ZAMBIA HIV Leadership through Accountability

Advancing the Sexual and Reproductive Health and Human Rights of People Living With HIV

An Exploratory Study of the Sexual and Reproductive Health Needs and Rights of Adolescents Living with HIV in Lusaka

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Network of Zambian People Living with HIV/AIDS (NZP+)

GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

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Acronyms

ASRH	Adolescent Sexual Reproductive Health
ART	Antiretroviral Therapy
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
ARVs	Antiretrovirals
CSO	Central Statistics Office
FGD	Focus Group Discussion
GNP+	Global Network of People Living with HIV
HIV	Human Immunodeficiency Virus
IPPF	International Planned Parenthood Federation
MOH	Ministry of Health
NAC	National AIDS Council
NZP+	Network of Zambian People Living with HIV/AIDS
PLHIV	People living with HIV
PMTCT	Prevention of Mother-To-Child Transmission
RTI	Reproductive Tract Infection
SRHR	Sexual Reproductive Health Rights
STI	Sexually Transmitted Infection
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
WHO	World Health Organisation
ZDHS	Zambia Demographic and Health Survey

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The Advancing the Sexual and Reproductive Health and Human Rights of People Living With HIV: A Guidance Package is one of five evidence-gathering tools being implemented through the HIV Leadership through Accountability programme. The programme combines specific HIV evidence-gathering tools, national AIDS campaigns and targeted advocacy to achieve Universal Access to prevention, treatment, care and support. For more information about the HIV Leadership through Accountability programme please visit www.hivleadership.org.

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Executive Summary

With improved access to treatment for people living with HIV, many are now able to live longer. As a result, there is growing interest in overall quality of life issues. In many countries, attention is increasingly being drawn to the unique and often neglected needs of different sub-groups including young people. This exploratory qualitative study sought to examine the sexual and reproductive health (SRH) needs, concerns and barriers to accessing related services for adolescents aged 10-19 years living with HIV in Zambia.

Methods

The study was conducted in five residential areas of Lusaka, Zambia. The techniques employed to collect data include a desk review of relevant policy documents and reports, focus group discussions and in-depth interviews with several respondents using respondent-specific interview guides. In total, 42 respondents including adolescents, parents and guardians, service providers and policy makers participated in the study.

Key Findings

- Policies and guidelines specifically targeting the SRH needs and concerns of adolescents living with HIV are lacking.
- HIV-related stigma and discrimination are common complaints among adolescents living with HIV. These affect adolescents' willingness to disclose their HIV status and their uptake of SRH services.
- The needs and concerns of adolescents living with HIV are numerous. Understanding their puberty signs and fear of infertility in adulthood are some of the challenges that affect even those adolescents who are not sexually active.
- Peers are the most important source of SRH information and advice for adolescents in this study setting. Although they regard it as inadequate, adolescents also appreciated the information obtained in school.
- Adolescents living with HIV face a number of barriers in accessing SRH information and services. Among the provider-related barriers are concerns about privacy and confidentiality within the health facility.
- Living with HIV does not hamper adolescents' future aspirations to found families and having biological children. Many of the adolescents in the study are aware that they have the right to do this.
- Parents and guardians of adolescents living with HIV rarely discuss SRH matters with their adolescent children. Underlying factors for this phenomenon include restrictive cultural norms and the inadequate information on the part of the parents themselves.

Recommendations

Addressing the SRH needs of adolescents living with HIV in Zambia cannot be left to the health care system or community alone. Recognizing this and in light of the findings of this study, the following recommendations are made:

- All stakeholders involved in the promotion of the sexual and reproductive health of adolescents living with HIV should advocate for the formulation of supportive policies and laws. An important starting point in this process is research such as this that builds a credible evidence base to inform the revision of the relevant policies, protocols and laws currently in place.
- Service providers and community members should promote the establishment of adolescent support groups. This would enhance the accuracy and accessibility of peer-provided SRH information.
- Where feasible and acceptable, steps should be taken to integrate ASRH and HIV services to improve their uptake by adolescents living with HIV.
- Interventions aimed at improving access to SRH information should incorporate components designed to equip parents and guardians with the knowledge and skills they need to provide such information to their HIV positive adolescents.
- At the health facility level, high quality, non-judgemental counselling and related services should be more readily available. This requires the provision of adequate SRH supplies, commodities and service providers trained to address the unique SRH needs of adolescents living with HIV.
- Interventions designed to challenge stigma and discrimination within the community and health facilities should include components designed to raise awareness of the sexual and reproductive health rights of people living with HIV, including adolescents.
- Health facilities providing youth-friendly services should consider involving adolescents living with HIV in the planning, design and delivery of such services.
- The findings presented and discussed in this report are based on a qualitative study and are, therefore, limited in generalisability. A follow-up quantitative study with a bigger, randomly selected sample is recommended as a way of adding breadth to the ASRH issues identified.
- This study focuses mainly on in-school adolescents in an urban setting. Similar studies should in future be extended to cover out-of-school adolescents and those in rural settings.
- Follow-up studies to identify the preferred package of integrated HIV and SRH services from the perspectives of prospective clients should be conducted.

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Introduction

According to the United Nations Population Fund (UNFPA), the term “adolescents” refers to boys and girls between the ages of 10 and 19 (UNFPA, 1998). For many people, adolescence marks a journey from childhood to adulthood that is characterised by considerable biological, physical and cognitive changes. Exploration of one’s sexuality and engaging in risky sexual behaviour are not uncommon for young people in this phase of life; making adolescence a period of vulnerability as well as opportunity. Viewed through the prism of the life cycle, the sexual and reproductive health (SRH) needs and concerns of an individual change with time from infancy to late adulthood, irrespective of HIV sero-status.

The effects of episodes of sexual or reproductive ill-health suffered during one phase of the lifecycle sometimes persist and can substantively affect later stages of one’s life. For instance, complications from an unsafe abortion during adolescence can result in life-long infertility for women. Similarly, untreated sexually transmitted infections (STI) suffered during childhood can potentially cause adverse reproductive outcomes for some men and women.

Coping with HIV infection can be a difficult aspect of life for young people as well as adults. For adolescents living with HIV, the normal challenges of this crucial growth phase are often compounded by HIV-related stressors including disclosure, fear of death, social exclusion and anxiety about future relationships.

Globally, about 33.4 million people were living with HIV as of 2008 (UNAIDS, 2009). In 2007, the number of children below age 15 living with HIV was estimated at 2 million throughout the world. An estimated 430,000 new HIV infections occurred in this age group in 2008 (UNAIDS, 2009). Most of these new infections are believed to have been perinatally acquired. Although a number of countries have reported declining HIV incidence, especially among young people, the prevalence among this population remains relatively high for particular regions, including sub-Saharan Africa. Figure 1.0 highlights the situation in selected southern African countries that have a national adult HIV prevalence in excess of 14%.

