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Addressing the sexual and reproductive health needs of young adolescents living with HIV in South Africa

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ABSTRACT

Adolescence, especially early adolescence (10–14 years) represents an important opportunity to assist children infected with HIV in developing positive behaviours that will safeguard their health and the health of others. In particular, by reaching such children before they become sexually active, programmes that build awareness of sexual and reproductive health issues can play a valuable role in preventing further spread of the disease, reducing the risk of reinfection and drug resistance and avoiding the chance of infection with another STI.
Our study examines programmatic approaches to the sexual and reproductive health of very young adolescents (VYAs). It engages VYAs themselves as an important source of information. Further, it seeks the views of service providers concerning the sexual and reproductive health issues of VYAs. Findings from the study suggest that HIV positive children in early adolescence are poorly informed about sexual and reproductive health matters. There is a strong need for programmes that can address a range of concerns specifically related to their illness as well as to broader issues that arise in the context of this developmental stage. However service providers do not feel confident to inform and educate young adolescents and lack the resources to guide and assist them. To address this gap study findings informed development of a resource for healthcare providers working with HIV positive VYAs in clinic and community settings.

1. Introduction

The fight against HIV and AIDS in Africa has focused attention on the sexual and reproductive health of adolescents, with prevention of HIV transmission identified as a core component of most programmes. There is a plethora of prevention-focused tools and resources aimed at helping adolescents to maintain sexual and reproductive health (SRH) and growing interest in early adolescence as an effective period for intervention (Dixon-Mueller, 2009; Institute for Reproductive Health, Georgetown University, 2010; Tylee, Haller, Graham, Churchill, & Sanci, 2007; UNAIDS, WHO & UNFPA, 2004; WHO, 2010, WHO, 2011).

Whilst the benefits of targeting adolescents generally is acknowledged and will be discussed briefly, attention is devoted to the SRH of a growing number of young people living with HIV, in particular the needs of young HIV positive adolescents (10–14 years) who were infected through mother-to-child transmission of the virus.

Adolescents growing up in South Africa face a host of social problems including poverty, violence, alcohol and drug abuse, and the disintegration of family life (Brook, Morojele, Zhang, & Brook, 2006). Despite the socio-economic context however many young people remain optimistic about their future and have a strong need to free themselves from poverty and fulfil their aspirations (Steyn, Badenhorst, & Kamper, 2010).

Whilst structural interventions are necessary recognising and responding to these needs call for a focus on programming that can help young people to safeguard their own health and that of others. Studies show that a significant number of young people in South Africa engage in unprotected sex, and that 39% of 15–19 year-olds are pregnant at least once. One in five pregnant adolescents is HIV positive (Department of Health, South Africa, 2011; Reddy et al., 2008).

In South Africa an estimated 460 000 children below the age of 15 were living with the infection in 2011 (UNAIDS, 2011). Around 152 000 were receiving antiretroviral therapy (Johnson, 2012). With HIV testing and increased access to treatment the number of children reaching adolescence is likely to escalate.

The importance of interventions that can improve the wellbeing of adolescents living with HIV is clear and is reflected in the country's National Strategic Plan (NSP) for HIV and TB, 2012–2016. The NSP not only prioritizes young people as a high risk group but also calls for increased access to a package of sexual and reproductive health services by young people living with HIV (Department of Health, South Africa, 2011).

Likewise, the national Adolescent and Youth Health Policy currently being developed in South Africa draws attention to the need for specific programmes that can support perinatally infected adolescents (Department of Health, South Africa, 2012). Sexual and reproductive health is the cornerstone of such initiatives. However, a scarcity of materials that can serve as a guide for service providers working with young HIV positive adolescents represents a potential stumbling block in the implementation of developmentally appropriate SRH programmes.

Early adolescence is a particularly important time since it offers a window of opportunity for intervention before sexual debut and the establishment of gender norms and attitudes that can impact negatively on sexual and reproductive health (Palmer, 2010; Yotebeing, Halpern, Mitchell, & Adimora, 2009).

Very young HIV positive adolescents face a number of challenges related to their status (Birungi et al., 2008; Fielden et al., 2006). These can include delays in puberty, fears related to status disclosure and treatment concerns (Rudy, 2005). Finding out what they know and believe about their bodies and sexuality is the key to designing

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programmes that can satisfactorily address their needs and help them maintain sexual health (Dago-Akribi & Adjoua, 2004; Dixon-Mueller, 2009).

However, relatively little is known about the sexual and reproductive health concerns of children in this age group, and few studies have asked them about their sexual and reproductive health needs. The active participation of young people is a fundamental aspect of the study which is underpinned by a rights framework. As an international priority, participatory programming is a key to the provision of appropriate and sustainable services for children and adolescents and is an integral part of legislation that seeks to protect and fulfil the rights of children in South Africa (Abrahams & Mathews, 2011).

Our study sought the opinions and concerns of very young HIV positive adolescents (VYAs) attending adolescent programmes at two sites in South Africa. In support of policy frameworks a central objective was the development of a sexual and reproductive health resource that could be used in work with this sub-population. Informed by VYAs and healthcare professionals the resource aimed to equip young people with the knowledge and skills required for positive sexual and reproductive health outcomes.

