11].

One of the key reasons for this lack of focus on the needs of people with disabilities regarding HIV/AIDS is that AIDS Service Organisations do not consider disability their issue [12]. Hence, they do not develop disability specific information or create programmes that encompass the specific circumstance of people with disabilities. Some NGOs have reported that they do not know how to integrate young people with disabilities in their HIV/AIDS programmes [13].

The Government and the private sector in South Africa have designed HIV/AIDS intervention strategies on the assumption that all young people have the same needs [14], while ignoring the unique circumstances faced by young people with disabilities. In addition, there seems to be limited understanding of disabled people's socio-cultural and economic circumstances in relation to sex and sexuality [15, 16]. For example, it is known that social isolation and poverty are common among disabled people but little is known of the consequences in terms of sexuality and HIV/AIDS.

Although society is aware that the danger of sexual abuse is increased by disabled young people's difficulty in escaping abusive situations and their need for assistance with personal tasks from their perpetrators [17], society seems helpless to protect these young people from such abuses. Furthermore, researchers have described a paradox among South African young people that despite their knowledge about HIV/AIDS and how it can be prevented there is still a high HIV prevalence rate in this group [18]. Generally, young people, including the disabled, do not practice safe sex; they engage with multiple sexual partners and transactional sex and do not use condoms [19].

It is often assumed that if people were informed of risk factors in their lives and their environment, they would strive to avoid or reduce such risks. However, researchers have described a gap between rational thinking of what constitutes risk behaviour and a more holistic perspective that aims to grasp the multiple concerns people have to take into account when making choices and decisions in their every day life [20, 21]. Therefore, it is also important not to assume that disabled individuals have the option of choice and can make autonomous decisions [21]. For example, their parents perceive them as infant like, and therefore, do not allow them the opportunity to make choices and decisions about their own sexual lives.

In addition to lack of focused studies on disabled young people's sexuality and HIV/AIDS, there seem to be no mainstream HIV/AIDS programmes in Nyanga that include or target this category. The assumption is that the barriers that contribute to the exclusion of disabled young people from sexuality and HIV/AIDS information and services should be identified. This identification would only be achieved by exploring the experiences and perceptions of young people with disabilities and their parents. In particular, understanding their lived experiences and perceptions might inform the development of sexuality and HIV/AIDS intervention strategies, which are sensitive and relevant to their special circumstances.

Method

Ten parents and ten young people with physical disabilities aged 15–24 whose disabilities included post polio paralysis, cerebral palsy, spinal cord injury, stroke and spina bifida participated in the study. They were recruited through an intermediary and the local UWC Community Rehabilitation Project. Although young people with physical disabilities were

the key participants, their parents were recruited to stand in for the young people who were not able to participate and to shed more light on the subject of raising disabled children in their circumstances. Each participant was asked for consent via an intermediary after the aim of the study was explained.

Procedure

The interviews and the focus group discussions, covered knowledge and experiences of sexuality and HIV/AIDS, factors contributing to vulnerability, responses and attitudes to personal risk. In-depth interviews were conducted with each participant. Following the results of the individual interviews, focus group discussions of 4–10 participants were conducted, two with young people with physical disabilities and two with parents over a 2-month period.

Demographic data of each participant, consent procedures, interviews and focus group discussions were all audio-taped and transcribed. Field notes were made afterwards regarding group dynamics and particular reactions and these were added to the transcripts. Transcripts were read back to participants who could not read or were not comfortable to read in English. This often gave them the opportunity to verify, expand or develop new ideas. The majority of the participants spoke only Xhosa fluently. Therefore, interview sessions were translated from English to Xhosa and Xhosa to English with the help of an intermediary.

Analysis

The first stage of the data analysis involved reading and re-reading of the transcripts to gain understanding of the meaning of sexuality and HIV/AIDS as experienced and perceived by young people with physical disabilities. The second stage involved sorting the transcripts into broad content categories. Each response was then summarised and coded by pattern coding as described by Miles and Huberman [22]. Codes were compiled to record the experiences and perceptions of these young people, focusing on the challenges of responding to sexuality and HIV/AIDS issues within the context of life in Nyanga. Codes were also compiled to understand the extent to which they were protecting themselves from the epidemic in the light of their special circumstances.