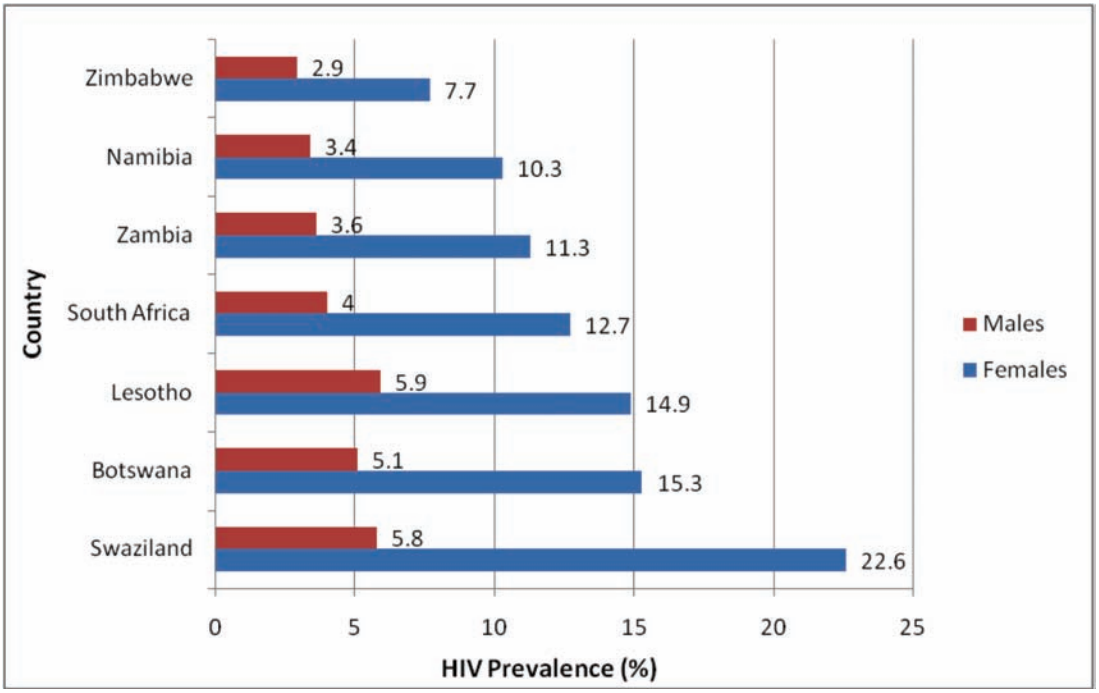

Figure 1.0 HIV prevalence among young people aged 15-24, selected southern African countries. Source: UNAIDS, 2008

About 82, 000 out of the estimated 1.4 million Zambians living with HIV are children (NAC, 2008). According to the 2007 Zambia Demographic and Health Survey, the HIV prevalence in 15-19 year olds in the country is 4.7%. At 5.7% the prevalence among girls in this age group is higher than that for boys which stands at 3.6%. A similar pattern is observed in the 20-39 age group, highlighting the feminisation of the epidemic. In Zambia, as in many other countries, reliable estimates on the number of adolescents (10-19 years old) living with HIV are unavailable. This largely stems from the different reporting formats in which the target group of interest is covered. Up to the age of 18, people are generally categorised as "children". Those between the ages of 10 and 24 are reported as "young people" and some reports list people between 15 and 24 years of age as "youth". Despite the considerable overlap among these groups, each possesses distinct characteristics which also have programmatic implications.

This report, commissioned by the Network of Zambian people living with HIV/AIDS (NZP+), is a culmination of the study on the sexual and reproductive health and rights (SRHR) of adolescents living with HIV. The term "adolescent" is used here to refer to boys and girls between the ages of 10 and 19. Adolescents living with HIV are one of the key groups addressed in the 'Guidance Package on Advancing the Sexual and Reproductive Health and Rights of People Living with HIV', a policy document developed by people living with HIV to assist policymakers, programme managers, health professionals, donors, and advocates in better understanding the specific steps that must be taken to support their sexual and

reproductive health and rights. This research aims to build the evidence base regarding the SRHR needs and concerns of adolescents living with HIV in Zambia, so as to guide the development of responsive and accessible services for this important target group. The study was funded by the United Kingdom Department for International Development (DFID)'s 'Governance Transparency Fund', with additional financial support provided by the United Nations Population Fund (UNFPA).

Study Design

Study setting

In-depth interviews and focus group discussions were conducted with adolescents, parents and guardians recruited through the support groups convened by ZNP+ in five residential areas of Lusaka namely: Chipata, Fairview, Garden, Kanyama, and Mandevu.

Sampling and data collection methods

Adolescents living with HIV were the principal study population in this qualitative exploratory study. Data collection began with a desk review of selected policy documents, guidelines and relevant study reports on the subject of interest.

Two focus group discussions (FGDs), one for boys and another for girls aged 10 to 14 years were held. A moderator guided the discussion using an FGD guide covering various topics on adolescent sexual reproductive health (ASRH). The researcher also held in-depth interviews with a purposive sample of 20 adolescents between 15 and 19 years old.

The rationale for employing FGDs for the younger adolescents was to help them overcome the shyness of discussing matters of sexuality with an older person. Separating them by sex was also aimed at creating a conducive "discussion space" during the FGDs. In cases where respondents chose to respond in *Nyanja* or *Bemba*, the researcher translated the discussion guide accordingly. The study's selection criteria were that all participants must be aged 10 to 19 years, aware of their HIV positive status, and willing to participate in the study.

Adults have a major impact on the health of young people through various channels (Hughes and Maculey, 1998). In recognition of the various roles adults play in the lives of the main study population, a series of in-depth interviews with selected adult key informants were also held. This category of respondents included parents and guardians of people living with HIV, policy makers from organisations involved in ASRH information and services, and service providers from three private facilities providing HIV and SRH services. Attempts to interview service providers from public health facilities were unsuccessful. Some providers cited pressure of work among the reasons for their non-participation in the study.

In all, 30 adolescents and 12 adults participated as respondents in the study. Table 1.0 overleaf summarises the distribution of respondents.

Table 1.0 Profile of respondents by data collection method		
INSTITUTION	**NO. OF RESPONDENTS**	**DATA COLLECTION METHOD**
POLICY INFLUENTIALS		
Ministry of Education	1	
National AIDS Council	1	In- depth interviews
United Nations Population Fund	1	
	1	
HIV and SRH SERVICE PROVIDERS		
Private faith-based facility	1	In-depth interviews
Private non-faith based facility	2	
PARENTS AND GUARDIANS		
Father	2	
Mother	2	In-depth interviews
Aunt	1	
ADOLESCENTS		
10-14 year old males	4	Focus group discussion
10-14 year olds females	6	Focus group discussion
15-19 year old males	4	In-depth interviews
15-19 year old females	16	In-depth interviews
OTHERS		
Traditional Marriage Counsellor (Alangizi)	1	In-depth interview
TOTAL	42	

Data Analysis

All interviews and FGDs were conducted with the aid of respondent-specific interview guides. For the qualitative component of the data, audio recordings of the interviews and FGDs were transcribed verbatim and analytic induction techniques were used to identify

common themes from this material (Pope and May, 2006). The background characteristics of the in-depth interview respondents were summarised using an Epi-Info statistical package.

Ethical considerations

Prior to the study, the protocol and the data collection instruments were reviewed and approved by the designated departments of NZP+ and GNP+ in Lusaka and Amsterdam respectively. All the adolescents, parents and guardians interviewed were drawn from among members of NZP+ support groups. Participation was voluntary for all respondents and, where applicable, parental consent was obtained from parents and guardians. No incentives were paid out to any of the respondents for participation in the study. The necessary measures to safeguard confidentiality and address the possibility of distressed respondents were in place.

Findings

Policy and Legal environment

Laws and policies have a considerable influence on the availability, distribution and delivery modes for health care services (Gruskin et al, 2007). Although it is fairly common for service delivery to precede policy formulation with regard to various HIV and AIDS interventions globally, a coherent and supportive policy environment is critical for improving access to sexual and reproductive health information and services to various sub-groups of PLHIV, including adolescents.

