Sexual, reproductive health needs and rights of young people with perinatally Acquired HIV in Uganda

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Abstract

Background: Numbers of young people with perinatally acquired HIV is growing significantly. With antiretroviral drugs, children who get infected at birth with HIV have an opportunity to graduate into adolescence and adulthood. This achievement notwithstanding, new challenges have emerged in their care and support needs. The most dynamic being, their sexual and reproductive health needs and rights (SRHR).

Objectives: This paper aimed at establishing the gaps at policy, program and health systems level as far as addressing sexual and reproductive health needs of young people who have lived with HIV since infancy is concerned.

Methods: This paper is based on a desk review of existing literature on sexual and reproductive health needs and rights of young positives.

Results: The results indicate young positives are sexually active and are engaging in risky sexual encounters. Yet, existing policies, programs and services are inadequate in responding to their sexual and reproductive health needs and rights.

Conclusion: Against these findings, it is important, that policies specifically targeting this subgroup are formulated and to make sure that such policies result in programs and services that are youth friendly. It is also important that integration of Sexual Reproductive Health (SRH) and HIV services is prioritized.

Key words: HIV and AIDS, perinatally infected children, sexual and reproductive health needs, sexual and reproductive rights, Young people living with HIV/AIDS, Adolescents living with HIV, HIV Programming, HIV policies in Uganda

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Introduction

Almost three decades into the HIV pandemic, the outlook of HIV/AIDS has evolved significantly from an automatic death sentence following a positive diagnosis with the HIV virus, to a chronically manageable disease that can be lived with for a long time[1]. This transformation has been possible because of antiretroviral drugs which allow those infected to live longer and enjoy healthier lives[2,3] . Nowhere has the impact of antiretroviral therapies been so remarkable like in the lives of children perinatally infected with the HIV virus[4]. Hitherto, those who contracted the HIV virus vertically would barely live for two years characterized by ill-health[5]. It was, therefore, not anticipated that children with perinatally acquired HIV would live long enough to experience the conventional challenges of adolescence and adulthood such as sexuality and childbearing decisions[6].

In Uganda as is the case elsewhere in the world, the first cohort of children born HIV positive has defied all odds to reach adolescence and early adulthood[6,7]. Like all young people growing up, they have reached a stage characterized by many physical and emotional changes. It is at this stage in the human cycle that young people begin to explore their sexuality putting themselves at the risk of unwanted pregnancies and sexually transmitted diseases (STIs). For Young People with perinataly acquired HIV, the conventional challenges of adolescence are even more complex considering the intricate relationship between sexual activity and HIV transmission. Despite their HIV positive status, Young People Living with HIV (YPLHIV) have sexual and reproductive health needs and rights[8]. They desire to love and to be loved and have plans to produce children. Besides, they have the freedom of choice

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regarding sexual matters, reproduction, marriage and the fundamental right to access sexual health information and comprehensive sexual health services[8,9].

Given the dynamics of sexual and reproductive needs and choices of people living with HIV (PLHIV)[10], addressing sexual and reproductive health needs of Young people with perinataly acquired HIV introduces a complex chapter in the fight against HIV and AIDS. This is because of the intricate relationship between sexuality and the main modes of HIV transmission. In Uganda for example, 80% of HIV infections are through heterosexual intercourse while mother to child transmission accounts for 22-25% of all HIV infections in the country[6]. It should also be noted that the complexity of dealing with sexuality matters among adolescents are even more challenging when dealing with YPLHIV. As many children with perinataly acquired HIV graduate into adolescence and adulthood, it is imperative that their sexual and reproductive health needs and rights are critically examined in relation to existing HIV programs, policy environment and health systems, to identify the gaps and opportunities.

This paper draws on emerging literature around the globe on sexual and reproductive health needs and rights for young people with perinatally acquired HIV, to assess the implications this phenomenon might have for HIV Programming in Uganda. It gives some recommendations for policy formulation/review and program design/evaluation to make specific reference to sexual and reproductive health needs and rights of this population.

