

## PERSPECTIVES PAPER

# Addressing the Socio-Development Needs of Adolescents Living with HIV/AIDS in Nigeria: A Call for Action

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## Abstract

The widespread use of antiretroviral therapy and remarkable success in the treatment of paediatric HIV infection has changed the face of the Human Immunodeficiency Virus (HIV) epidemic in children from a fatal disease to that of a chronic illness. Many children living with HIV are surviving into adolescence. This sub-population of people living with HIV is emerging as a public health challenge and burden in terms of healthcare management and service utilization than previously anticipated. This article provides an overview of the socio-developmental challenges facing adolescents living with HIV especially in a resource-limited setting like Nigeria. These include concerns about their healthy sexuality, safer sex and transition to adulthood, disclosure of their status and potential stigma, challenges faced with daily living, access and adherence to treatment, access to care and support, and clinic transition. Other issues include reality of death and implications for fertility intentions, mental health concerns and neurocognitive development. Coping strategies and needed support for adolescents living with HIV are also discussed, and the implications for policy formulation and programme design and implementation in Nigeria are highlighted. (*Afr J Reprod Health 2014; 18[3]: 93-101*)

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**Keywords:** Nigeria, Adolescents living with HIV, socio-development, research

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## Résumé

L'utilisation généralisée de la thérapie antirétrovirale et des succès remarquables dans le traitement de l'infection du VIH chez les enfants a changé le visage de l'épidémie du virus d'immunodéficience humaine (VIH) chez les enfants d'une maladie mortelle à celui d'une maladie chronique. Beaucoup d'enfants vivant avec le VIH survivent à l'adolescence. Cette sous-population de personnes vivant avec le VIH est en train de devenir un problème de santé publique et de la charge en termes de gestion des soins de santé et l'utilisation des services que prévu avant. Cet article donne un aperçu des défis du développement social auxquels sont confrontés les adolescents vivant avec le VIH en particulier dans un contexte de ressources limitées comme le Nigeria. Il s'agit notamment des préoccupations concernant leur santé sexuelle, les rapports sexuels protégés et le passage à l'âge adulte, la divulgation de leur statut et de la stigmatisation potentielle, les défis rencontrés dans la vie quotidienne, l'accès au traitement et l'observance du traitement, l'accès aux soins et au soutien, et la transition de la clinique. D'autres questions comprennent la réalité de la mort et des implications pour les intentions de la fécondité, des problèmes de santé mentale et le développement neurocognitif. Les stratégies d'adaptation et le soutien nécessaire pour les adolescents vivant avec le VIH sont également discutés, et les implications pour la formulation des politiques et de la conception des programmes et la mise en œuvre au Nigeria sont mis en évidence. (*Afr J Reprod Health 2014; 18[3]: 93-101*)

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**Mots-clés:** Nigeria, les adolescents vivant avec le VIH, socio-développement, la recherche

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## Introduction

Over the last 30 years of the HIV/AIDS epidemic, there have been major improvements made in the provision of HIV prevention, treatment and care and support services. The impact of this on the lives of women and the very young girls has been

well studied and documented. Unfortunately, the effect on adolescents' (boys and girls aged 10 to 19years) health has received little attention except for the many publications that have emanated from developed countries such as the USA where adolescents perinatally infected with HIV have been present for some time. Economic

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development and the advent of anti-retroviral therapy (ART) have significantly reduced the risks of morbidity and mortality from severe medical illnesses for those living with HIV in sub-Saharan Africa. Global successes in reducing the impact of HIV in early childhood has also resulted in the shift of attention from HIV infection to problems that are prominent during adolescence such as injury, mental health, chronic physical illness, sexual and reproductive health amongst others.