2. Methods

2.1. Sample strategy and participants

Very young HIV positive adolescents (10–14 years) who participated in adolescent programmes were invited by programme staff to join focus group discussions (FGDs) at two clinics in South Africa. An urban site, situated in Alexandra Township, Gauteng, one of the most overcrowded townships in South Africa was identified together with a rural clinic located in Groblersdal, Limpopo Province, which ranks amongst the poorest of the country's nine provinces.

The focus group method of data collection is regarded as a valuable means of obtaining children's views on sex, sexuality and HIV (Heary & Hennessy, 2002; Jankie, Geregau & Tsheko, 2011). In line with the aims of the study, some important benefits of this approach were removal of the emphasis on adult–child relationship that can occur in individual interviews, less pressure to respond and the opportunity to acknowledge young participants as valued experts whose opinions count (Heary & Hennessy, 2002; Peterson-Sweeney, 2005).

A total of 27 children (10–14 years) participated in FGDs: 17 girls and 10 boys. Nine children were from a rural facility and 18 from an urban clinic. The majority of children were between 12 and 14 years of age. All were attending either primary or secondary schools in the two areas.

All of the children who participated in FGDs knew their HIV status.

Nine service providers participated in in-depth interviews at the two sites. Interviews were conducted with various members of the paediatric team supporting an urban clinic in Alexandra Township, Gauteng. They included two doctors, a social worker and two counsellors. A doctor, nurse, social worker and counsellor participated in interviews at the rural clinic in Limpopo Province.

Service providers who were involved in adolescent programmes at the two clinics were given the option of participating in one-on-one face-to-face or telephonic interviews.

2.1.1. FGD and interview procedure

On average the focus groups lasted about 80 min. Amongst other questions, participants were asked about body changes, what they thought about these and what they felt young people might need to know. Their views were sought on romantic relationships together with their thoughts about sexual and reproductive health services for adolescents.

A range of activities was selected to encourage participation. Puppetry, story-telling and the use of drawings of hypothetical figures were all utilised before discussion as a non-threatening means of obtaining information around different topics (Vincent, 2008). For example, male participants were given the outline of a male figure who the facilitator named as “Lebo”. The group was then asked to fill in any physical changes that they thought “Lebo” might be experiencing and to say how he might have felt about these.

Prior to the FGDs written informed consent for participation and electronic recording was obtained from the parents or caregivers of the children using their preferred language (Zulu or English). Participants gave informed assent using forms written in child-friendly language (Zulu and English) with programme staff helping to read through the documents where necessary. At each site, separate FGDs were run for males and females. These were facilitated by a same sex facilitator in the participants' preferred language and recorded electronically. The participants each received taxi fare to cover the cost of transport to and from the clinic.

One-on-one interviews with healthcare providers lasted between 60 and 90 min and were recorded electronically. Informed consent was obtained from each participant prior to administering a standardised semi-structured questionnaire that was informed by a review of relevant literature.

The research protocol was reviewed and approved by the Human Research Ethics Committee of the University of the Witwatersrand, South Africa.

2.2. Research challenges

The relatively low numbers of HIV positive children who have been told their HIV status influenced recruitment, particularly in rural Limpopo province, where over 70% of the HIV positive children attending the clinic did not know their HIV status. The reluctance of parents and caregivers to disclose to a child his or her HIV status is common (Kouyoumdjian, Meyers, & Mtshizane, 2005; Li, 2009) and represents a considerable challenge in the provisioning of sexual and reproductive health programmes for VYAs who are HIV positive.

Since chronological age is not a reliable indicator of cognitive ability or reproductive maturation, an important challenge was to enable the participation of all the young adolescents in the FGDs. The capacity of the children to engage and participate differed considerably. To some extent this was addressed by employing a variety of different approaches that could accommodate the varied abilities and styles of communication of children in this age group. Whilst these activities were well-received, participants were particularly responsive when given the chance to anonymously write and submit questions about sexual and reproductive health to the facilitator.

The provision of refreshments was an important consideration. Since FGDs could only take place after school, in the afternoon, the children were tired and hungry by the time the groups commenced. In rural Limpopo, children had often travelled long distances and needed refreshments prior to starting the FGDs. Despite these challenges, the groups provided children with a brief opportunity to participate in activities outside the limitations of their normal lives, to express their concerns and have their opinions taken seriously.

2.3. Analysis

Thematic analysis was used to identify themes and patterns emerging from a distillation of interviews and FGD transcripts. This allowed for a particularly rich description of the data (Braun & Clarke, 2006).

Audio recordings of FGDs were transcribed by the group facilitator who checked for accuracy against the tape recordings and translated from Zulu into English where necessary. Tape recordings of one-on-one interviews with service providers from the two clinics were transcribed and checked by the interviewer using the audio recording to ensure accuracy. All the interviews were conducted in English.

The process included a thorough reading of the data set to ensure complete familiarisation with the content and repeated readings prior to coding, where interesting features of the data were categorised into various themes and sub-themes.

As a final step, names for each theme were formulated, and particularly illustrative and compelling extracts identified for use in the final report. These extracts reflected the research question and literature findings (Attride-Stirling, 2001; Braun & Clarke, 2006).

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