Methods

This paper is based on a desk review of literature on the sexual and reproductive health needs and rights of YPLHIV. A number of relevant materials and documents on this subject were searched using both the Bio medical and Social science data bases. These included Google Scholar, Pubmed, Medline, Popline and HINARI. Other publications and reports that had relevant materials on this subject matter were also reviewed. Abstracts/papers and documents were considered for review if they had information that was in line with the search objectives and published from 2000 onwards.

Results

Overview on adolescents perinatally infected with HIV

From available literature, it is evident that sexual and reproductive health needs of adolescents with perinataly acquired HIV are not so different from those of their counterparts who are HIV negative[10]. They are experimenting with sex, are sexually active, some have multiple sexual partners, do not consistently use protection in sexual encounters and some have initiated childbearing[5,10]. However, YPLHIV have special needs dictated by both biological and social factors that are pertinent to being HIV positive[11]. For example, they need skills to deal with issues of disclosure to their partners to prevent the spread of the HIV virus and making informed decisions about reproductive health issues like childbearing[12].

Although exact numbers of YPLHIV are hard to determine because HIV data is normally disaggregated between adults and children[13,14] it is evident that their population is steadily growing across the globe. In Uganda for example, TASO a non governmental organization dealing with HIV positive people had by 2006 registered 4,692 young people aged 10-19 years who have lived with HIV since infancy[6]. Other service centers such as the Pediatric Infectious Disease Centre (PIDC) and Mildmay Uganda have equally registered substantive numbers of this subgroup at 600 and 700 respectively[2,6].

In the United States which has a long history of antiretroviral therapies, some children with perinataly acquired HIV have entered the third decade[3,15] and there are indications that many more will join them. In the US which has a long history with antiretroviral drugs, the number of teenagers with perinatally acquired HIV was about 2400 in 1999 based on the analysis of data from the Pediatric Spectrum of HIV Project and CDC HIV/AIDS surveillance databases[4,16]. The researchers projected that many more will be 13 years and above in 2005. The NISDI pediatric study carried out in Brazil, Argentina and Mexico with an objective of determining the mode of HIV transmission among 109 adolescents aged 12-19 revealed that most of them (61%) had lived with HIV since infancy[17] this underlines the fact that significant numbers of young positives will reach adolescence and adulthood with access to antiretroviral drugs.

As the population of perinatally infected adolescents/adults grows, policy makers, HIVAIDS

programmers, service providers and all stakeholders in the fight against HIV/AIDS need information to effectively respond to their evolving needs for effective treatment and psychosocial support and most importantly responding to their sexual and reproductive health needs and rights[18].

Sexual behaviors of young people with perinatally acquired HIV.

In Uganda, young people initiate sexual activities very early in life. According to the 2004/05 National HIV/AIDS Sero-Behavioural Survey, age at first sex was estimated at 16.7 years for girls and 18.8 years for boys[14]. Despite some evidence that long term survival with HIV/AIDS impacts on normal growth and might delay transition to puberty leading to delayed sexual initiation[21], it is evident that age at first sex among these young people does not differ significantly from that of the general population. By late adolescence and early adulthood majority are already sexually active and some will have produced children[2,6].

As far as sexual behaviours are concerned, young people who have lived with HIV since infancy YPLHIV rarely use protection at first sex nor are condoms used consistently in subsequent sexual encounters. It is evident from the literature that sexual behaviours of these young people are as risky as those of their counterparts who were born HIV negative. A study in Uganda a study involving 732 adolescents aged 15-19 years with perinatally acquired HIV revealed that 61% of the sexually experienced did not use condoms at first sexual intercourse[6]. Similarly, a cross sectional retrospective study in the US[21] among older children, adolescents and young adults who had lived with HIV since infancy reported inconsistent condom usage among the sexually active[22].

The above studies not withstanding, risky sexual encounters are also manifest in the increasing number of pregnancies occurring in this subgroup and also those who present with sexually transmitted diseases at treatment centers[21]. In Uganda, TASO has registered over 184 pregnancies among this subgroup[5] while PIDC has recorded 6 pregnancies among their born positives. Some studies from the United States indicate that young women with perinataly acquired HIV have presented with second time pregnancies. All these are indications that sexual and reproductive health needs of young people who have lived with HIV since infancy are not different from their counterparts who acquired HIV behaviorally or were born HIV negative.

