

SHORT REPORT

Secret Languages of Sex: Disabled Youth's Experiences of Sexual and HIV Communication with their Parents/Caregivers in KwaZulu-Natal, South Africa

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Abstract

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 to 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.

Keywords: disabled youth; parents; sexuality; communication; HIV; South Africa

Introduction

Given that the HIV pandemic has had the greatest impact on youth between the ages of 15 to 24 year olds in South Africa, there has been wealth of studies that have explored sexual talk and practices amongst non-disabled youth (Zisser and Francis 2006; Harrison 2008; Lubinga et al. 2010; Gevers, Jewkes and Matthews 2013). In an attempt to curb new cases of HIV infection among young people, there exists a plethora of health promotion strategies in South Africa (such as those of loveLife and Soul City), that aim to encourage young people to talk about sex, relationships and HIV with their parents/caregivers (Paruk et al. 2005; Zisser and Francis 2006; Wilbraham 2008; Soon et al. 2013). These strategies are based on the premise that youth-parent/caregiver communications about sexuality and HIV can play a pivotal role in influencing sexual behaviour and sexual decision-making. For example, studies conducted among non-disabled young people have found that youth-parent/caregiver communication about sexuality increased contraceptive use and delayed sexual debut (Markham et al. 2010; Namisi et al. 2013).

By reflecting critically on these studies and health promotion strategies, it is possible to see that none of them appear to include the experiences of disabled youth and as a result, very little is known about how disabled young people between the ages of 15 to 24 years old communicate about sexuality and HIV with their parents/caregivers. The absence of disabled youth from sexuality studies can be largely attributed to the influence of socio-medical discourses that generally depict young people with disabilities as being unable to perform normative gender and sexual roles due to their impaired bodies and minds (Rembis 2010). Nevertheless, this absence is rapidly being brought into question, especially in the light of the growing body of literature that links the vulnerability of young people with disabilities to HIV (Hanass-Hancock 2009; Groce et al. 2013; DeBeaudrap et al. 2014) and the increasing recognition of the need to provide sexuality education for youth with disabilities (Rohleder and Swartz 2009; Reus et al. 2015).

Using a Foucauldian inspired form of discourse analysis, this paper will examine how a group of Zulu-speaking youth with physical and visual disabilities in KwaZulu-Natal (KZN), South Africa, perceive youth-parent/caregiver communication about sexuality and HIV. I will examine what young people with physical and visual disabilities report their parents say about sex, how these messages are received, and how young people with physical and visual disabilities themselves respond to these messages. In doing so, I aim to provide evidence on which to develop more comprehensive strategies that promote positive sexuality and HIV communication amongst youth with disabilities with their parents/caregivers.

The governmentality of sexuality in Zulu culture

WHO (2002)'s working definition describes sexuality as:

a central aspect of human life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors (5).

As illustrated by the WHO definition, although sexuality is largely perceived as a private and personal discourse, it is, at the same time also public and political. As noted by Foucault (1978), sexuality is governed and shaped in by cultural institutions, laws, religion, schools, hospitals and families. These, Foucault contends, constitute a diverse collection of sites of power/knowledge whereby certain people (e.g. medical practitioners, psychologists, lawyers, politicians, religious leaders, educators, parents) are positioned to enforce regulatory control of our sexual behaviour (Foucault 1978). One of the key aspects of these sites of discourse is to ensure that individuals are effectively incorporated into systems of knowledge and disciplinary practices that privilege particular understandings of sexuality as ‘sexual truths’.

Although individuals are recognised as autonomous agents, these sites of discourse instil modes of self-discipline wherein individuals are able to regulate their own and others’ sexual behaviour, attitudes and actions in line with ‘sexual truths’ (Crowley and Kitchen 2008). This process of critical reflective thought is very much the cornerstone of what Foucault later described as ‘technologies of the self’ (Foucault, 1988). These

permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality (16).

One of the governing technologies used to instil sexual truths is that of sexuality education, which aims to equip young people with the “knowledge, skills and values to make responsible choices about their sexual and social relationships in a world affected by HIV” (UNESCO 2009, 3). Central to the provision of sexuality education is the family, and in particular, parents/caregivers. In line with Crowley and Kitchin (2008, 359), families may be perceived to be a “key social and political sexual site” in which a child’s sexual socialisation begins, and where cultural values and beliefs around sexuality are instilled.