Adolescents are central to many ongoing global discussions in the field of HIV and AIDS. These discussions also highlight the socio-developmental needs of adolescents and how to address them to enable adolescents meet the future global aspirations, including having them aptly play roles in promoting economic development. The potential to contribute to economic development as they become part of the national workforce is dependent on their health and educational status. The health and education of adolescent girls is also a major determinant of child health in the next generation, thus making these themes central in various global discussions about adolescents<sup>1-3</sup>. These discussions also highlight the socio-developmental needs of adolescents and how to address these to enable adolescents meet the future global aspirations. Many of these global discussions also include dialogue about adolescents living with HIV (ALHIV)

The experiences of ALHIV are unique to their life stage and differ from older young people living with HIV. Many adolescents live with and are dependent on their parent(s) or caregiver(s), limiting their ability to freely make decisions, access health services, and realise their sexual and reproductive rights. These adolescents also need to navigate the complexities of HIV and at the same time, cope with normative socio-developmental changes with less life experience than their older peers<sup>4</sup>. Living with HIV infection may therefore impact on the pattern and or process of change exhibited by these individuals as they grow through their formative years. This paper discusses the various socio-developmental challenges ALHIV may face and highlights peculiarities with ALHIV in Nigeria where there is data to support the assertions or deductions.

## Discussion

### *Healthy sexuality, safer and safer sex*

There are multiple factors that affect adolescents that may equally pose peculiar socio-developmental challenges for ALHIV. The multiple changes taking place during puberty often gets many young people confused, particularly in developing countries like Nigeria where most parents refrain from discussing matters of sex and sexuality with children who have little or no exposure to adolescent and youth-friendly information and services<sup>5</sup>. Poor parent-child communication on sex and reproductive health persists even between parents and children living with HIV<sup>6</sup>. This is a critical issue as young people in developing countries continue to struggle with intergenerational responsibility, family tensions, economic pressures, and violence; issues hardly focused on by most adolescent health service providers<sup>6</sup>. Yet, family and friends remain important and central to adolescents learning about sexual and reproductive health (SRH)<sup>6</sup>. Understanding this has resulted in a shift in the global agenda of adolescent health behaviour and risk research from the narrow focus on the individual to a broadened one utilising an ecological framework wherein the individual is viewed as nested within peer, family, school and community social environments<sup>7</sup>. It is therefore important to understand the feeling, experiences, challenges and struggles ALHIV deal with during this transition period of their lives and how an ecological framework can best be utilised to address their needs so as to ensure a healthy successful transition to adulthood.

### *Disclosure, stigma and transition to adulthood*

The needs of ALHIV are also much more sensitive and varied than those of adults living with HIV, as they must simultaneously deal with 'adult' issues such as disclosure, practicing safe sex, and adhering to treatment, while also addressing issues traditionally associated with adolescence such as body image, first sexual experience, peer pressure and forming personal identity<sup>8,9</sup>. Loos et al<sup>10</sup> noted

that that HIV-positive young people concurrently felt empowered and excited about growing older, while also being weary of the potential restrictions and increased responsibility resulting from their HIV status. As adolescents, issues about body image, sexual identity, increased importance to peers, envisioning the future, and independence increasing become central themes in their adolescent development.

However, managing the challenges of being HIV positive becomes a highlight of their life that may make or mar this transition period. For many, disclosure proved to be a “pivotal step in their lives”, often resulting in positive life changes including increased care and financial and emotional support<sup>11</sup>. Bakeera-Kitaka et al<sup>11</sup> however noted that for ALHIV in Uganda, partner disclosure proved to be most challenging when compared with disclosure to peers, friends and family. Only about a third of ALHIV disclose their HIV status to their partners<sup>7</sup>. A similar observation was made for ALHIV in Zambia<sup>12</sup>. Non-disclosure to partners makes individuals feel burdened with the responsibility to “control things” and prevent the onward transmission of the HIV virus. Yet, HIV-positive adolescents – like other young people - face pressure from peers and partners to have sex or not use condoms<sup>5</sup>. HIV related stigma and discrimination are common reasons cited by ALHIV for non-disclosure and poor uptake of SRH services<sup>13</sup>. Fear of rejection and loss of respect and care if their status became known is also a major concern<sup>14</sup>. Disclosure to family members is also avoided in order to protect them from receiving distressing information. Disclosure to health service provider was more comforting<sup>13</sup>.

### ***Life events and challenges for ALHIV***

There are other multiple issues that affect adolescents that may equally have peculiar socio-developmental challenges for ALHIV. In 2000, the United National High Commission on Refugee noted that a third of displaced persons, refugees and returnees are adolescents between the age of 12 and 24 years<sup>15</sup>. Also, the increased rural-urban migration has led to an increasing number of adolescents moving to large cities and towns for employment opportunities with a consequent reduction in access of adolescents to extended kin

network supports as traditional family and customary social networks disintegrate<sup>16</sup>. This loss of access to social networks and poor employment opportunities increase the tendency for youths to be homeless and live in the streets, face violence and contemplate suicide<sup>16</sup>. For a country like Nigeria where investment in social sector development such as health and education remains poor, access to quality health services and education remaining a challenge. Ninety percent of young people in Nigeria live on less than US\$2.00 a day<sup>16</sup>.