Globally, a number of policy guidelines and service protocols have been developed by various institutions that highlight the SRH concerns and make recommendations regarding information and services that should be available to people living with HIV. In its publication on the SRH of HIV positive women, the World Health Organisation (WHO) provides guidance on the recommended family planning methods for women on anti-retroviral therapy. This document also offers guidance on the pregnancy, childbirth and postpartum care that should be provided (WHO, 2006).

Despite not having the status of a binding international instrument, the Guidance Package on Advancing the Sexual and Reproductive Health and Rights of People Living with HIV released in 2009 is one of the most comprehensive guidelines covering ASRH issues for adolescents living with HIV. The guidance package is the result of a collaborative process involving a number of organisations including Young Positives, Global Network of People living with HIV (GNP+), EngenderHealth, International Planned Parenthood Federation (IPPF) and the United Nations Population Fund (UNFPA).

In advocating a more responsive policy environment, the package states:

> *"...National frameworks and curricula need to do more to address the SRH concerns of young people who are already living with HIV, including forming relationships, practising safe, pleasurable sex and disclosing their status. Existing programmes tend to ignore the needs of young people who have been HIV positive since birth because until recently, HIV infected infants were not expected to survive to adolescence. Guidelines should be revised to specifically address the situation of young people who were born HIV positive as well as those infected at a later stage."*
> (GNP+ et al, 2009:35)

The review of available policy documents and service protocols relating to adolescents in Zambia revealed that no national policies specifically address the adolescent sexual reproductive health (ASRH) needs of HIV positive adolescents. Some of the existing policies that could potentially provide the necessary policy framework are presented in the following section.

National Reproductive Health Policy (2005)

The aim of the recently adopted National Reproductive Health Policy is the attainment of the "highest possible integrated reproductive health for all Zambians" (MOH, 2005: 4). Specific areas of reproductive health have been identified for urgent attention. These include: safe motherhood, family planning, maternal nutrition, mother-to-child-transmission of HIV, sexually transmitted infections, abortion, infertility, and reproductive health service delivery.

ASRH is also recognised as a key area of concern. However, the discussion of adolescents with regard to HIV in the policy simply highlights their increased vulnerability to HIV infection. Although the policy refers to some of the challenges adolescents face in accessing SRH services and information, no interventions specifically for adolescents living with HIV are mentioned.

National HIV/AIDS Policy (2005)

The overarching national policy on HIV and AIDS, launched in 2005, makes reference to a wide range of interventions aimed at prevention, treatment and impact mitigation (NAC, 2005). There is no specific mention of adolescents living with HIV in the policy. Equally absent is any discussion of their SRH needs, concerns and services.

It is worth noting though that, throughout the document, young people, children and youth are mentioned as target groups for specific measures but working definitions of these terms are not provided in the document. Also, the prescribed measures related to ASRH are aimed at preventing HIV infection, a goal which does address the needs of adolescents living with HIV.

National Child Health Policy (2008)

The National Child Health Policy was drafted in 2008 with the main aim of providing a policy framework through which the implementation of preventive, curative and rehabilitative activities pertaining to child health could be coordinated. The need to uphold the rights of children to affordable and accessible treatment is mentioned as one of the guiding principles (MOH, 2008). Additionally, the growing incidence of sexual abuse, particularly of young girls, is cited as a major concern. However, there is no reference to the SRH needs and services for adolescents living with HIV in the document.

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Zambia Family Planning Guidelines and Protocols (2006)

These guidelines, originally developed in 1997, underwent revision in 2006 to reflect new approaches and up-to-date information in family planning. One of the main objectives of the guidelines is the integration of family planning with other reproductive health initiatives for more comprehensive delivery of services. The WHO recommendations on hormonal contraceptives and other fertility regulation services for HIV positive women are reflected in the guidelines. However, the package of SRH services to be offered to adolescents living with HIV is not defined.

National Strategy for the Prevention of HIV and STIs (2009)

As part of the re-orientation of the national HIV response, the government of Zambia recently launched the national HIV and STI prevention strategy. As indicated by its title, the prevention strategy is aimed at identifying areas where efforts must be focussed so as to reduce the incidence of HIV in the country. As is the case with many other policy documents, SRH interventions for HIV positive adolescents are not specifically mentioned. However, the strategy does call for the "integration of prevention interventions into other HIV and health services, with special attention to prevention with positives" (NAC, 2009: 37).

The absence of clear policy guidelines on ASRH for adolescents living with HIV was identified by key informants as an impediment in the efforts to reach out to this target group. As one policy influential noted,

> *"Adolescents living with HIV are not being specifically targeted in Zambia unless within programmes addressing sex work, migrant populations and human trafficking. Even in these programmes the targeting is for both negative and positive adolescents. There is no specific study conducted to identify and target this particular group.*
>
> *The health system does not adequately address ASRH concerns in the RH service provision. Most of the health facilities do not have a conducive environment, space and equipment for providing quality ASRH services. There are some restrictions in the provision of some RH commodities such as condoms to sexually active adolescents and youths. This hinders those who may be in need of these commodities (for prevention of STI/HIV and unintended pregnancies) from accessing".*
>
> Policy influential, UNFPA

Under the Zambian legal system, the minimum age for consensual sex is 16 years. However, the evidence from a number of surveys on young people's sexual behaviour shows that it is

not uncommon for adolescents as young as 10 years old to be sexually active. The 2007 Zambia Demographic and Health Survey, for example, reveal that 15.3% of all the sexually active respondents reported having had their first sexual encounter before the age of 16 years (CSO, 2008).

In Uganda, a study on the SRH needs of adolescents perinatally infected with HIV and between 15 and 19 years old found that 52% of respondents were in a relationship. Furthermore, 33% were sexually active at the time of the survey (Birungi et al, 2008). In Zambia, this early sexual debut coupled with the prevalence of early marriages particularly among girls in the rural areas highlights the importance of removing the age-related barriers to accessing SRH services that some adolescents living with HIV face.

The policy review and key informant data collected suggest that the SRH needs and concerns of adolescents living with HIV in Zambia are assumed to be addressed through the existing policies targeting youth, people living with HIV, children or most-at-risk populations. This is not entirely valid, as the evidence from the adolescents, themselves, shows.

As one policy influential remarked:

> *"We have undertaken research as National AIDS Council and we have it documented that youths are one of the sub-groups that are not well attended to in terms of information. We have realised that most implementing partners do not design information materials to specifically address the needs of adolescents living with HIV. We are much into the general way of communicating, which does not address the specifics, and that presents a challenge...We don't have targeted messages"*
> Policy influential, National AIDS Council

Selected characteristics of adolescents in in-depth interviews

Although other key informants were interviewed as part of the data collection exercise, this study's main focus group was adolescents living with HIV. As indicated earlier, the younger adolescents were interviewed via FGDs while the views of the older ones (15-19) were elicited through in-depth interviews. Table 2.0 provides an overview of selected background characteristics of the latter group.