According to Erlank (2004) and Wilbraham (2008), the notion of youth-parent/caregiver sexual communication implies a largely western-centric construct of parenting. Prior to colonisation and the introduction of Christianity into South Africa, the task of youth sexuality education in Zulu culture was not usually carried out by parents, but rather by other elders or older peers in the homestead (Delius and Glaser 2002; Erlank 2004; Harrison 2008). Although highly gendered, sexuality education was governed by customary Zulu practices and rules of sexual conduct, in particular the prohibition of pre-marital penetrative sex (Delius and Glaser 2002; and Buthelezi 2006). Despite the fact that penetrative sex was forbidden, Zulu pre-colonial culture still recognised the hormonal changes and strong passions that arise during puberty and allowed young people to engage in non-penetrative forms of sexual activity such as fondling and *ukusoma* or thigh sex (Delius and Glaser 2002). These customary practices meant Zulu-speaking young people were able to align their behaviour, attitudes and actions with culturally acceptable standards. In this context, Rose, O’Malley and Valverde (2009, 20) assert that “culture in itself could be analysed as a set of technologies for governing habits, morals and ethics for governing subjects”.

The introduction of Christianity and the rise of colonialism and migrant labour during the late 19th and early 20th century began to alter family structures, cultural practices and ultimately, change sexual communication in Zulu society. As indicated by Erlank (2004),

Christian missionaries sought to eliminate those practices which they classed as primitive or backward such as puberty ceremonies, *ukusoma* and virginity testing, and introduced the notion of parents (mainly mothers) as the providers of sexuality education (1). In this analysis of the hegemonic discourses of Christianity and colonialism, I contend that the intersection of 'race' with sexuality, created the African sexual subject and their practices as fundamentally 'other'. As captured in the words of Reid and Walker (2005: 186), "images of African sexuality as pathological, perverse and primitive construct the sexuality of the European in opposition as healthy, normal and civilized".

Youth-parent/caregiver sexual communication in Zulu culture

Regardless of the influence of Christian doctrine and emergent HIV prevention campaigns that urge parents/caregivers to "love [their children] enough to talk about sex" (Francis 2013, 4), many Zulu-speaking parents still do not discuss sexual topics with their teenage children (Buthelezi 2006; Wilbraham 2008). This silence has been attributed to the role of colonialism and apartheid in eroding family structures due to enforced migrant labour (Posel 2004). According to scholars such as Erlank (2004), Paruk et al. (2005), Phetla et al. (2008) and Goodnight et al. (2014), initiating discussion on sexuality education with their immediate offspring, is a difficult process for many parents/caregivers who see it as a violation of cultural traditions and norms. Moreover, Paruk et al (2005) report that many Zulu-speaking parents felt their parental authority and cultural norms are being eroded by government and media acceptance of Western cultural sexual messages. In this respect, Zulu-speaking parents (mostly mothers) living in rural and peri-urban areas often report feeling disempowered and unable to assist their children in developing positive sexual ~~practices~~ identities (Paruk et al. 2005). The main reported reason for this feeling was the generational knowledge gap between parents and young people, with parents in particular being (or feeling) less educated (Paruk et al 2005, 60).

Looking at youth-parent/caregiver sexual communication from the perspectives of young people themselves, studies in South Africa indicate that non-disabled youth are often reluctant to talk to their parents/caregivers about sexuality for a number of reasons. For instance, Soon et al. (2013) and Campbell and MacPhail (2002), for example, found that young people living in peri-urban areas of Johannesburg, did not initiate sexual talk with their parents/caregivers due to fear of angry or violent reactions. Besides violent reactions, Leseko (2007) found that young people also reported difficulties in discussing the messages portrayed by youth-focused HIV campaigns such as loveLife, with their parents/caregivers. These difficulties were accentuated by their parents/caregivers' beliefs that these messages only advocate for young people to engage in sex.

Disabled youth-parent/caregiver sexual communication

Even though youth-parent/caregiver sexual communication is generally governed by cultural norms, the situation for disabled youth is further compromised by hegemonic socio-cultural beliefs surrounding disabled sexuality. For instance, not dissimilar to more general constructs of African sexuality, the discourse of disabled sexuality has been subject to similar ahistorical and apolitical disregard. Specifically in relation to South Africa, there still remains a silence surrounding the public discourse of disabled sexuality (Chappell 2013). Popular notions of disabled sexuality have been formed within a medical paradigm that constructs people with disabilities in terms of "deviance, lack and tragedy" and/or as victims of impairment (Corker

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and Shakespeare 2002, 2). In this context, the wider non-disabled community has made assumptions that people with physical and sensory disabilities are typically non-sexual and incapable of sexual feelings and relationships.