Results and Discussion

The experiences and perceptions of young people with physical disabilities regarding sexuality and HIV/AIDS are presented and discussed in terms of the inter-relatedness of social-cultural issues, factors increasing risk to HIV/AIDS and participants' response to risk.

Socio-cultural Issues

Participants experienced attitude barriers such as discrimination and marginalisation owing to their having a physical disability. Using the concept of stigma, researchers have described how people with disabilities are discriminated against and considered 'invisible to normal' people, who largely avoid them and segregate them [23, 24]. Participants perceived that they were considered as being devoid of human feelings as illustrated by the following quote:

Bonginkosi: *The community discriminates against me; they see me as a useless person. Some people treat me like someone who does not know what he is doing, others laugh at me, others do not talk to me ... sometimes I ask why God made me disabled.*

The above statement might imply, among other things, that the participants would find it difficult to interact with society that did not appreciate disabled people as equals. Forming and maintaining non-sexual relationships with family, friends or relevant communities was found to provide comfort to disabled people. Sexuality is also one aspect of the overall communication they desire [25]. Being denied this form of expression has detrimental effects on many disabled people's confidence and sense of self-worth.

Parents of disabled offspring expressed apprehension at the birth of a disabled child as expressed by one parent:

Parent 1: *I did not accept that I gave birth to a disabled child; some people were laughing at me saying I gave a wrong birth.*

The concept of 'disability' is often loaded with negative connotations [25] including witchcraft, so that no human being would wish it for themselves or their offspring. Not surprising this parent and the community in this study had difficulty accepting the birth of a disabled child. Consequently, parents may have, albeit unintentionally, communicated their own frustrations and negative feelings to their disabled offspring. This may in turn have communicated disabled young people's 'undesirability' as equal human beings or sexual beings and possible future sexual partners [3] thereby negatively affecting their self-esteem.

Participants in the present study did not only experience negative attitudes, some of their peers accepted and played with them as stated below:

Vuyisela: *My friends are nice to me ... others do not love me, they laugh at me, and they make me cry.*

The ambivalence of being accepted and teased at the same time would have been confusing for Vuyisela's construction of his identity in terms of identifying himself as disabled. A variety of elements fuse to form an identity and sexuality is an important part of that [26]. Therefore, this ambivalence would also have negatively affected Vuyisela's sense of sexual identity as well as his handling of HIV/AIDS matters.

Some participants went into social isolation in response to the discrimination they suffered, while others found it easier to ignore their tormenters and identify with fellow disabled young people.

Nomaqhawe: *I don't know how to talk to people outside ... so I always stay in the house. When I was at school, they would drop me [school shuttle] at the front door of the house ... so I don't have to walk long distance to the house ... children laughed at me so I took that shortcut to avoid meeting them. Nomthandazo: I like school for disabled only, boarding school ... children there are like me ... they don't laugh at you.*

Staying in the house all the time or attending at special schools reinforced the social exclusion of these young people as they had limited opportunities to interact with their non-disabled peers. Social interactions have been described as important aspects of developing social skills as well as sexual expression [32]. It follows that lack of such interactions would also have denied these young people opportunities for sexual expression; thereby impacting negatively on their confidence and quality of life.

In addition, cultural barriers played a significant role in denying participants access to sexuality information. Disabled young people and parents alike reported that it is taboo in Xhosa culture for parents to discuss sexuality matters with their children, disabled or not. This finding was repeatedly confirmed during individual interviews and focus group discussions as shown by the following quotes:

Thamsanqa: No one [talked to me about sexuality] ... my mother told me to clean the house and to wash myself when I have my periods ... I must not sleep with boys otherwise I will become pregnant ... but I do not have a boyfriend.. My mother is just being careful because I move around alone, so I can be raped. Nonceba: Nobody talks to you about that [sexuality and HIV/AIDS] even family, friends or at school. Mkuseli: My brothers told me about sex ... in my culture, parents do not speak to their children about sexual issues.