Table 2.0 Background characteristics of in-depth interview respondents, adolescents		
Characteristics	**Frequency (n=20)**	**Percentage (%)**
Age		
Below 16	9	45
Above 16	11	55
Sex		
Male	13	65
Female	7	35
School attendance		
In school	17	85
Out of School	3	15
Living arrangements		
With both parents	7	35
With single parent	5	25
With other relative	8	40
With spouse	1	5
Current relationship status		
Single	19	95
In relationship	1	5
Had sexual intercourse in last 12 months		
Yes	3	15
No	17	85

Stigma, discrimination and disclosure

Stigma and discrimination related to living with HIV emerged quickly as a key issue in the majority of the interviews conducted in this study. For some of the adolescents, the knowledge that HIV was primarily a sexually transmitted infection evoked feelings of shame and bitterness, especially for those who reported having acquired the infection perinatally. This is illustrated in the following comment from a focus group discussion:

> *"We are sometimes treated in a strange way at school. It's unfair because some of us have never had sex. We were just born with it.*
> FGD, 10-14 years old female adolescents

For the adolescents in this study, HIV-related stigma and discrimination were not confined to the school setting. Younger adolescents in particular identified the fear of mocking by

friends as one of the main reasons they avoided playing with their peers in the neighbourhood. One male respondent, an orphan under the care of a relative, narrated the experience of stigma within the home.

> *"My guardians have told everyone in the neighbourhood that I'm HIV positive. When I have a difference with playmates, my status is often brought up. It hurts me. I don't feel free when I'm playing."*
> FGD, 10-14 year old male adolescents

One of the study criteria for inclusion was that all adolescent participants had to be aware of their HIV positive status. Interestingly, in Chinyanja, a local language, the term "nimamwa mankwala" is consistently used to denote HIV positive status, although its literal translation is "I drink medicine". To some extent, adolescent living with HIV exhibit self-stigma as evidenced in the following remark:

> *"I won't get married when I grow up since I drink medicine (I'm HIV positive). I would rather be a nun."*
> 15 year old female adolescent

Regarding disclosure, an overwhelming majority of the adolescents interviewed disclosed that they learnt about their HIV positive status from health care providers and not their parents. Closer examination of the underlying reasons for this was beyond the scope of the study. Nonetheless, the observations by some parents and service providers interviewed suggest that many parents may not know how to handle the challenge of telling their children how they came to be HIV infected and may refrain for fear of possible adverse reactions from the child. As one service provider noted:

> *"It's a very big problem. A majority of our adolescents here are on treatment without the parents telling them why. We try as much as possible to help the parents to disclose the status to the child since HIV is talked about in schools, on TV and other places and we don't want the child to learn about their status from a different source. Our message to parents is not to tell lies to their children."*
> Service provider, faith-based facility

The observation of the service provider quoted above is supported by the response by a female adolescent:

> *"The nurse at the clinic told me that I am HIV positive. I know I was born like this. I'm still waiting for my mother to tell me."*
> 16 year old female adolescent

Perspectives on SRH needs and concerns

In the FGDs and the interviews with the adolescents, lack of information on SRH emerged as the most common concern for both sexes. A number of the younger adolescents stated that the FGD provided their first opportunity to ask questions about sexuality and reproduction in a friendly atmosphere. When asked what they considered the appropriate age for the provision of SRH information and education, the female adolescents indicated younger ages than did the males. Equally evident was the variation between the younger and older adolescents regarding the specific SRH issues about which they sought more information and education. This is indicative of the evolving SRH needs and concerns across the life cycle.

Concerns about puberty signs in the context of HIV infection were cited by most of the respondents, irrespective of age. For instance, a participant in the FGD for 10-14 year old male adolescents asked whether it was true that HIV affected the growth of pubic hair. The interviews with parents and guardians of adolescents living with HIV provided further evidence of the existence of concerns around puberty. As one guardian stated,

> *"My niece was almost going into depression a few years ago. We didn't know what the problem was until she told me that she was worried that her breasts would not grow normally like a woman because of HIV."*
> Aunt, 15-year old female adolescent

Only 3 out of the 30 adolescents who participated in the study reported being sexually active. It is likely that this may reflect the under-reporting that is characteristic of self-reported sexual behaviour. The fact that the study sample was comprised mainly of in-school adolescents may also contribute somewhat to the reported low rate of sexual activity among the participants. Unplanned pregnancies and pressure to have unprotected sex were among the concerns raised by the sexually active adolescents.

> *"I fell pregnant when I was 17 years old. Whenever we had sex, my boyfriend refused to use condoms saying that there was no need since we were going to get married. He was excited when I told him I was pregnant. The last time I ever saw him was the day I told him I was HIV positive. He just disappeared. I just hear stories that he lives in Livingstone (another town) now."*
> 18 years old female adolescent

Peer pressure to engage in sexual activity was also mentioned by the male adolescents as a problem they encountered especially when they sought advice from older peers. One 14-

year old male respondent said that his older friends often called him a small boy because he had never had sex.

Adolescents living with HIV are not immune to the gender norms that sometimes make negotiating safer sex within the matrimonial setting a risky undertaking. When asked about condom use, a married adolescent had this to say:

> *"My husband refuses to use condoms so we don't use them. He says there is no need since we are both already infected (with HIV). I was told at the hospital that I need to start treatment now. He says I must wait so we can start taking the medication at the same time. He always gets annoyed when I advise him to get tested."*
> 17 year old female adolescent

To provide some degree of data triangulation in the study, the question on the SRH needs and concerns of adolescents living with HIV was also posed to the service providers interviewed. Highlighting the demand for SRH information, a service provider from a non-faith-based health facility had this to say:

> *"I think from my organisation's experience, inadequate information is one of the problems. You find that yes, as services providers we are there, we are able to give out information but you find that most of them do not have adequate information (on SRH) and also they do not know where to access the services"*
> Service provider, private non-faith-based facility

The need for SRH information was echoed by another service provider who also cast some light on some of the questions frequently encountered.

> *"They face a lot of challenges. They ask questions like, "Am I ever going to get married now that I'm HIV positive?" "If I have sex with my partner, am I going to infect them?" Some concerns that they normally have relate to puberty. Even when a child is 16, they could be looking like a 10 year old. When they start experiencing the (puberty) changes on their bodies, they tend to wonder what is happening."*
> Service provider, faith-based facility

According to some providers, STIs were prevalent among adolescents living with HIV. Syphilis, in particular, was identified as the most common STI for which they sought medical attention. Contraceptives and pregnancy testing were also mentioned among the services and commodities usually asked for.

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Sources of SRH Information and Advice

In Zambia, cultural norms in most communities dictate that discussions relating to sexuality be shrouded in secrecy. Additionally, any discussion of matters relating to SRH between parents and their children is generally considered taboo. Thus, it is not surprising that only 10% of the adolescents interviewed indicated parents as their main source of SRH information and advice. For more than half of the respondents, friends were cited as the main source of SRH information and advice. This is demonstrated by the following quotes:

> *"I ask my friend. My mother does not discuss such issues (SRH) with me. We live with my grandmother but she is too old to know.... I don't ask her anything".*
> 16 year old female adolescent

> *"I had my first period while at school. When I told my teacher, she allowed me to go home. I told my mother, who told me I was now a woman. I was not scared or surprised when it happened because my friend, who is older than me had told me all about it when she started her periods.*
> 15 year old female adolescent

The clinic was also identified as another important source of information especially for those adolescents on antiretroviral therapy (ART).

