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HIV/AIDS Programming and Sexuality of Young People Perinatally Infected with HIV

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ABSTRACT

This paper draws on preliminary data from an ongoing project implemented by TASO Uganda and Population Council, which aims to contribute to promotion of the sexual and reproductive health (SRH) rights of young people aged 10-19 years perinatally infected with HIV. The key argument in this paper is that HIV/AIDS programming in Uganda and elsewhere in Africa will need to acknowledge that the population of young people perinatally infected with HIV is growing and to specifically target them. HIV/AIDS programming will also address the sexuality dreams and desires of young people perinatally infected with HIV by providing them with information and practical support to understand their sexuality as they grow. This information is critical to guide them to negotiate vital aspects of their sexuality, enjoy positive lifestyles, and avoid undesired consequences such as unwanted pregnancies, infection of others and self re-infection. Effective sexuality counseling should also be provided so that young people living with HIV can make informed choices and be able to balance responsibility with sexuality desires.

INTRODUCTION

In HIV/AIDS programming, concern for the vulnerability of young people to HIV infection overwhelms some of the more positive realities of sexuality, which is an equally important part of growing up[1, 2]. Emerging research has highlighted wide programmatic gaps in addressing sexual and reproductive health needs of young people with perinatally acquired HIV now maturing into adolescence and adulthood[3-5]. The almost exclusive focus on the negative implications of sexuality has limited a broader understanding of sexuality young people living with HIV and its

application in HIV/AIDS programming, a problem compounded by the wrong assumption that surviving young people (10 to 19 years) living with HIV may be too few to justify targeted programming and a reluctance to acknowledge that it is quite natural for them to have sexual needs and desires and to act upon them. Worse still, studies on the sexuality of people living with HIV tend not to ask questions about desire or how sexuality may be a source of happiness, personal fulfillment and well-being. More often than not, these studies have been conceptualized within the disease framework, mainly responding to questions related to risky sexual behavior to the neglect of other vital elements of sexuality[6]. For instance, recent studies on PLHA receiving antiretroviral therapy (ART) have been premised on the assumption that the success of ART may be closely associated with a reduction in protective and preventive behaviors. Consequently, these studies have tended to explore high-risk sexual behavior of patients receiving ART. The questions normally asked relate to sexual intercourse in the last six months, number and type of sexual partners, knowledge of sexual partner's HIV status, disclosure of HIV status to partner, condom use during last sexual intercourse and experience of sexually transmitted disease.

In addition, if at all sexuality is discussed during young people's counseling it tends to be on discouragement of sexual initiation. Yet, in a recent clinic based study young people living with HIV lamented that: "If you say HIV infected people should abstain, it's like condemning us to die"[5]. However, service providers seem neither interested nor motivated nor prepared to find out about client sexuality desires. Even though HIV/AIDS programs promote the concept of positive living, the content has been on proper nutrition, exercise and controlling stress. Issues related to sexual desires are not given due attention, thus threatening the very right for young people living with HIV to exist, let alone to love and to be loved. Talking about positive living without embracing issues of sexuality has often left most clients unprepared for satisfying sexual lives; and worse, it encourages non-disclosure of their HIV status to potential and existing partners.

Increased access to ART has enabled people living with HIV to live positively and resulted in improved quality of life. Most young people living with HIV describe quality of life as "wanting to be like any other young boy or girl", an aspiration connoting sexuality. Therefore, it can only be anticipated that young people infected with HIV increasingly desire to act upon their sexuality and would appreciate the opportunity to talk and ask questions about their sexuality.

Young People Living with HIV: Sexuality Experiences, Dreams, and Desires

The number of African children living with HIV continues to escalate despite the advances made in prevention of mother-to-child transmission. According to UNAIDS, an estimated 110,000 Uganda children under the age of 14 are living with HIV and about 7,000 of them are obtaining free antiretroviral (ART) treatment from various HIV/AIDS treatment, care and support centers across the country. Whereas previously it was never anticipated that infants born with HIV would have the opportunity to live on to adulthood and sexual development, the roll-out of ART treatment programmes has made this possible, albeit for a small but growing proportion. True numbers of living children and young people aged between 10 to 19 years born HIV-positive are almost impossible to find, but some indications are available. For instance, TASO Uganda's oldest surviving HIV perinatally infected client turned 23 years in 2006. TASO has also registered 4,696 young people living with HIV since infancy. The Pediatric Infectious Disease Clinic (PIDC) in Mulago Hospital in Uganda has over 600 young people living with HIV between the ages of 10 and 19 years and Mildmay clinic is attending to over 600 young people.