This subjugation of disabled sexuality has played a significant role in the governmentality of sexuality amongst young people with disabilities. This is evident in the fact that young people with disabilities are generally discouraged by parents/caregivers from engaging in discussions around sex and relationships (Reus et al. 2015). For instance, in a study conducted in the Northern Cape, Sait et al. (2011) found that the mothers of girls with intellectual disabilities ignored their daughters' attempts to talk about issues of a sexual nature. What is more, the majority of the parents perceived sexuality education as consisting only of discussing the sex act, which they believed was inappropriate for their disabled daughters (Sait et al. 2011). Similar findings were reported in studies by Wazakili et al. (2006) and Maart and Jelsma (2010), who found that parents of young people with physical disabilities in the Western Cape limited sexual talk with their disabled offspring, believing them to be asexual and not in need of sexuality education. Likewise, McKenzie (2013) found that Xhosa-speaking parents of disabled youth in the Eastern Cape were reluctant to talk about issues of sexuality due to doubts about disabled young people's sexual and reproductive capacities.

Separate from these doubts concerning youth with disabilities' sexual capacities, Milligan and Neufeldt (2001) contend that the reluctance of parents to talk about sex may be further attributed to their efforts to protect disabled young people from future rejection and vulnerability to sexual abuse. This is of particular relevance to the South African context where sexual violence is rife and where, according to Hanass-Hancock (2009), children and youth with disabilities are two to five times more likely to experience sexual abuse than their non-disabled peers.

In analysing the reluctance of parents of disabled youth to discuss sexuality, the evidence clearly demonstrates that many parents in South Africa perceive young people with disabilities as innocent, sexually passive and unable to exercise sexual agency. Although this is not too dissimilar to the experiences of non-disabled youth, sexuality is not seen as a significant part of the lives of disabled young people as they grow up. In the light of this, such perceptions perpetuate ableist constructs of disabled sexuality. Despite studies looking at parents of disabled young people's perceptions of sexuality education (Reus et al. 2015; Sait et al. 2011), very few studies have actually examined how disabled youth themselves experience or perceive youth-parent/caregiver sexual communication. The present study therefore set out to address this gap.

Methodology

This study aimed to investigate how twenty-two, 15 to 20 year-old Zulu-speaking young people with physical and visual disabilities bring into discourse issues surrounding love, sex, relationships and HIV in their conversations. This paper focuses specifically on how these discourses unfold in participants' conversations with their parents/caregivers. In recognition of young people with disabilities as sexual beings and as social agents (Chappell et al. 2014), three of the young participants were trained as co-researchers before commencing data collection. The one-week training workshop, which was conducted by myself, included sessions on confidentiality and informed consent, different types of questioning, listening and

communication skills, ethical considerations in conducting research and practical skills in using a tape recorder for data collection.

The co-researchers (2) and I undertook the study in the uMgungundlovu district in KwaZulu-Natal (KZN) South Africa. The district, which is made up of seven local municipalities, has an approximate population of just over 1 million people, of which 42.7% are between the ages of 15 to 24 years (Statistics South Africa 2012, 4). Although there are no available statistics for the number of people with disabilities in the uMgungundlovu district, recent prevalence data estimates that approximately 8.4% of the population in KZN may be classified as having a disability compared to the national prevalence of 7.5% (Statistics South Africa 2014, 57). The majority of the occupants in the district are Zulu and the main languages spoken are isiZulu and English. The uMgungundlovu district is also characterised by one of the highest rates of HIV infection at 16.9% compared to a national prevalence of 12.2% in 2012 (Shisana et al. 2014, 36).

The study adopted a qualitative methodology and used a participatory research design. As part of the data collection process, I carried out initial focus group discussions with the co-researchers. However, the co-researchers were responsible for carrying out four single-sex and one mixed-sex focus group discussions and a total of four individual interviews with the other young disabled participants, as well as being involved in some aspects of the data analysis of this study. Interview questions were developed in partnership between the co-researchers and myself for both the focus group discussions and interviews.

Participants

Through the use of purposive sampling, co-researchers and participants were selected according to their age (between 15-20 years), type of disability (visual and physical), and geographical location. The three co-researchers, who all had varying degrees of physical impairment, were made up of two young women, aged 17 and 20, and one young man, aged 15. The nineteen participants consisted of nine young women and ten young men with an average age of 18 years. Fourteen of the participants identified themselves as having visual impairments (6 female, and 8 male) and the other five participants (3 female, and 2 male) identified as having a physical impairment. In terms of geographical location, the co-researchers and participants all came from rural communities in the uMgungundlovu district.