> *When I go to get medicine from the hospital, we have a meeting with other young people and the nurse talks about such things (SRH matters).*
> FGD, 10-14 year old female adolescents

Although the Ministry of Education has incorporated sexuality education in the school curricula at various levels, the extent to which teachers discuss SRH matters during lessons is not clear. While some of the respondents stated that they obtained their information on SRH from school, others were of the opinion that their teachers did not provide sufficient information on the subject. A policy influential from the education sector explained the difficulty of translating policy into tangible action in the following way:

> *"Our policies on SRH and HIV issues for learners are very good. The problem is implementation at school level...Since the topics are non-examinable; some teachers do not bother to present them in class. In some cases, there are not enough reading materials for every learner."*
> Policy influential, Ministry of Education

Parental involvement in provision of SRH information and advice

The majority of adolescent participants in this study were under the care of their parents or other guardians. Accordingly, the study sought their views (as well as those of other key informants) on the role of parents and guardians as providers of SRH information and advice. It is evident from their responses that very little parental-child communication on SRH matters is occurring. In one FGD, a 14 year old male responded explained that, although his aunty freely discussed HIV matters with him, he considered it inappropriate to ask her anything related to SRH. Surprisingly, many of the adolescents mentioned parents and guardians among their preferred sources of SRH information and advice in future.

The parents interviewed cited a number of reasons for not discussing SRH matters with their adolescents living with HIV. These are illustrated in the following quotes:

> *"It is taboo for me as a father to discuss such things (SRH) with my daughter."*
> Father, 15-year old female adolescent

> *"I think as parents, we lack information. What can I teach my child if I don't know myself? We need to be empowered with information"*
> Father, 14-year old female adolescent

In contrast, some of the parents were of the opinion that the HIV positive adolescents had unique SRH needs which could best be addressed by the parents themselves. Some of the respondents commented:

> *"As a parent, I will do it myself. I don't think any other person would understand my daughter's problem. She has special needs"*
> Mother, 13-year old female adolescent

> *He (son) is still young. I share with him stories on HIV now. When he is old enough, I will tell him everything. It will be easier for him to understand then. It is challenging at the moment*
> Mother, 10-year old male adolescent

The study also explored the extent to which SRH information and advice were discussed during the initiation ceremonies that are conducted as a rite of passage among many ethnic groups in Zambia. For adolescents living with HIV, such ceremonies represent an opportunity to access SRH information and advice. A female traditional counsellor or alangizi described

the difficulties associated with integrating SRH and HIV in the traditional counselling sessions as follows:

> *Most traditional counsellors do not raise the issue of HIV for fear of upsetting the family...In my case, I do discuss such issues. For example, during the pre-marital counselling sessions involving a young person who may be living with HIV, I ask the couple if they have slept together. They girl may sometimes lie...I still advise them to go for VCT.*
> Female traditional counsellor

Access to SRH services and commodities

Generally, confidentiality and privacy during service delivery are key factors in adolescent decisions regarding where to seek help when in need of SRH services. Other factors influencing an adolescent's decisions about whether and where to seek SRH services include perceptions on the severity of the illness, direct and indirect costs of accessing treatment and individual beliefs on the aetiology of the illness or condition.

During the FGDs and the in-depth interviews, adolescents were asked if they had experienced an SRH-related condition and their motivations for selecting the service provider they opted to consult. Those who had experienced such a condition reported having taken the following steps: use of traditional medicine provided by a relative, self-treatment with medication from private drugstores, and not seeking any help at all.

When asked who they approached when in need of psychosocial support, a number of respondents talked about being counselled by adults in the neighbourhood whom they knew to be living with HIV. Particular support group members were identified a number of respondents as approachable adults.

Remarkably, a large number of respondents opted not to seek help at all; convinced that the condition was simply a result of their HIV positive status. This is highlighted in the following quotes:

> *"I sometimes have a rash on my genitals. I think it's because of my status. I do not go to the clinic...They disappear on their own.*
> 18 year old female adolescent

> *"Last year, I had no periods for three months. It happened again this year but I'm used now."*
> 19 year old female adolescent

The health seeking behaviour (or lack thereof) exhibited by the respondents suggests a serious lack of access to accurate information tailored to the SRH needs of adolescents living with HIV. At the same time, the responses point to the opportunities that could be explored to improve the accessibility of SRH services and commodities.

Relationships, marriage and fertility desires

A number of studies on the SRH needs and concerns of people living with HIV show that, in many cultures, being HIV positive *per se* modifies but does not remove desires for romantic relationships or child-bearing (Cooper et al, 2007;Mangani, 2009). In their review of studies on the fertility intentions of people living with HIV, Nattabi and colleagues (2009) argue that such intentions are strongly influenced by demographic, stigma-related, psychosocial and cultural factors. Other studies in Canada and Uganda also confirm that many adolescents living with HIV harbour intentions of finding partners and bearing children in future (Birungi et al, 2008, Fernet et al, 2007).

Regarding relationships, marriage and childbearing in future, nearly all the adolescents in this study indicated that they would like to have wives or husbands and their own children in future. Partner notification and choosing a partner who was also HIV positive (sero-sorting) were mentioned as coping strategies for HIV-related stigma. Furthermore, female respondents in particular exhibited a high degree of awareness of prevention of mother-to-child transmission (PMTCT) as way of reducing the risk of passing the infection to one's offspring.

> *"Everyone is free to marry and raise a family. Even an HIV positive couple can bear HIV negative children"*
> FGD, 10-14 year old female adolescents

> *A woman makes a home. When I grow up, I will marry and have two children. We talk about it with my friends at school.*
> FGD, 10-14 year old male adolescents

Younger and older adolescents alike viewed engaging in relationships and bearing children as among their human rights that should be respected. The findings suggest that being HIV positive does not have much influence on the adolescents' attitudes towards relationships and childbearing in adulthood. Also, the fertility intentions are perhaps a reflection of the socio-cultural factors that underpin the reproductive decisions of many Zambians.

Zambia

Challenges in accessing SRH information and services

Adolescents face many barriers in accessing health care services. These include: legal barriers such parental or spousal consent requirements, or age limits for providing contraception. Although most SRH services are ostensibly free in public health facilities in Zambia, the indirect costs associated with accessing these services can deter adolescents from seeking appropriate help when in need. Some of the respondents mentioned the cost of transport to the health facility as the reason they did not collect the free condoms they knew were available in government-run clinics.

For some of the respondents on ART, the long travel times they experienced when collecting their monthly supply of drugs discouraged them from seeking psychosocial help at the clinic for their SRH concerns. One sexually active male adolescent described the lack of youth-counsellors at the local clinic as the main reason he could not go there to obtain SRH information and advice.

To gain deeper insight into the supply-side factors that influence access to ASRH information and services, the services providers interviewed were asked to identify some of the challenges they faced in providing SRH services to adolescents living with HIV. The responses brought to light a broad range of organisational and structural changes required to improve the fit between supply and demand of ASRH information and services. These start with institutional policies regarding ASRH services, as illustrated by the following observation from a service provider:

> *"As a faith-based health facility, our policy is that we do not provide certain services such as condoms. In my view, this is a big problem as we are not able to offer a holistic service to our clients."*
> Female service provider, faith-based facility 1

Lamenting the limitations of SRH interventions driven by ideology rather than evidence, one service provider noted:

> *"...we are being questioned by some of our implementing partners for focussing too much on abstinence and prevention approaches in our programming. The situation has improved in the last few years, but there is still a lot to be done. To promote abstinence only to a sexually active young person living with HIV is failing to recognise reality."*
> Female service provider, faith-based facility 2

Sexual and Reproductive Health and Rights

One strategy consistently promoted in the global discourse on improving access to SRH services for people living with HIV is the integration of HIV and SRH services. Farell (2007) describes it as an approach in which health care providers use the available opportunities to engage the client in addressing health and social needs, even when this goes beyond the original purpose of the visit to the health facility.