Concerning the choice of sexual partners, some studies have revealed that many young people with perinatally acquired HIV prefer HIV negative partners[2,6]. Some of the reasons advanced for this preference include avoiding re-infection and the need for begetting HIV negative children[6]. Although not much literature exists on this subject, it is a significant revelation that many policy makers and programmers in HIV/AIDS need to critically analyze given its implications. This is important because YPLHIV have serious challenges when it comes to disclosure of their HIV status fearing rejection from potential sexual partners[6].

Pregnancy and childbearing by YPLHIV

Fertility intentions and choices are central to every human being and young people with perinataly acquired HIV are not any different. As many graduate into adolescence and adulthood, it is anticipated that a significant number will initiate childbearing. In fact literature reveals that not only are they planning to produce children, some have already initiated childbearing[2,5,22]. Although there isn't much evidence in the literature as to whether these pregnancies are planned or not, some studies indicate that many are unintended.

In summary, evidence from the literature indicates that young people who have lived with HIV since infancy are not any different from their counterparts who were born HIV negative as far SRH needs are concerned. They are in relationships, some are sexually active, engaging in risky sexual encounters and initiating childbearing.

Sexual and reproductive health rights

Sexual and reproductive rights (SRR) are enshrined in many international conventions, agreements, laws and declarations. The right to sexual and reproductive health provides that people are able to enjoy a mutually satisfying and safe relationship free from coercion or violence[23]. These rights provide a frame work within which sexual and reproductive well-being can be achieved.

Like many other declarations made at international gatherings, commitments undertaken to protect and guarantee SRR for PLHIV have not translated into policies and programs in member countries Uganda inclusive. This is because member states lack either the commitment, resources or will to implement them. Also, the international

community lacks the mechanism and mandate to enforce implementation of such declarations.

Existing policies and Sexual and reproductive health needs and rights of YPLHIV. In Uganda some policies that relate to adolescence health are in place though most of them lack specific reference to adolescents with perinataly acquired HIV. However, if reflected upon in program design and service provision, these policies would provide a supportive and conducive environment for addressing sexual and reproductive health needs of YPLHIV. Some of the policies include the National policy Guidelines and Service Standards for Sexual and Reproductive Health rights by the Ministry of health (2006), National Health Policy, National adolescent Health policy and the sexual and reproductive health minimum package for Uganda.

Despite having clauses that clearly pertain to adolescent sexual and reproductive health, these policies rarely inform programs or services that are aimed at addressing the needs of young people in general more so those living with HIV[24]. The divide between policies and programs is mainly attributed to bureaucracies that hinder swift dissemination of these policy guidelines to all stakeholders.

HIV/AIDS programs and SRHR of young people with perinatally acquired HIV in Uganda

In many developing countries Uganda inclusive, HIV/AIDS programs and services are designed around pediatric and adult care[6]. In either setting, the needs of YPLHIV can not be adequately addressed more so their sexual and reproductive health needs. This is for the basic reason that YPLHIV differ from children and adults infected with HIV. Whereas children living with HIV are treated as innocent, YPLHIV are often discriminated against on prejudices of immorality commonly associated with the HIV epidemic[23,24]. Likewise, sexual and reproductive health needs of YPLHIV are not the same like those of older PLHIV[23]. For example, older people are much more likely to have initiated sex, are most likely to have long term sexual partners and may have children of their own.

It should also be noted that HIV programming in Uganda is focused around prevention activities such as HIV counseling and testing and increasingly HIV/AIDS treatment care and support[24]. In the early days of the epidemic, high levels of morbity and mortality among those infected with HIV blinded programmers to other services needs especially sexual and reproductive health needs. The failure to integrate SRHR services into HIV/AIDS care for YPLHIV further undermines the ability of HIV programs to effectively address SRH needs of YPLHIV[25]. It is a known fact that young people prefer "one stop shopping" which literally means accessing all services from one place and preferably by the same provider[26]. In case of referral, there is documented evidence that very few clients make it to the referred point[27].