Well meaning parents in the present study limited sexuality talk with their disabled offspring to hygiene matters at menses as well as abstinence to avoid pregnancy (not sexually transmitted diseases), confirming the view that they may have felt uncomfortable discussing the subject in any detail. This finding is consistent with that of DiGiulio [3] who noted that parents of disabled children were sometimes reluctant to acknowledge these young people's potential as sexual beings. Hence, they sheltered them from sexuality information and typical sexual related experiences of adolescence, contributing to their social inhibition. It is noteworthy that participants often mentioned the occurrence of rape as if it were an expected aspect of their existence in Nyanga. It appeared that in most instances disabled females did not report rape for fear of violence, because more often than not, familiar or family members committed such offences. What is also striking is the seemingly helplessness of the parents and community in protecting disabled young people against rape in this community. It seemed that the responsibility was left with the disabled young females to protect themselves.

Apart from the culture of silence over cross-generational sexuality talks, some parents held the belief that their disabled offspring were asexual as shown below:

Parent 2: In our culture it's hard to talk about sex with children. Parent 3: My child has no sexual desires, when a man comes in she will be chicky and refuse to talk to him.

In line with these parents' beliefs, Goldberg [27] noted that parents of children with physical disabilities (in most societies in the world) consider their offspring as asexual, therefore, without need for sexuality information. In contrast to this point, Bonnie asserts:

'I would rather someone considered the thought of me being sexually active as distasteful rather than believing me to be asexual; at least with the former, they are thinking of me as a sexual being' [26, p. 124].

Such is the level of importance disabled people attach to their sexual expression. It follows that similar cultural barriers applied to the provision of sexuality information were also applied to the provision of HIV/AIDS information. The difficulty parents experienced teaching their children about HIV/AIDS stems from its close link to sex and sexuality. One cannot speak about HIV/AIDS in sub-Saharan Africa without speaking about sex and sexuality because most HIV transmission is through sexual intercourse [28]. Consequently, the young disabled people and parents alike reported that the media and the clinic were their main source of information as illustrated below:

Sisanda: *On TV they say that HIV is transmitted by a man who you do not know and also when you do not use a condom when doing sex ... Mkuseli: They told us at the clinic that you get AIDS when you sleep with someone who has got a discharge ... they also said we must get gloves when we want to help someone who has had an accident.*

Although there is some accuracy in the above statements, there is also misleading information. By believing that AIDS is transmitted by ‘someone you do not know’, this participant might believe it would be safe to sleep with a familiar person without knowledge of their HIV status. Similarly, they might feel safe to sleep with someone who does not have a ‘discharge’ without knowing their HIV status. Both positions would place them at risk of contracting HIV infection. Furthermore, participants did not know any HIV/AIDS programmes in Nyanga targeting young people, disabled or not. Therefore, they relied on the media for information with the disadvantage that they could not ask questions about aspects they may not have understood. Although the local clinic was said to routinely give health talks on HIV/AIDS, the occasional or incidental visits to a clinic would not provide the full, continuous information these issues obviously require. The level of misinformation demonstrated by these young people, is enough ground to call for provision of personalised and accurate HIV/AIDS information to help them make informed decisions about their sexual behaviour and its implications.

Parents also felt that they did not know enough about HIV/AIDS themselves to be able to educate their disabled offspring as stated below:

Parent: *We need information about HIV/AIDS ... we do not know much ...* Parent: *The government should give us information ... the reason we want assistance is that our children get used to us ... they don't listen ... they might listen if they see a new face.*

The parents' recognition of their need for HIV/AIDS information, as well as that of their offspring, underscores the need for training of parents and young people alike in HIV/AIDS matters.

Vulnerability to HIV/AIDS

It would appear that disabled females were socialised to believe that sexual relationships including marriage were not good for them. Consequently, they may have believed that they were asexual beings, therefore, unaffected by HIV/AIDS. Some of them felt insecure about involvement in sexual relationships in the first place, while others were simply disinclined to get involved as illustrated by these quotes:

Siphokazi: [female] *It is hard for me [to form sexual relationships] because I am afraid that boys would like to sleep with me and then leave me.* Philisiwe [Female]: [with a tone of irritation in her voice] *I have no boyfriend ... I don't want him ... I don't want to marry ... I don't want children ... I want to be alone.*

These statements demonstrate a lack of knowledge about handling sexual relationships. McCabe et al. [29] also found that people with physical disabilities experienced low levels of sexual knowledge, held negative feelings about sexuality and experienced low level of sexual experience.