The Guidance Package on the SRHR of people living with HIV explains integration as the arrangement whereby clients obtain HIV and SRH services at the same site (GNP+, et al, 2009). Depending on the availability of resources, integration could also mean that health care workers have the capacity to provide a clearly defined basic package of services and make the appropriate referrals where necessary (GNP+ et al, 2009).

At country level, one of the recommendations made by the NZP+ in its review of existing HIV and SRH policies is that communities be actively involved in the provision of integrated services (NZP+, 2008). Figure 2.0 depicts some areas of integration promoted by the World Health Organisation (WHO) and other partners.

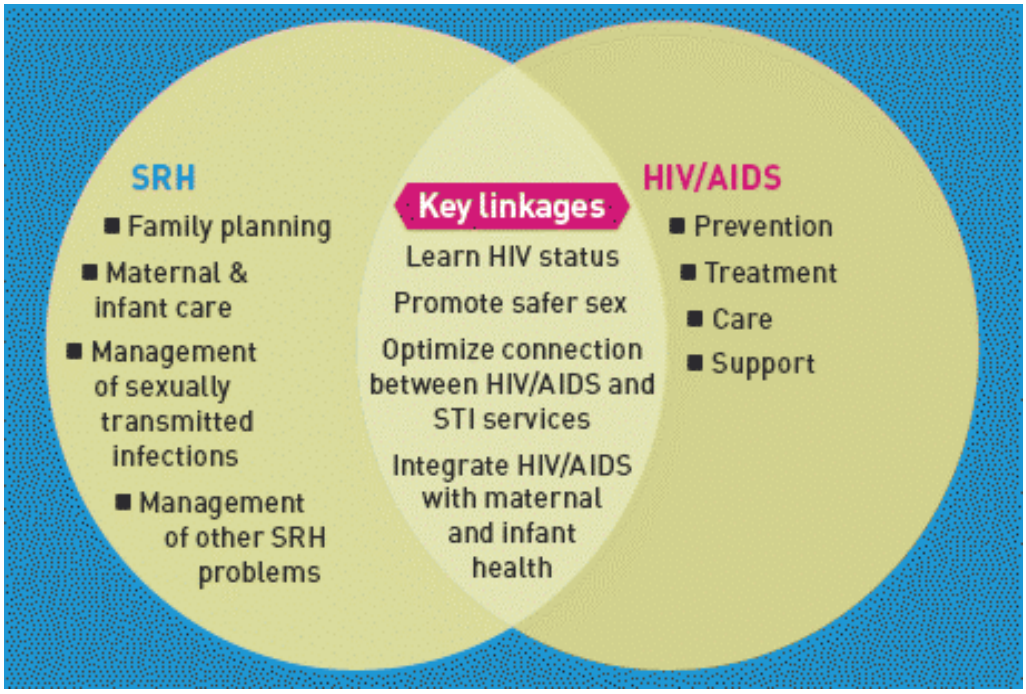

Figure 2.0 A framework for HIV and SRH linkages. Source: WHO, 2005

The few service providers interviewed in this study mentioned various forms of SRH and HIV services integration occurring within their facilities. For instance, one of the facilities provides psychosocial support, temporary shelter and legal services to adolescents living with HIV. Many of these clients got infected through sexual abuse by older family members or other persons well known to them. Another facility provides contraceptives and STI

screening services but refers clients seeking certain HIV-related services to other health facilities.

Even where integration is being undertaken, however, some programmatic gaps in service linkages remain, as the following service provider observations indicate:

> *"I think for us the biggest problem is that we don't provide certain specialised services that probably an adolescent living with HIV would need...All our services are free to young people below 24 years. When a person needs a specialised service and we have to refer them somewhere else and they have to pay for it, it's really a challenge for us...*
> Female service provider, non-faith based facility

> *"We do not provide a comprehensive package of services. We have some clients lost to follow-up whenever refer them to other institutions for other services"*
> Female service provider, faith based facility 2

The need for integrated HIV and SRH services was also evident among some of the parents and guardians interviews. The mother of a young male adolescent used the following words to justify her recommendation for health care workers in the ART clinics to provide SRH information and advice as well:

> *"The doctors and the counsellors at the ART clinic should provide the (SRH) information to the adolescents. The friendship that they develop with the adolescents through regular interaction makes it easier for them to discuss such matters."*
> Mother, 10-year old male adolescent

Summary Discussion

Based on the life-cycle approach to the SRH needs and concerns of people living with HIV, a comprehensive continuum of care is one that considers access to services at all life stages. Provision of tailored ASRH information and services is key to ensuring good SRH status across one's lifetime given that, as noted above, SRH-related diseases or conditions experienced in adolescence can have persist and damaging impacts in subsequent life stages. Furthermore, both public health and human rights imperatives require paying due consideration to the needs of the growing population of adolescents living with HIV in Zambia. A number of illuminating findings emerged from the data collected in this study.

Regarding challenges in accessing SRH services, the findings demonstrate the additional burden that HIV infection places on adolescents who, by virtue of their age, are often already required to overcome a host of barriers to obtaining SRH services. Even in cases where the institutional policies provide for the non-discriminatory provision of SRH services to young people and adults alike, the personal values and beliefs of the services providers may nevertheless dictate at times whether a young client will be served or not.

Warenius and colleagues (2006) examined the attitudes of nurses and midwives towards the SRH needs of adolescents in Zambia and Kenya. According to their findings, 81% of the Zambian respondents said that their first option would be to recommend abstinence to any adolescent who approached them for contraceptives. Additionally, nearly all the respondents (94%) in Zambia stated that abortion should not be allowed for adolescent girls with unwanted pregnancies (Warenius et al, 2006).

It is sometimes argued that orienting SRH services towards adolescents, irrespective of sero-status improves uptake by addressing HIV-related stigma and discrimination. By contrast, the findings of this study suggest that the unique needs of adolescents living with HIV are more likely to remain unmet where such modes of service delivery are applied. Some respondents mentioned negative service provider attitudes in public facilities as the reason they opted to obtain SRH services or commodities from private providers. A useful corrective measure in such settings would be to equip service providers with the necessary skills and knowledge to effectively serve HIV positive adolescents and address their concerns explicitly.

There is also a growing body of evidence emphasising the heterogeneity that exists among people living with HIV. Age, gender, sexual orientation, marital status and whether one is in

confinement or not are some of the parameters that define different sub-groups with distinct SRH needs and concerns.

Additionally, some studies on the SRH concerns of adolescents living with HIV distinguish between perinatally infected adolescents and those who acquired the infection at a later stage (Bakeera-Kitaka et al., 2009; Birungi et al., 2008; Fernet et al., 2007; Levine et al., 2007). The mode of infection was not among the selection criteria for the respondents in the present study. One an area for future investigation is the differences in attitudes, beliefs and other variables between the two mode-of-transmission groups of Zambian adolescents living with HIV.

The observed lack of parental involvement in the provision of SRH information among this study's respondents mirrors the findings by Birungi et al., (2008) conducted in Uganda. In many African cultures, designated older members of the extended family were responsible for providing this information in the past. However, rural-urban migration and economic hardships have contributed to the break-down of the extended family system and other social structures through which SRH information and advice were previously transmitted. The findings suggest that cultural and capacity factors must be taken into account and addressed if parents and guardians are to play a bigger role as sources of SRH information.

A notable finding of this study is the prominent place peers hold in the provision of SRH information for most of the adolescents interviewed. Part of the explanation lies in the quest for independence from parental control that is often characteristic of adolescence. For some of the respondents, turning to peers was a coping strategy and friends provided them with information (albeit not uniformly accurate) that they could not obtain from their parents or guardians.