There is increased outcry among young people living with HIV about limited financial support for youth friendly programs and services[8]. Their sentiments have been aired at many international conferences and most recently at the landmark global consultation on sexual and reproductive health needs and rights of PLHIV that took place in Amsterdam the Netherlands. At this conference, YPLHIV lamented of the failure by the international community and individual states to commit enough money for youth friendly services[8]. This is believed to hinder efforts of ensuring universal access to care and support[28].

Lastly, many HIV programs rarely involve young people living with HIV in planning, designing, implementation and evaluation of programs meant to benefit them[8,28]. Moreover, the right of involvement is enshrined in the United Nations General Assembly document (UNGASS)[10]. This undermines the effectiveness of these programs because there is evidence that young people prefer services by their peers or those that reflect their ideologies[26,29].

Health systems and sexual and reproductive health needs and rights of YPLHIV

Health systems and a skilled workforce are the backbone of all efforts to combat HIV/AIDS. In many developing countries, however, health systems are badly undermined by limited budget allocation and inadequate investments in health infrastructure[12]. This has been exacerbated by the heavy burden of HIV/AIDS because funds are withdrawn from other sectors to finance HIV/AIDS care, treatment and support activities[28].

In many developing countries, health facilities are understaffed hindering comprehensive service delivery including sexual and reproductive health services especially for PLHIV. As a result, services are characterised by long hours of waiting and overcrowding[8]. These factors are a stumbling

block when it comes to addressing sexual and reproductive health needs of YPLHIV.

More so, poor health workers' attitude has been cited as a major problem when it comes to addressing sexual and reproductive health needs of People living with HIV/AIDS. Literature indicates that most health workers still hold the view that PLHIV should be asexual in total disregard of their needs, aspirations and rights[5]. This, however, is delaying the inevitable because young people with HIV are not any different from those who are HIV negative[31,32].

Another factor that undermines health systems abilities to adequately address sexual and reproductive health needs and rights of young people in general and those living with HIV particular, is limited skills among health workers[30]. Many health workers are not trained to work with young people more so those who have lived with HIV since infancy. They are, therefore not in position to provide appropriate, effective and non judgmental information to YPLHIV to help them balance rights and responsibilities.

Lastly, the evolution of HIV/AIDS programs vertically from traditional health systems has resulted in unequal access to quality health services between those who access care from traditional health systems vis-à-vis those in vertical HIIV programs[33]. Although proponents of the vertical HIV/AIDS programs argue that this has not undermined services in the general healthcare system, it is evident that HIV/AIDS programs which have emerged vertically from traditional health systems have drained specialized personnel from the traditional system because they tend to pay better. Moreover, these programs are also concentrated in urban areas, a bais consistent with all health systems.

Discussion

Meeting sexual and reproductive health needs and rights of young people perinatally infected with HIV is a challenging and dynamic chapter in the fight against HIV and AIDS. This is largely due to the intricate relationship between the main modes of HIV transmission and most aspects of sexual and reproductive health[34]. As a result, many HIV/AIDS programs and policies especially in developing countries like Uganda lack specific components and strategies targeting this group which can result in serious consequences.

It is evident from the data that these young people are engaging in risky sexual encounters which has implications for prevention strategies. In a study by Birungi et al, 2008 among 732 (15-19 year olds) who contracted HIV vertically and were drawn from different HIV programs in Uganda, 33% had initiated sex and only 1/3 used condoms at first sex. Inconsistent condom usage in subsequent sexual encounters has also been reported in this population. A comparative study between perinatally and behaviourally infected young people with HIV in the US[37], reported that both sets of adolescents were engaging in risky sexual encounters. Of the 49 adolescents who reported risky sexual behaviours, 12 had lived with HIV since infancy. This evidence is a clear indication that sexual and reproductive health needs and rights of young people with perinatally acquired HIV should be prioritised in programs and policies. This is crucial given the unique relationship between most aspects of reproductive health and the main modes of HIV transmission.