In addition, adolescents and youths live and deal with the challenges, conflicts and tension arising from globalisation, and the clash of culture with the attachment to traditional norms and cultural values amongst others. One of such clashes relate to premarital sex. A study by Birungi et al<sup>17</sup> noted that many ALHIV in Uganda felt that having sex is unavoidable and abstinence from sexual intercourse is nearly impossible. Yet little is known or understood about how ALHIV deal with these realities in their daily life situations; how adolescents HIV status inform choices made when faced with these mirages of challenges, conflicts and tensions that have possible impact on one’s mental health; and how these challenges impact on their daily medication needs and the various life choices they make.

### ***Challenges with adherence to treatment and clinic transition***

Even in the absence of the challenges that migration might place on medication adherence, most adolescents still struggle with adherence to medication at some point in their lives<sup>18</sup>. Adherence is often affected by misconceptions surrounding the need for good adherence, as well as by fears of unwanted disclosure and frustrations stemming from a sense of limited freedom associated with a treatment regimen<sup>18</sup>. Also, transiting from child to adult care poses its own challenges that result in many adolescents being lost to follow up<sup>11</sup>. Many ALHIV who were infected perinatally are at high risk of having treatment failure and multiclass antiretroviral (ARV) drug resistance due to multiple factors including socio-economic difficulties associated orphan-hood that can result in challenges with

drug adherence<sup>19</sup>. Many would have changed HIV treatment combinations several times before adulthood<sup>20-22</sup>. As at 2010, Nigeria had the largest number of children on ART in the world with 360,000 children on treatment representing 11% of the world's population of children with HIV<sup>23</sup>. This sub-population of people living with HIV may emerge as a major public health challenge and burden in terms of healthcare management and service utilization than previously anticipated.

Usually, most perinatally HIV-infected adolescents have received comprehensive care in the same clinic from the same provider throughout their life, and so may have developed a level of trust and familiarity with the clinic staff and philosophy of care that are rarely seen in any other practice settings<sup>23</sup>. For many adolescents it is challenging to leave this environment a start a new life in an adult clinic, and a reminder of the disruption associated with their lives as a result of the infection<sup>23</sup>. Other logistical barriers results from movement from a more forgiving and accommodating pediatric clinic to an anxiety- and fear-producing adult clinic where expectations and responsibilities are usually non-negotiable and support to navigate the system is poor<sup>24</sup>. Despite this reality, very little attention has been paid to understanding how to address the challenges associated with this transition<sup>25</sup>.

### ***Challenges accessing treatment and care***

For adolescents who were not infected perinatally, access to services remains a challenge and a psychologically torturing experience. Minimal support is offered and there are long waits to see a specialist. Immediate follow-up, counseling, and resources for adolescents who test HIV positive are also not readily available. The onus now lies on the young person to find HIV resources to address his/her needs. This emotional upheaval associated with a positive HIV diagnosis is compounded by real or feared negative impacts on the adolescent's relationships, education, career, and family goals. Thus, the psychosocial challenges ALHIV face may also differ based on the source of infection (perinatal or sexual), the duration of the time individuals learn about their HIV status, and time of access to support and services.

Studies conducted in Africa show that adolescents perinatally infected with HIV and on antiretroviral therapy may not know their HIV status as parents have challenges discussing SRH issues with their children due to restrictive cultural norms. Parents may also not be adequately informed to be able to discuss the issue. These parents or guardians may feel a sense of guilt for having infected their child; they may think the child is not mature enough to cope or are afraid of how the child will react; they may feel unable to answer the questions that would follow; they may be afraid of how their peers and community could react; or they may not know the best way to disclose such information<sup>13</sup>.

Therefore, care and support services for ALHIV need to recognise the specific needs of those who are born with HIV vis a vis those who acquire HIV in later life, and respond to their changing psychological and physical needs as they grow into adulthood. The questions of identity, sexual awakening, and reproductive rights are also most critical at this age. Programmes need to respond to these complex psychological and physical needs of adolescence<sup>5</sup>; and address their medical, psychosocial, and educational or vocational needs<sup>19</sup>.