Conclusion

Using a qualitative approach, this study has revealed a number of socio-economic, institutional and cultural factors that interact to create the challenging environment within which adolescents living with HIV in Zambia make their SRH decisions. Furthermore, living with HIV often compounds other challenges usually associated with the transition from childhood to adulthood.

The conclusions drawn from the study are as follows:

- Policies and guidelines specifically targeting the SRH needs and concerns of adolescents living with HIV are lacking.
- HIV-related stigma and discrimination are common complaints among adolescents living with HIV. They affect disclosure of status and the uptake of SRH services.
- The needs and concerns of adolescents living with HIV are numerous. Understanding their puberty signs and fear of infertility in adulthood are some of the challenges that affect even those adolescents who are not sexually active.
- Peers are the most important source of SRH information and advice for adolescents in this study. Although they consider it inadequate, adolescents also appreciated the information obtained in school.
- Adolescents living with HIV face a number of barriers in accessing SRH information and services. Provider-related factors include concerns about privacy and confidentiality within the health facility.
- Living with HIV does not hamper future aspirations of founding families and having biological children. Many of the adolescents in the study setting consider these as rights.
- Parents and guardians of adolescents living with HIV rarely discuss SRH matters with them. Underlying factors for this phenomenon include restrictive cultural norms and the inadequate information on the part of the parents, themselves.

Recommendations

Addressing the SRH needs of adolescents living with HIV in Zambia cannot be left to the health care system or community alone. Recognizing this, and on the basis of the above conclusions, the following recommendations are made:

- All stakeholders involved in the promotion of the sexual and reproductive health of adolescents living with HIV should advocate the formulation of supportive policies and laws. An important starting point in this process is the development of a credible evidence base to inform the revision of the relevant policies, protocols and laws currently in place.
- Service providers and community members should promote the establishment of adolescent support groups. This would enhance the accuracy and accessibility of peer-provided SRH information.
- Where feasible and acceptable, steps should be taken to integrate ASRH and HIV services to improve uptake of both areas of service by adolescents living with HIV.
- Interventions aimed at improving access to SRH information should incorporate components designed to equip parents and guardians with the knowledge and skills they need to provide such information to their HIV positive adolescents.
- At the health facility level, the availability of high quality, non-judgemental counselling and related services should be strengthened. This could be achieved through the provision of adequate SRH supplies, commodities and service providers trained to address the unique SRH needs of adolescents living with HIV.
- Interventions designed to challenge stigma and discrimination within the community and health facilities should include activities to raise awareness of the sexual and reproductive health rights of people living with HIV, including adolescents.
- Health facilities providing youth-friendly services should consider the involvement of adolescents living with HIV in the planning, design and delivery of such services.
- The findings presented and discussed in this report are based on a qualitative study and are therefore, limited in generalisability. A follow-up quantitative study with a bigger, randomly selected sample is recommended as a way of adding breadth to the ASRH issues identified.
- This study focuses mainly on in-school adolescents in an urban setting. Similar studies should in future be extended to cover out-of-school adolescents and those in rural settings.
- Follow-up studies to identify the preferred package of integrated HIV and SRH services from the perspectives of prospective clients should be conducted.

References

Barbour, R. and Kitzinger, J. (1999) Developing focus group research: Politics, theory and practice. London: Sage.

Birungi H., Mugisha J.F., Nyombi J., Obare F., Evelia H., and Nkanyivu, H. (2008) Sexual and reproductive health needs of adolescents perinatally infected with HIV in Uganda. FRONTIERS Final Report. Washington DC, Population Council.

Bakeera-Kitaka, S., Nabukeera-Barunigi, N., Nostlinger, C., Kekitiina, A., Colebunders, R. (2008) Sexual risk reduction needs of adolescents living with HIV in a clinical care setting *AIDS Care* 20 (4), 426-433

CSO (2008) 2007 *Zambia Demographic and Health Survey*. Calverton, Maryland: Central Statistical Office, Ministry of Health and Macro International Inc.

Farrell, B. L. (2007) *Family planning–integrated HIV services: A framework for integrating family planning and antiretroviral therapy services.* New York: EngenderHealth/The ACQUIRE Project.

Fernet, K., Proulx-Boucher, K., Richard, M., Lévy J.J., Otis, J.,Samson, J., *et al*. (2007) Issues of sexuality among adolescents living with HIV/AIDS since birth *The Canadian Journal of Human Sexuality* 16 (3/4), 101-111

GNP+, EngenderHealth, ICW, IPPF, UNAIDS, Young Positives. (2009) Advancing the Sexual and Reproductive Health and Human Rights of People Living With HIV: A Guidance Package. Amsterdam, GNP+.

Hughes, J. and Macauley, A.P., (1998) Improving the fit: Adolescents' needs and future programs for sexual and reproductive health in developing countries *Studies in family planning* 29, 233-245.

Levine, A.B., Aaron, E., and Foster, J. (2006) Pregnancy in perinatally HIV-infected adolescents: Clinical observation. *Journal of Adolescent Health*, 38, 765-768

Mangani, F. (2009) Meeting the sexual and reproductive health needs of people living with HIV in Zambia: Challenges and opportunities *Unpublished Master of Public Health dissertation* Vrije Universiteit Amsterdam, Amsterdam

MOH (2008a) *National Reproductive Health Policy* Government of Zambia: Lusaka

MOH (2008b) *National Child Health Policy* Government of Zambia: Lusaka

NAC (2006) *National HIV/AIDS Policy* Government of Zambia: Lusaka

NAC (2009) *National Strategy for the Prevention of HIV and STIs* Government of Zambia: Lusaka

Nattabi, B., Li, J., Thompson S.C., Orach C.G., Earnest J. (2009) A Systematic Review of Factors Influencing Fertility Desires and Intentions Among People Living with HIV/AIDS: Implications for Policy and Service Delivery. *AIDS Behaviour*. DOI 10.1007/s10461-009-9537-y

NZP+ (2008) Desk review of existing national policies on HIV/AIDS and sexual reproductive health.NZP+: Lusaka.

Pope, C. and Mays, N (2006) Qualitative research in health care. Masachusetts: Blackwell publishing

UNFPA (2000) Partnering: A new approach to Sexual and Reproductive Health *Technical Paper Number 3*. Geneva: UNFPA

UNAIDS (2008) *2008 Report on the Global AIDS Epidemic*, Annex 1.Geneva: UNAIDS

UNAIDS (2009) *2009 AIDS Epidemic update*. Available at http://data.unaids.org/pub/Report/2009/2009_epidemic_update_en.pdf (Accessed: 29th November, 2009)

Warenius, L.U., Faxelid, A.E., Chishimba, P.N., Musandu, J.O., Ong'any, A.A., and Nissen, E. (2006) Nurse-Midwives' Attitudes towards Adolescent Sexual and Reproductive Health Needs in Kenya and Zambia *Reproductive Health Matters* 14 (27), 119–128

WHO, UNFPA, UNAIDS and IPPF (2005). Sexual and Reproductive Health & HIV/AIDS: *A Framework for Priority Linkages.* Geneva: WHO

WHO (2006) Sexual and reproductive health of women living with HIV/AIDS: *Guidelines on care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings*. Geneva: WHO

Annexure 1: In-depth Interview guide: Adolescents

NZP+ Adolescent Sexual and Reproductive Health and Rights Study

In-depth interview guide: Adolescents

Introduction

Greetings, self-introduction and affiliation

Purpose and procedure

The aim of this interview is to get your views on the sexual and reproductive health needs and concerns of adolescents living with HIV. I am particularly interested in your experiences and recommendations on how the access and quality of related sexual and reproductive health services can be improved. All that will be said in this interview will treated as confidential and you will remain anonymous. You can choose not to answer any question and should you feel unable to proceed with the interview at any stage, kindly let me know and we will end the discussion.