Co-researchers were randomly selected from amongst participants who attended local HIV and sexuality workshops, which I had facilitated prior to the study. Not only did this mean they were already familiar with talking about sexuality and HIV, but they also had some familiarity with myself as principal researcher. According to Christensen (2004), this establishment of early relationships with young co-researchers is essential so as to ensure their involvement throughout the research process. The other young disabled participants were identified by both the co-researchers and myself from within the uMgungundlovu district.

Ethical considerations

Before commencing data collection, an informed consent form and letter describing the study were distributed to and signed by both the young participants and their parents. Participants younger than 18 years were only included if both they themselves and their parents had signed the consent form.

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The co-researchers and participants each chose pseudonyms in order to protect their confidentiality and anonymity during the analysis and write up of the research. Although it was not needed, if any of the participants had needed support in dealing with any sensitive issues that arose from this study, they would have been referred to local service agencies such as social workers or Childline.

Data analysis

All the focus group discussions and interviews were translated and transcribed by a professional transcriber from isiZulu to English. The transcripts were verified by the co-researchers. Data were initially analysed using content analysis in order to categorise the data into themes and highlight significant findings in relation to the research question. Following this, I then applied a form of Foucauldian discourse analysis, which involved examining issues of power and cultural ideologies within the text.

Findings

The findings below outline how young participants perceive their communications about love, sex, relationships and HIV with their parents/caregivers. Through their discussion, the participants did not see their relationships with their parents/caregivers to be any different to that of their non-disabled siblings or peers.

Generational gap with parents/caregivers over sexual knowledge

Throughout the findings, most of the participants reported great difficulty in talking to their parents/caregivers about issues of love, sex and relationships. Most of these difficulties related to the perceptions both parents/caregivers and youth with disabilities have of each other. For instance, according to the participants, the reasons why parents/caregivers do not talk to them about love, sex and relationships is due to their perceptions that young people are too young to understand or even talk about these issues:

Professor: It is difficult to talk to your parents about this [sex] because they may ask me where I learnt about these things at my age (Male, 15 years old, visual impairment).

Thandeka: My aunties would say to me “what do you know, what is it that you know, what is a boy, a young person like yourself doesn’t go anywhere near a boy”...They say I should forget about boys for now, I am still too young to even think about them. They would ask me “what do you know about love, what kind of a person would you say you love? You do not love anyone; you only love your mother” (Female, 19 years old, visual impairment).

Although participants’ reported that parents/caregivers tended to perceive young people as being too young to learn about sexual matters, most participants perceived their parents/caregivers as being too old and lacking in knowledge and experience when it comes to love, sex and relationships. They blamed their parents’ lack of sexual knowledge and inability to talk about sex and relationships on past cultural practices, which they believed were enshrined in a discourse of sexual secrecy:

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Mavela: But I don't talk to my parents because they are so ancient. They haven't explored issues of sex extensively and they practice what was done to them by their elders. Meaning they were told not to talk about sex as children and they also believe that we shouldn't (Male, 17 years old, visual impairment).

Phumzile: It's something that you shouldn't talk about. I don't know why but sex is something that you shouldn't talk about, something that's secret – that's just the way they [parents] are thinking. I think it's a secret because our parents were raised not talking about that, their parents never talked about sex to them (Female, 20 years old, physical impairment).

The cultural significance of ukhlonipha (respect)

Besides this veil of secrecy around sexuality, many participants also highlighted another reason for not talking about love, sex and relationships with their parents, which linked closely to the discourse of *ukhlonipha* – isiZulu for respect. According to Rudwick (2008), *ukhlonipha* reinforces “a complex value system based on the social variables of age, status and gender” (155). Because of this, for young people to talk about issues of love, sex and relationships with their parents or elders was perceived as disrespectful:

Professor: I don't talk to adults and my parents about these issues [love and sex] because as a child I can't just go and talk to adults about this and *vice versa* (Male, 15 years old, visual impairment).

Mbali: In my situation at home, my sister was telling me about her boyfriend while my mum was sitting outside. My mum said “it is very rude for you to talk about this while I am sitting right here, can't you move away and then talk. You are so disrespectful!” (Female, 17 years old, physical impairment).