Parents of disabled females expressed similar views to those held by their daughters:

Parent 4: *I don't want her to get married and my daughter does not want...*

Parental overprotection has been cited as a hindrance to social experience [30]. Furthermore, it has been found that parents tend to overprotect their disabled offspring, especially females, treating them as unable and childlike [26]. These events create a vicious cycle, which increases disabled female's vulnerability to HIV/AIDS. It is clear that the silence surrounding sexuality and relationship matters is due to shame should disabled young people get involved sexually. This leads to fear of reporting any sexual encounter or rape. They may not be able to associate their sexual encounter with the possibility of getting infected; they may also be ignorant about appropriate and inappropriate sexual behaviour and so may view any sexual encounter as normal. They may also not realise when they get infected in order to seek medical help.

In contrast, disabled males are more likely to openly engage in sexual relationships and they also have the liberty to approach women of their choice as stated below:

Mkuseli [male]: *You see, I am disabled and to marry another disabled person, I do not think it is right. She would not be able to help me if I am in trouble ... I need someone who can help me...It has never been in my dream to marry a disabled person.*

Disabled young men were not without their own prejudices as they expressed reluctance to date disabled females, whom they perceived as incapable of performing household chores. Their parents shared similar views:

Parent 5: *I wish him to grow up and get a family of his own ... I like him to get a family ... also disabled, but not physically disabled like him so he can help to push his wheel chair ... it does not matter the disability, deaf at least ...*

The above statement shows how disabled males were advantaged compared to disabled females, who suffered additional discrimination over and above that of being disabled. Females have limited opportunity for dating, thus contributing to their engagement in secret multiple sexual relationships which increase their vulnerability to HIV infection. In addition, economic factors make participants vulnerable of HIV infection. For example, the monthly disability social grant provided by the South Africa government makes disabled young people financially better off than their unemployed non-disabled peers who receive no unemployment grant. This makes them more vulnerable to opportunistic lovers who place them at risk of contracting HIV infection as stated below:

Sizwe: *Yes, there were many guys who came to me ... they were just using me ... they wanted my money [disability grant] and to sleep with me. Then I realised that they did not love me ... they were just using me.*

In addition, most mothers were not in gainful employment. Even those who were employed had menial jobs, which did not pay them well enough to support their families and so they allowed their daughters to go out with men and bring food on the table:

Parent: *I do not have a husband and so I do not have everything that my daughter may need ... so she decides to go and be an 'escort' [mistress] so that she can bring food in this house ... so that is another factor that is increasing the disease.*

Researchers have described the association between transactional sex and HIV/AIDS as a survival strategy for some women [22]. Most mothers raised disabled children alone because fathers tended to walk away once a disabled child was born into the family. Because

of the belief that a man does not produce a disabled child such a birth was considered a woman's 'fault'.

Awareness of HIV/AIDS Risk and Response

In spite of the reported limited access to HIV/AIDS information, some participants were well aware of the nature of HIV, their own vulnerability and that of their peers to the disease, but others were not as illustrated below:

Nonzwakazi: Yes, they [disabled young people] are more at risk because disabled girls like men ... they sleep with many men ... They go to the shebeens [drinking places] and when they are drunk the men take them to their house and sleep there the whole night ... parents do not know until morning because they are also busy drinking at night. Mkuseli Yes, I am at risk of contracting AIDS ... because the girls I have slept with were unfaithful to me.

In the absence of recreation facilities for disabled young people, shebeens were the only places that provided entertainment and pleasure to the old and the young, disabled or not. Along with this form of entertainment was the risk of getting involved in indiscriminate sexual acts or being raped. Although participants said they knew they were at risk of contracting HIV infection, none had been for an HIV test because they were afraid of knowing their HIV status. Apart from the expressed fear, there were no facilities for HIV testing in Nyanga except for the one clinic in the neighbouring Guguletu Clinic, which was inaccessible to many with mobility problems because of distance.

Some young people felt they were not at risk despite their sexual encounters or sexual behaviour as Nomthandazo said:

No ... [I am not at risk] I do not sleep with men. I was once called by a stranger to go to his house ... but I refused ... I told him that I do not know him.