### ***Reality of death and implication for fertility intentions***

ALHIV also have to live with the reality of possible death. Statistics continue to reveal high rates of adolescent mortality due to AIDS in both developed and developing countries. Adolescents in sub-Saharan Africa have only a 50% probability of surviving till 60 years compared to counterparts in developed countries who have up to 90% probability of surviving till 60 years<sup>26</sup>. For adolescents in Nigeria, this probability could be as low as 20%<sup>16</sup>. AIDS is a leading cause of death for adolescents in sub-Saharan Africa and the second leading cause of death worldwide after unintended injuries arising from road traffic accidents and the use of psychoactive substances. In the face of this reality, how do ALHIV make life choices that affect their development and future? Do adolescents who live within cultures that place a high premium on childbearing face pressures for

childbearing or succumb to familial/social pressure to have children early so that they do not die without an offspring? Do the existing HIV care and support programmes accessed by ALHIV address the fertility aspirations or concerns? Loos<sup>10</sup> noted that for ALHIV in Uganda and Kenya, the realities of living with HIV often results in many experimenting with sex at an earlier age than their peers as young people. Many reported that ALHIV “did not want to die without having sex”. In Zambia, this experience is different as ALHIV report that they also want children but after the completion of their education and when they have obtained a job<sup>12</sup>.

Puberty and growth offered a new start and chance for ALHIV to transform from a social outsider to a social insider, as those previously sickly in appearance and smaller than their peers grew into healthy adults<sup>17</sup>. Peer influence becomes central to their understanding of sexuality, sexual norms and identity, with positive adolescents attempting to mirror so-called 'normal' behaviour. Due to notions of AIDS as a deadly virus, many adolescents “live in the moment” and want to get “the most out of a life with HIV”<sup>10</sup>. Pubertal development is however delayed in both male and female ALHIV who acquire HIV perinatally and are not virologically suppressed<sup>27</sup>. ALHIV should therefore be counselled about this potential thereby reducing a tendency for anxiety and concern as they develop into adolescents and start to observe developmental differences when compared with their peers.

### ***Mental health concerns and neurocognitive development***

ALHIV live and cope with health challenges beyond the social and behavioural concerns associated with their HIV status. They have high rates of psychiatric illness and neurocognitive dysfunction (fine motor strength, language, executive skills and memory, academic achievement, and general cognitive ability) due to the impact of advanced HIV infection<sup>28-30</sup>. These learning or behavioural disorders may be asymptomatic or subtle<sup>31</sup>. Academic achievements of ALHIV are often below average<sup>32,33</sup>. Anxiety disorders and major depression have also been reported<sup>33</sup>. This highlights the need for increased

prevention and intervention strategies for ALHIV to improve their quality of life. There have been suggestions that the route of infection impacts on the neuropsychological challenges ALHIV may face and that environmental influences (poverty, poor education, single parent household) on neurocognitive functioning may be negligible<sup>9</sup>.

In addition to the above enumerated challenges, repeated hospitalisation and isolation from peers, and experiences of more negative life events such as death of parents or siblings, and abuse<sup>34</sup> impacts negatively on ALHIV's social, cognitive and communication development<sup>35</sup>. They experience more subjective distress than their uninfected peers including dysphoria, hopelessness, preoccupation with illness, and poor body image<sup>34</sup>. Some also engage in riskier sexual behaviours<sup>36</sup>. Depressive disorder rate is as high as 56% amongst ALHIV<sup>37</sup>. Also, they experience greater physical pain such as chest pain, oral pain, headache, abdominal pain and peripheral neuropathy compared to their peers, negatively affecting their quality of life and sleep pattern<sup>38,39</sup>.

Mental health services remain one of the weakest services accessed by PLHIV in general and by ALHIV in particular. Unfortunately, the UNGASS indicators do not capture information on provision of mental health service for PLHIV and so there is little information on access to mental health services by affected persons globally. Yet there are evidences to show that depression is associated with disease progression and death<sup>40</sup> and increased sexual risk behaviour<sup>41,42</sup>. Proactively addressing mental health issues in adolescents is beneficial because it results in better romantic relationships, heightened ability to resolve conflicts and problems with their partners, and higher expectations of themselves and their partners<sup>33</sup>.