Tomololo: If or when you try to talk to some of them [parents] about it [sex] they say “no, no, no I am not your friend for you to talk to me about such things, go and talk to your friends” (Female, 20 years old, visual impairment).

Secret languages of sex s and 'knowledgeable' friends

In response to parents/caregivers' silence and the influence of *ukhlonipha*, participants reported having developed their own secret language with peers and siblings to talk about love, sex and relationships:

Tomololo: Me and my eighteen year-old brother have a secret language we use at home when we talk about love. We twist words around, for example if I want to say 'Babu' I would say 'Luba'. We also do the same thing at school when we talk and we don't want adults to hear what we are talking about (Female, 20 years old, visual impairment).

[Nokuthula](#): If I am with a friend and I want to remain behind with a boyfriend and I don't want adults to hear I would say "ziyachusha", meaning I am not going with the friend but I am staying with the boyfriend and my friends shouldn't stay (Female, 17 years old, visual impairment).

Some participants also reported having secret words for discussing HIV as demonstrated in the following dialogue:

Spha: Are there any secret words you use when talking about HIV? (Male, 15 years old, physical impairment).

Tomololo: "OMO" because the word HIV has three letters like the word OMO (Female, 20 years old, visual impairment).

Thandeka: We call it "Hlengiwe Ivan Vilakazi" – We use the letters that spell HIV (Female, 19 years old, visual impairment).

Professor: I use the word "qhoks" because it attacks any part of the body it wants to attack (Male, 15 years old, visual impairment).

Dudu: I also know it as "qhoks" (Female, 18 years old, physical impairment).

From my discussions with co-researchers, it became clear that these secret languages are only understood by other young people, both disabled and non-disabled alike. This was also confirmed by the adult who translated and transcribed the transcripts who was unable to translate the 'coded' words used by the young participants. As illustrated by the following quotation from one of the female co-researchers, young people often use this secret language to discuss issues of love, sex, relationships and HIV in the presence of their parents/caregivers, thus re-positioning notions of *ukuhlonipha*:

[Phumzile](#): It's pretty obvious why we use different words. As uS'pha has said before that it causes a problem. It would seem like you are not respecting your parents and you are being rude, telling about that kind of stuff in front of them. So it's understandable why we use a different word. It's more or less the same kind of language that everybody uses but with changes here and there so that the parents do not understand (Female, 20 years old, physical impairment).

Given the existence of this secret language and the generation gap between young people and their parents, it was no surprise to find that most participants perceived their peers as being more knowledgeable and experienced about love, sex, relationships and HIV compared to their parents:

[Nokuthula](#): I need to talk to people of my age like my friends and my boyfriend... Maybe it's because they are my age and because they are more knowledgeable about sex since they also do some of these things (Female, 17 years old, visual impairment).

Professor: Our parents know about things but they may not know much about HIV, but our friends know more about HIV and it's easier to talk with them (Male, 15 years old, physical impairment).

Thandeka: I think it's better to talk to friends about love and relationships because they might have gone through difficult times around these things and I maybe haven't gone through those things myself. They can warn me not to do these things because I will end up with such results (Female, 19 years old, visual impairment).

Even though most participants reported their peers to be more experienced and knowledgeable about sexuality and HIV, some of them had reservations about the information that was being shared amongst peers. As a result, some participants expressed a desire to receive information on love, sex, relationships and HIV from their parents/caregivers as demonstrated in the following quotations:

Marius: There should be a way for them [parents] to talk to us about this because at the end of the day we get information from outside and it may not be the correct information (Male, 18 years old, physical impairment).

Discussion

Reflecting on study participants' perceptions of youth-parent/caregiver sexual communication, it is clear that a dualistic relationship exists, mainly driven by the generational gap between the participants and their parents/caregivers, and notions of cultural hegemony. For instance, despite participants' age, young people reported their parents/caregivers thought they were 'too young' to talk about sexuality and HIV. Participants' parents/caregivers construct young people as 'children' in need of protection rather than young people who, in accordance with Mitchell et al. (2004), "have the right to relevant information about their own bodies and their sexuality" (36). Seen in the light of findings from other studies amongst non-disabled youth in South Africa (Mitchell et al. 2004; Morrell, 2003), this protection of 'innocence' as a means of avoiding youth-parent/caregiver sexual communication is not just unique to young people with disabilities. However, efforts to protect innocence are accentuated for youth with disabilities because it is believed that sex will never be part of their lives (McKenzie, 2013; Sait et al. 2011). This silence surrounding sexuality not only reflects adultist constructs of young people, but also perpetuates ableist constructs of disabled sexuality. Moreover, it demonstrates a general disregard to recognising the sexual agency of young people with disabilities. As argued by Coppock (2010), such discourses of silence and protectionism do nothing more than "skilfully disguise a fundamental distrust in young peoples' competence" (439).