Young people living with HIV are now beginning to explore their sexuality; they are dating and some of them are beginning to share intimacy. During this year alone, TASO reported 184 pregnancies and PIDC reported 9 pregnancies among young people receiving HIV/AIIDS treatment, care and support through these organizations, and staff at these centers suspect that more are likely to become pregnant. In 2006, Mildmay clinic had recorded 7 pregnancies among its young cohort. It is unclear whether these pregnancies were intended or unintended. But it appears that HIV infection may not have significantly changed attitudes towards childbearing in Uganda[7]. The desire to have children early in adult life is very high, including for young people living with HIV. In the on-going study by TASO Uganda and Population Council some young people living with HIV strongly expressed the desire to live independently soon so as to have children of their own. Generally, Ugandans have their first sexual experience very early in life. According to the 2004-2005 HIV/AIDS sero-behavioral survey, 14 per cent of young women and men have sex before age 15 and 63 per cent of women and 47 per cent of young men have sex before 18 years of age[8]. Thus in this context, young people living with HIV may desire and/or succumb to

family and social pressure to have children early so that they do not die without offspring, but existing HIV care and support programs do not seem to address the fertility aspirations or desires of this small but rapidly growing population of young people.

The difficulties of working with young people in general on issues of sexuality are made even more complex in the case of young people living with HIV. At present, key interventions to alter disease transmission and prevent pregnancy among young people have tended to emphasize delaying sexual debut, reducing the number of sexual partners, and increasing correct and consistent condom use. A major limitation, however, is that these interventions have tended to target the general population, who are assumed to be either HIV-negative or unaware of their HIV status. The absence of targeted research on the sexuality of young people perinatally infected with HIV has rendered this impossible. At the very best, treatment, care and support programs continue to encourage young people living with HIV to postpone sexual initiation. This, however, is not always possible since some young people are always going to have sex, whether or not they are discouraged from doing so. Preliminary findings from TASO Uganda and Population Council study show that many young people living with HIV are sexually active and prefer HIV negative partners. These young people also stated that they are least worried about being HIV positive because this is a condition they have lived with since infancy; but they have real concerns about infecting other people with HIV, disclosing their HIV status to other people and they are worried about their looks. Becoming pregnant or impregnating someone is also a concern among a few of the respondents.

In another study conducted through PIDC which included 75 adolescents living with HIV confirmed that adolescents living with HIV are sexually active. Here, it was found that 25 per cent of them had had penetrative sex. The preference for HIV- negative partners was reported high among adolescents attending PIDC because of the perceived fear of re-infection. The PIDC study also revealed several myths held by adolescents living with HIV. For instance, some held the myth that semen does not have the virus, and yet other thought that adolescents living with HIV are not fertile[5]. This emerging evidence reinforces the need to understand relationships, fears and desires of young people living with HIV and their implications for HIV/AIDS programming.

Sexual Rights of Young People Living with HIV

WHO (2005) emphasizes that for sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled[9]. Nonetheless, the right to sexuality information and services for young people living with HIV continues to be neglected. The UN (General Assembly Comment NO 3 January 2003) Convention on the Rights of the Child highlights the need to give careful attention to the sexuality of children[10]. The convention underscores the fact that children require relevant, appropriate and timely information tailored to age levels and capacity that enables them to deal positively and responsibly with their sexuality. The convention also emphasizes that effective HIV/AIDS prevention must avoid censoring, withholding or intentionally misrepresenting health-related information, including sexual education and information. Consistent with their obligations to ensure children's survival and development, signatories of the convention must ensure that children have the ability to acquire the knowledge and skills to protect themselves and others as they begin to express their sexuality. Recent WHO/UNFPA guidelines on care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings have also underscored the need to address the particular sexual and reproductive health needs of adolescent girls with HIV, ensuring the availability of age-appropriate information and counseling on sexuality and safer sexual practices, and offering adolescent-friendly family planning counseling and services[11].