### ***Coping strategies and support for ALHIV***

Coping with HIV infection itself is challenging. It is a complex phenomenon involving multiple interactive variables<sup>43</sup>. Cultural traditions and social norms inform coping strategies adopted by adolescents<sup>44</sup>. Where the culture is one that promotes shame, fear, humiliation, anger, stigma and discrimination, the negative impact of HIV infection is often more profound<sup>43</sup>. Attempting to

cope with a HIV positive serostatus may trigger social withdrawal, depression, loneliness, anger, confusion, fear, numbness and guilt<sup>45</sup>. Reminders about HIV status still cause significant degree of distress in adolescents even after several years of living with the status<sup>46</sup>. Coping strategies vary widely from resignation, self-calming and distraction, to less used techniques such as resorting to alcohol and substance abuse<sup>40</sup>. Interventions are needed to help ALHIV cope<sup>47</sup>. This includes the use of support groups and development of structured programmes (psychotherapeutic and psycho-educational) that help adolescents deal with these challenges<sup>12,46,48</sup>. The existing support groups and clubs are weak and so programs will need to provide training and support to their leaders for them to become sustainable and responsive to the needs of the members<sup>17</sup>.

Living and dealing with stigma is a constant challenge for all persons living with HIV. Birungi et al<sup>17</sup> however notes that young people living with HIV in Uganda do not primarily construct their lives around their illness but appear to have their concerns constructed around a better life in the future, their looks, and around issues of dating and loving. Despite this observation, a third of the respondents were worried about being HIV positive, almost one in six adolescents were worried about discrimination from friends and partners, and some expressed concerns about getting ill because it may implicitly lead to disclosure<sup>17</sup>.

Some ALHIV also have to contend with self-stigma<sup>13</sup>. The experience of stigma is worse for ALHIV who are men who have sex with men, sex workers, or people who inject drugs. This is because they often have to live through the jeopardy of being stigmatised for their sexual orientation, sexual behaviour and lifestyle, for being HIV positive, and 'being different' from their peers so early in life. The resulting 'condemnation' especially from loved ones is far more damaging and makes coping difficult for the individual.

## Conclusion

While it may be apparent that there might not be

too many differences in the needs and challenges ALHIV may face when compared with their peers who do not live with the virus, there might be significant socio-developmental concerns that programmes and policies may need to address with respect to ALHIV. Strategies adopted need to place the adolescent years at centre stage and plan for their health needs within a framework that addresses their socio-developmental needs. There is very little known about the situation of ALHIV living in Africa, Nigeria inclusive, and how their needs differ from those of their peers in other regions of the world. There is also little known and understood about how the socio-economic context of Africa in general and Nigeria specifically affects the socio-developmental needs of ALHIV. There is the urgent need to formulate relevant policies and programmes as challenges ALHIV face lead to morbidity and mortality arising from behavioural causes exacerbated by unfavourable national policy and failures of health service delivery systems, or both<sup>49</sup>. There is currently little evidence based informed derived from research to inform the development of policies and programmes for ALHIV in Nigeria. This is a real course for concern.

Adolescents living with HIV need services designed to meet their needs in an effective manner, respond to their challenges with sufficient understanding, use approaches that are appropriate and acceptable to them, set in an environment that is respectful to young people, is friendly, ensures confidentiality, and is accessible by in and out of school youths<sup>50,51</sup>. Such services need providers that are trained in the issues of young people's health and have the right attitudes. The socio-developmental needs of ALHIV must not be addressed from the viewpoint of problems that need to be solved or addressed; rather, adolescents must be recognised as entities with great potentials whose needs must be addressed as a matter of rights. Support provided should enable them achieve their maximum potential as they transit through adolescence to become healthy, productive adults.

For Nigeria, where the population of ALHIV is large and growing, there is a urgent need to design studies to identify their specific socio-developmental needs, evaluate how well current

services provided for adolescents and PLHIV meets the needs of ALHIV, and generate the needed evidence that can inform programming for ALHIV where gaps are identified.

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## Contribution of Authors

MOF conceived the idea of the paper. MOF, MO, AH, BB were involved with the collected of the papers needed for the writing of the manuscript, were all engaged in the preparation of the manuscript and gave final consent to its publication.

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