If it's fine with you, I will record our interview to make sure I accurately capture all that we shall discuss. The interview will last about 30 minutes.

Background Characteristics

Interview no.	.....
Age	.....
Sex	.....
Place of residence (locality)	.....
Living arrangement	.....
School attendance	.....
Employment status	.....
Membership to support group	.....

Discussion

1. **What are some of your sexual and reproductive health needs and concerns as an adolescent living with HIV?**

Probe: Access to accurate information, counselling, forming relationships, contraceptives

2. **What are your sources of information and advice on sexual and reproductive health matters?**

Probe: Friends, counsellors, media. Prompt on the level of importance of the sources mentioned.

3. **Are you currently in any romantic relationship?**

Probe: Marital status, disclosure challenges

4. **Have you ever had sexual intercourse in the last 12 months?**

Probe: Use of protection, contraceptives

5. **Have you ever been pregnant or made someone pregnant before?**

6. **Have you ever experienced any SRH related condition that required you to seek help? Where did you seek assistance for the concern specified?**

Probe: STI symptoms, puberty signs. Explore reasons guiding choice of provider, whether satisfied with the service received

7. **As an adolescent living with HIV, what are the challenges that you face in accessing information and advice on the needs concerns discussed earlier?**

Probe: Use a particular concern e.g. STI symptoms to initiate the discussion

8. **As an adolescent living with HIV, what are some of the barriers that you face in accessing sexual and reproductive health services?**

Probe: Cost, availability spousal or parental consent.

9. **What are sexual and reproductive health services and commodities that you feel should be offered but are currently not available?**

10. **In future, where would you prefer to obtain information, advice and services on sexual and reproductive health from?**

11. **What are your views and experiences on romantic relationships, marriage and childbearing for adolescents living with HIV?**

Probe: Future plans for marriage, child bearing and underlying reasons for responses

12. **Ask the respondent if there are any other points s/he would like to add.**

Thank you for your time

Annexure 2: In-depth Interview guide: Policy influentials

NZP+ Adolescent Sexual and Reproductive Health and Rights Study

In-depth interview guide: Policy influentals

Introduction

Greetings, self-introduction and affiliation

Purpose and procedure

The aim of this interview is to get your views on the sexual and reproductive health needs and concerns of adolescents living with HIV in Zambia. I am particularly interested in your experiences and recommendations on how the access to, and quality of related sexual and reproductive health services can be improved. All that will be said in this interview will treated as confidential and you will remain anonymous.

If you have no objection, I will record our interview to make sure I accurately capture all that we shall discuss. The interview will last about 30 minutes.

Background Characteristics

Interview no.	.....
Date of Interview	.....
Interviewee's designation	.....
Sex	.....

Discussion

1. **What are some of the sexual and reproductive health needs and concerns of adolescents living with HIV?**

2. **To what extent is your organisation involved in the provision of sexual and reproductive health information and services for adolescents living with HIV?**

Probe: Policy formulation, technical support, financial support, regulation of services

3. **What policies and operational guidelines influence your organisation's programmes on sexual and reproductive health for adolescents living with HIV?**

4. **How does the current policy environment impact on your organisation's sexual and reproductive health initiatives for adolescents living with HIV?**

Probe: Specific policies and interventions e.g. sexuality education in schools

5. **In your opinion, what barriers do adolescents living with HIV currently face in accessing sexual and reproductive health information and services?**

6. **What measures would you recommend for improving access to SRH information and services for adolescents living with HIV?**

Thank you for your time

Annexure 3: In-depth Interview guide: Service Providers

NZP+ Adolescent Sexual and Reproductive Health and Rights Study

In-depth interview guide: Service Providers

Introduction

Greetings, self-introduction and affiliation

Purpose and procedure

The aim of this interview is to get your views on the sexual and reproductive health needs and concerns of adolescents living with HIV in Zambia. I am particularly interested in your experiences and recommendations on how the access to, and quality of related sexual and reproductive health services can be improved. All that will be said in this interview will treated as confidential and you will remain anonymous.

If you have no objection, I will record our interview to make sure I accurately capture all that we shall discuss. The interview will last about 30 minutes.

Background Characteristics

Interview no. .....
Date of Interview .....
Designation .....
Sex .....

Discussion

1. **What are some of the sexual and reproductive health needs and concerns of adolescents living with HIV?**

2. **What are the SRH services that your facility provides?**

1. Family planning
2. Prevention and management of STIs
3. Maternal and newborn care
4. Prevention and management of gender-based violence
5. SRH information and education
6. Prevention of unsafe abortion and post-abortion care
7. Others (specify): .....

3. **To what extent are the services you have mentioned tailored to meet the SRH needs of adolescents living with HIV?**

Probe: Referrals, youth-friendly corners

4. **In your view, what are the challenges that your facility faces in providing SRH services to adolescents living with HIV?**

Probe: Policy constraints, demand for services, lack of appropriate skills symptoms to initiate the discussion

5. **What measures would you recommend for improving the access to SRH services for adolescents living with HIV?**

Thank you for your time

Annexure 4: Focus group discussion guide: 10-14 years old adolescents

NZP+ Adolescent Sexual and Reproductive Health and Rights Study

Focus group discussion guide

Introduction

Good morning. My name is ..... and this is my colleague .....
Thank you for coming.

Purpose and procedure

We would like to get your views on sexual and reproductive health issues as young people living with HIV. Feel free to express yourselves as there is no right or wrong answer in our discussion. To ensure everyone's opinion is heard we suggest that we speak one at a time and clearly. Feel free to point out your disagreement if you have any during the discussion. We would appreciate it if you are able to speak freely during the discussion.

Everything you share with us will be treated as confidential and will not be shared with anyone outside this room. My colleague will be recording the discussion to ensure we correctly capture all that we will share this morning. Our session will last for about 1 hour.

Discussion

1. **What are some the sexual and reproductive health concerns that adolescents living with HIV in Zambia face?**

Probes: Access to accurate information, counselling, forming relationships, contraceptives

2. **What are the main sources of information on sexual and reproductive health for adolescents living with HIV?**

Probe: Friends, classmates, radio and television

3. **Where do adolescents living with HIV obtain sexual and reproductive health services for the concerns discussed earlier?**

Probe: Prompt the participants for reasons guiding choice of provider

4. **What are the challenges adolescents living with HIV face in accessing information and advice on the concerns discussed earlier?**

Probe: Use a particular concern e.g. STI symptoms to initiate the discussion

5. **What are the challenges adolescents living with HIV face in accessing sexual and reproductive health services?**

6. **In future, where would adolescents living with HIV prefer to obtain information and advice on sexual and reproductive health from?**

7. **What are sexual and reproductive health services and commodities that adolescents living with HIV would like to be provided to them?**

Probe: Prompt participants to explain more on the preferred service provider, e.g. counsellor, school teacher etc.

8. **What are the views on relationships, marriage and childbearing for adolescents living with HIV?**

Probe: Explore perceptions on future plans on marriage and fertility desires.

9. **Summarise the main points raised in the discussion. Ask the participants if there are any other points they would like to add.**

Thank you for your time

Notes

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