Possible Solutions: Researching the Sexuality of Young People Living with HIV

Generally, the sexuality dreams and desires of young people living with HIV in Uganda and elsewhere in Africa are hardly known. Researchers need to generate a body of knowledge/evidence to inform programming and policy making. The framework developed by framework developed by WHO/Global is useful tool in this research engagement. WHO has described sexuality as something experienced and expressed in thoughts, fantasies, desires, beliefs, values, behavior, practices, roles and relationships. In relation to sexuality, WHO has also emphasized that sexual health is not merely the absence of disease, dysfunction or infirmity, but rather a state of physical, emotional, mental and social well-being. Therefore, addressing sexual health requires a positive and respectful approach to sexuality and sexual relationships.

Exploratory and descriptive studies are needed within the broad framework this of sexuality to guide the design and development of interventions that integrate HIV/AIDS with other sexual and reproductive health services. These studies should address the following issues: (i) family background, reflections on childhood, puberty and adulthood, lifestyle, and friendships; (ii) emotional acceptance of HIV and life in general including perspectives on growing up, feelings and thoughts about personal life, life goals and what they wish to be; (iii) perspectives on motherhood and fatherhood including attitudes, experiences and perceptions about early parenthood (whether boys have ever made their partners pregnant), responses to unintended pregnancies; readiness to be a parent; (iv) self-esteem including anxieties, dreams and hopes about self, relationships; (v) love and loving including dating, justifications regarding love, sex and dating, reasons for relationships; (vi) sexual histories including sexual desires and intentions/experiences/exploration/expression, worries, emotions and excitement about sex, general views about sex; (vii) sexual experiences including concerns about sex, identifying the right moment for girls and boys to start having sex, expression of feelings, whether they have ever had sex, both desired and undesired (sexual abuse and coercion); (viii) puberty and development including perceptions about masculinity and femininity, negotiating puberty, self-care, decision-making and partner communication, most difficult and confusing part of sexual development; (ix) having and not having children including attitudes, desires, pressures, expectations and knowledge of ways to prevent pregnancy; and (x) services and information including sources, need and demand, utilization of sexual and reproductive health services, opinions and preferences regarding existing services and what type of services they would like to have.

Methodologically, these studies should be both quantitative and qualitative in nature. Ethnographies on young people living with HIV are needed to gain an insight into their inner lives and how they navigate their passage to sexual maturity. Distinctions will need to be made between young people living with HIV by their social characteristics: those in and out of school, married, pregnant, parents, singles, those in relationships, those involved in support groups, etc. In-depth data on the personal lives, feelings, desires, social and interpersonal dynamics that influence their sexuality should be gathered through recording life-history narratives and case stories. Emphasis here should be on an "emic" approach; that is, on trying to understand how young people living with

HIV construct their sexuality while living with HIV and discovering how they view their own situation, and how they go about life in general. Case stories illustrating events around sexuality should be elicited, and young people living with HIV should be encouraged as much as possible to relate particular events of relevance in their lives.

Group discussions could also generate useful data on group opinions, perceptions, and attitudes around sexuality as well as sexual and reproductive health education and service needs. Group discussions could be organized around: 1) young women living with HIV who are single; 2) young men living with HIV who are single; 3) young women living with HIV who are pregnant; 4) young men living with HIV who are fathers; 5) young men and women living with HIV who are in school; and 6) young married women living with HIV.

Surveys on young people perinatally infected with HIV are also necessary to provide quantitative data that could be used as evidence to urge policymakers and program managers to consider the inclusion of different sexuality perspectives into HIV/AIDS programming.