At program level, the diversity of sexual and reproductive health needs of YPLHIV makes it hard to design suitably tailored sexual and reproductive health programs that can accommodate the needs of all YPLHIV. This is because sexual and reproductive health needs of YPLHIV are as diverse as the epidemic itself[35]. They differ according to gender, age and social economic status. Yet, unlike their counterparts who are HIV negative, any lapses at programming level can have serious consequences for the prevention strategies. This, therefore, calls for a lot of innovation on the part of program designers to put in place programs that can adequately address sexual and reproductive health needs of YPLHIV.

In many resource constrained countries like Uganda, programs with services for this subgroup are still limited in terms of scope and coverage[25]. Most of them have emerged as separate entities from existing health systems which are easily accessible by many. It is also important to note that most HIV/AIDS programs that deal with perinatally infected adolescents are located in urban areas and are almost non existent in rural areas[33]. The fact that most HIV interventions operate as programs/projects, there are issues of sustainability since these initiatives have not been integrated in the traditional health systems.

Another challenge is the failure to involve YPLHIV in the planning, designing, implementation and evaluation of programs aimed at meeting their needs including sexual and reproductive health[28]. Research shows that young people prefer services that are offered by their peers and also those that revolve around their ideologies.

The HIV prevention strategies aside, social attitudes and biases which are echoed in policies that target people living with HIV make it harder to address sexual and reproductive health needs of people living with HIV including the young positives[37] The negative attitudes have come to light in the attempts to criminalize the spread of HIV in some countries irrespective of the 2001 commitment by 189 world leaders at the United Nations (UN) General Assembly Special Session on HIV/AIDS to ensuring that "people living with HIV and AIDS experience "the full enjoyment of all human rights and fundamental freedoms[38]"

As far as access to sexual and reproductive health services are concerned, most HIV/AIDS programs in developing countries Uganda inclusive, are designed around pediatric or adult care[38]. In either setting, sexual and reproductive health needs and rights of YPLHIV can not be adequately addressed because young positives are neither children nor adults. More so, literature indicates that the quality of services is compromised by the unskilled health workers who are not trained to deal with adolescents. It also emerges that sexuality of these young people is as complex as that of any other adolescents[33]. Many are reluctant to discuss their sexuality with either the parents/guardians or service providers. This creates an information gap on how to adequately address their sexual and reproductive health needs.

Recommendations

Regarding programs, it is very important that integration of reproductive health services and HIV/AIDS services is prioritised to increase uptake of such services and avoid missed opportunities. Such programs should be youth friendly and tailored to meet the diverse needs of different groups according to age, gender and social backgrounds. There is need for creativity in designing programs and services for YPLHIV because of the complexity this matter presents. All innovations in this area should be informed by the latest findings in science.

Similarly, deliberate efforts should be taken to ensure that IEC strategies address sexual and reproductive heatlth issues for young positives in general and those with perinatally acquired HIV in particular. This is important because SRH information is part and partial of the comprehensive SRHS package for these adolescents. Given that successes in HIV medical management have not been matched by successes in behavioral interventions, new developments should have a dissemination strategy with a clear monitoring and evaluation plan.

Lastly, there is need for more research to explore reproductive health needs of young people according to different determinants such as age, gender, school status orphan hood status and school status. Such findings are very important if programs designed are to be suitably tailored and have the desired impact.

Conclusion

In view of the issues emerging in the literature about sexual and reproductive health needs and rights of YPLHIV, it is prudent that policies are formulated that address key issues about the sexuality of YPLHIV. For example, the fact that these young people are initiating childbearing, it is critical that policy issues regarding contraceptives are handled so that YPLHIV are protected against unwanted pregnancies and for those planning reproduction mechanisms should be put in place to provide them with adequate information regarding PMTCT, breastfeeding and safe days to help them make informed decisions for their lives and the children. These policies should be disseminated widely to inform programs other than shelving them as is the norm in many countries.

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