Nomthandazo had said earlier that she had been raped before, which could have placed her at risk of HIV infection, but she did not focus on that risk. Asked if she had thought of going for an HIV test after she was raped, she replied: *No, I am afraid ...* Most participants in the study echoed the same fear, about an HIV test. Others claimed they had no need for an HIV test because they 'trusted' their partners:

Philisiwe: No, I am not at risk because I have one boyfriend and I trust him ... but this does not mean that I cannot get it, I could be unlucky ... Other accidents happen, my sister could be involved in a car accident and I go to help to save her life without putting on gloves ... I can get AIDS.

Sometimes participants tended to rationalise and explain why they did not feel at risk of HIV infection in spite of their involvement in risky sexual behaviour. Even parents shared similar views that disabled young people were not at risk of HIV infection as stated below:

Parent: I do not think my son is at risk because he stays in the house all the time ... I do not see how he can get involved with a girl without my knowledge.

Others demonstrated ignorance of the connection between sexual encounter and their own risk like this participant told her story:

Sipho: *We were just gossiping about him [in the ‘Protective Workshop’] ... people in here said that the man was infected [with HIV] one day the man invited me to visit him in his house to have Christmas with him ... I went because I felt sorry for him. I felt sympathy ... We had Christmas food and after that we slept together. Asked what she meant by sleeping together, she answered, having sex.*

Heedlessness about the seriousness of the disease and lack of negotiating skills placed her in a compromising situation. She did not question the invitation to a meal and neither did she question the sexual encounter she had with a man believed to be HIV positive who has since died. Therefore, Sipho could easily have contracted HIV infection out of ignorance.

In general, the study found that participants whether aware or unaware of their vulnerability to HIV/AIDS did not protect themselves through safe sex. Other studies have shown mixed evidence for a relationship between knowledge and risky sexual behaviour [31, 32] and have suggested that a range of other variables are also important in determining behaviour [28]. In the case of the present study, avoiding risk through negotiating ‘safe sex’ was not part of the discourse among the participants. They claimed they trusted their lovers on the one hand, and felt helpless on the other hand. Issues of survival, like lack of employment, providing for the family or getting pleasure were more important than HIV/AIDS. Others claimed:

Ncedo: *HIV/AIDS is like any other disease, if you are meant to have it, there is nothing you can do’. Parent: If we got information and got enough food ... our children don’t go out and we teach them how to protect themselves.*

This fatalistic attitude is what spurred some participants on. For others, getting food on the table was more important than HIV/AIDS protection.

In the face of full awareness of the danger of becoming infected, disabled young people simply took chances and hoped for the best. Since they had dealt with stigma and prejudice long before they had been aware of sexuality and HIV/AIDS issues, they seemed to take a pragmatic approach to misfortune [21]. Thus it can be concluded that contextualised local knowledge about people’s real life situations is necessary for the identification of barriers to behaviour change within the limits possible.

Conclusion

In this paper, the exploration is limited to the experiences and perceptions of the participant of the current study, focusing on the socio-cultural issues which impact on accessing of sexuality and HIV/AIDS information and services by disabled young people. The awareness and response of disabled young people and their parents of vulnerability to HIV/AIDS is reported. The study has shown that disabled young people in Nyanga have limited factual knowledge about HIV/AIDS. The decisions and choices they make about sexual behaviour are not only informed by what they know; rather, they are part of the whole life situation in the context of Nyanga. It is important to underscore the concept of individual risk behaviour as perceived by disabled young people. Their whole life situation including their need to be loved and accepted, need for job security and family life, are more important than practicing ‘safe sex’. Therefore, it is recommended that sexuality and HIV/AIDS intervention programme developers should take into account the experiences and perceptions of the targeted population, particularly of disabled young people and their parents.

Limitations of the Study

This study focused on physically disabled young people thus may not reflect the experiences of other disability groups. In addition, there were other physically disabled young people who could not be reached because they lived in areas that were considered unsafe due to high crime rate. Thus the qualitative nature of this study does not claim that the results would be generalisable to all people with disabilities in Nyanga. Rather it illustrates the complex ways in which young people with physical disabilities experience and perceive sexuality and HIV/AIDS and how they respond to the threat of HIV.

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