In addition, existing HIV/AIDS treatment and support programs will need to be reviewed in order to identify existing intervention gaps in sexuality-related services and information for young people living with HIV. The review should involve both a desk and stakeholder appraisal. A desk review of current treatment, care and support HIV/AIDS programs documents is necessary to determine the content and the extent to which they facilitate or influence the provision of sexuality-related supportive information and services to young people living with HIV. The stakeholder analysis should include key informants from governmental institutions, private organizations, non-governmental organizations, faith-based organizations, health development partners, and technical assistance agencies. Possible areas of focus for discussions with key stakeholders include the following: (i) factors that influence the provision of sexuality counseling to HIV-positive young people; probe for funding ideology, technical gaps, etc.; (ii) service providers' understandings and/or interpretations of sexuality counseling for HIV-positive young people and level of support for it; (iii) the extent to which sexuality and reproductive health counseling and related services have been integrated; (iv) content of counseling training and services: issues recognized/receiving attention and which aspects are not receiving attention and why? (v) how is sexual and reproductive health counseling introduced and what is its content? To whom it is offered and why? (vi) how are

broad sexual and reproductive health concerns of HIV-positive young people handled within existing services? and (vii) capacity for existing HIV/AIDS treatment, care and support programs to handle the sexuality concerns of HIV-positive young people including skilled personnel (composition and training of service providers), existence of necessary infrastructure, protocols and guidelines, review of training needs and other resources.

Linking Research to Interventions

It is critical that research on young people living with HIV is linked to interventions. Researchers should facilitate this link through the data interpretation process and by identifying possible interventions together with policymakers, program managers, donors, and beneficiaries. Generally, actual interventions that embrace a broad perspective on sexuality only become apparent after detailed information on notion of sexuality among young people living with HIV has been gathered. However, possible strategies or interventions may include the following: (i) integrating of sexuality and family planning concerns into treatment, care and support programs for young people living with HIV; (ii) developing sexuality counseling guidelines and a sexuality desire assessment tool for young people living with HIV. The sexuality desire tool could be used to screen clients systematically for their sexuality desires and needs so that service providers can offer the appropriate information or services, or refer clients appropriately; (iii) developing a counseling curriculum for young people living with HIV for counselors; and (iv) developing a life skills curriculum for young people living with HIV.

Currently, HIV/AIDS care in Uganda and other African countries is organized around pediatric and adult care. Most young people living with HIV receive their treatment, care and support through pediatric care clinics and a few receive services through adult care clinics. Either way, the tendency has been to handle young people living with HIV as if they were young children. While some service outlets have incorporated child counseling into their treatment, care and support package, this falls short of mentioning sexuality issues let alone empowering young people living with HIV with necessary information to enable them balance rights and responsibilities, make informed decisions about their lives and contribute to their quality of life in general.

Existing counseling and support packages will need to be updated, reorganized and/or redesigned to: (i) address the gap between pediatric and adult care; and (ii) embrace vital elements of sexuality for young people living with HIV. In order to be effective, interventions will need to address the sexuality desires and dreams of young people living with HIV and engage different agencies and groups working with young people living with HIV. To facilitate this link, researchers will need to create strong liaisons with existing stakeholder communities as well as existing support groups for young people living with HIV to solidify consensus on possible interventions and their design as well as to stimulate exchange between research teams and actors involved in programming.

Emphasis should be on ensuring that adolescents living with HIV, programs and organizations are all involved in designing the interventions. A key analytical issue to be addressed is the negotiation of the gap between treatment, care and support programs and the actual sexuality needs of young people living with HIV. Researchers should use data from the exploratory studies to make program managers aware of the sexuality desires and dreams of young people living with HIV that need to be addressed. Up to now, treatment, care and support programs have focused on changing people's behavior. I anticipate that data from these studies will serve instead as a concrete basis for generating discussions on how existing HIV/AIDS programs will have to change to incorporate, for instance family planning and life skills needs for young people living with HIV. The possibility of programs offering value-free information on sexuality to young people living with HIV also has to be debated.

CONCLUSIONS AND RECOMMENDATIONS

Sexuality of young people living with HIV remains neglected in HIV/AIDS programming. In order to guide HIV/AIDS programming appropriately, researcher are encouraged to engage with the WHO framework on sexuality and create a body of knowledge that balances concern for disease with issues of positive sexuality such as loving, dating, desires, happiness and growing up among young people living with HIV. Following this model of sexuality, HIV/AIDS treatment, care and support programs will need to provide young people living with HIV with information and practical support to understand their sexuality as they grow up in order for them to negotiate vital aspects of their sexuality, enjoy positive lifestyles, and avoid undesired consequences such as unwanted pregnancies, infection of others and self re-infection.

Effective sexuality counseling should also be provided so that young people living with HIV can make informed choices and be able to balance responsibility with sexual and reproductive rights.

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