In contrast to the above, participants interpreted their parents/caregivers avoidance of sexual communication as a lack of competence and knowledge surrounding sexuality and HIV. These findings reflect what Paruk et al. (2005) have described as a generational knowledge gap between parents and young people, with parents being less educated than their children. As demonstrated in the findings, this gap led to some participants constructing their parents as 'ancient' or 'inexperienced' in the realm of sexuality and HIV in comparison to their peers. In the face of such a response, Paruk et al. (2005) have suggested that some parents subsequently draw upon unhelpful parenting styles (i.e. silence or anger) to

compensate for the disempowerment they feel. Although parents' refusal to talk about sexuality maintains their power and authority, it hides their disempowerment and lack of skills when it comes to talking to young people about sexuality (Preston-Whyte 2003).

Repositioning cultural customs of sex talk in families

Besides the generation knowledge gap, it is clear from the findings that participants felt youth-parent/caregiver sexual communication is also limited by the cultural custom of *ukuhlonipha*. Participants' conversations about *ukuhlonipha* demonstrate how cultural customs such as this continue to play an influential role in governing sexual communication in Zulu culture for both disabled and non-disabled youth. Despite this, individuals are autonomous agents who are capable of resisting dominant discourse (Foucault 1988). This is clearly portrayed by the participants' development of secret sex languages, which they use with their peers in the presence of their parents and other adults. By critically examining the development and use of this secret sex language, it is not only possible to see the emergence of a counter-discourse to cultural customs of *ukuhlonipha*, but also participants' resistance to their parents' perceptions of them being 'too young' to talk about sexuality.

Even though the use of a secret sex language demonstrates participants' ability to reposition cultural customs, the discourse of 'secrecy', however, continues to perpetuate adult constructs of sexuality as matters that need to be hidden (Preston-Whyte 2003; Harrison 2008). In this respect, it might be suggested that participants, along with their peers, have created their own hidden world, which essentially, is closed off to their parents. Within this hidden world, although participants report their peers as being 'more knowledgeable' about love, sex, relationships and HIV in comparison to their parents/caregivers, it is clear some participants have reservations about the information shared within their peer groups. The use of secret sex languages may therefore create what Preston-Whyte (2003, 91) describes as "sites of danger and vulnerability". For example, participants are left to interpret their own emerging sexual feelings with their peers, which as Wazakili et al. (2006) contend, may leave them more susceptible to pressure to experiment dangerously with sex. In the absence of positive disabled role models and the need to 'fit in' with their non-disabled peers, Johnstone (2004) suggests that some young people with disabilities may overcompensate for their differences. Although this was not explicitly identified in the findings, one of the co-researchers explained to me that from her experience, young people with disabilities often feel they have more to prove when meeting with non-disabled peers. As a result, this may lead some to practise unsafe sex in an attempt to prove their self-worth.

Conclusion

This participatory study set out to investigate how a group of Zulu-speaking young people with physical and visual disabilities perceive youth-parent/caregiver communication about love, sex, relationships and HIV. In recognition of young people with disabilities as active social agents, the study took a unique position by training three of the twenty-two participants as co-researchers. Study findings highlight how regulatory control by adults seeks to curtail the sexual agency of young people with disabilities. While dominant discourses of 'youth' and 'disability' aim to reinforce power relations between adults and young people as well as between disabled and non-disabled persons, the development of secret sex languages demonstrates young people's resistance to parental and caregiver efforts at control. Young people with disabilities' perceptions of sex, sexuality and relationships are critical to efforts

to more adequately educate parents/caregivers about message content and communication to help disabled youth make sense of love, sex, relationships and HIV. To achieve this, however, educational programmes are needed for parents/caregivers of youth with disabilities. From their outset, these educational programmes must recognise young people with disabilities as 'capable social agents' and not just innocent vessels when it comes to sexuality and HIV.

Footnotes

1. The idea of mothers providing sexuality education only applied to children younger than six. Once they were of school going age, the task of sexuality education was taken over by the school.

2. [The co-researchers were Mfana Dlamini, Nompilo Nkala and Balu Mbeje.](#)

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