



USAID
FROM THE AMERICAN PEOPLE



IMPROVING ADOLESCENT HIV TREATMENT, CARE, PREVENTION AND FAMILY PLANNING SERVICES

A MULTI COUNTRY ASSESSMENT

July 2012

This publication was prepared for review by the United States Agency for International Development. It was prepared by the Africa's Health in 2010 Project, managed by FHI 360.

CONTENTS

ACRONYMS AND ABBREVIATIONS	4
NOTES ON TERMINOLOGY	5
EXECUTIVE SUMMARY.....	7
INTRODUCTION.....	9
METHODS.....	9
LITERATURE REVIEW	9
KEY INFORMANT INTERVIEWS.....	10
STUDY LIMITATIONS.....	10
SYNTHESIS OF LITERATURE.....	10
DEMOGRAPHICS	11
UNDER DIAGNOSIS OF HIV INFECTIONS.....	12
FINDINGS.....	12
DRUG ACCESSIBILITY AND AVAILABILITY.....	12
CLINICAL CARE.....	15
ADOLESCENT SPECIFIC TRAINING.....	15
YOUTH CENTERED APPROACH.....	16
ADHERENCE.....	17
HOLISTIC SUPPORT	19
EVIDENCE BASED STRATEGIES.....	20
RECOMMENDATIONS	21
NUTRITIONAL CARE.....	22
RECOMMENDATIONS	23
SEXUAL AND REPRODUCTIVE HEALTH.....	24
RELATIONSHIPS.....	24

SEX EDUCATION..... 25

YOUTH FRIENDLY SERVICES 25

FAMILY PLANNING 25

TRAINING AND GUIDANCE 27

YOUTH ENGAGEMENT 27

RECOMMENDATIONS 29

PSYCHOLOGICAL SUPPORT..... 30

 SUPPORT GROUPS 31

 INDIVIDUAL SUPPORT..... 35

 SAFETY AND SECURITY..... 35

 GAPS IN PSYCHOLIGICAL SUPPORT 36

SOCIAL SUPPORT 39

 RECOMMENDATIONS 42

TRANSITION OF CARE..... 43

 PROMISING PRACTICES..... 44

 RECOMMENDATIONS 46

RESOURCES 47

RECOMMENDATIONS 49

ADVOCACY 50

 DISSEMINATION 51

 RECOMMENDATIONS 52

CROSS-CUTTING THEMES 53

 COLLABORATION 53

 EMERGING TECHNOLOGIES 53

ACRONYMS AND ABBREVIATIONS

AIDS:	Acquired Immunodeficiency Syndrome
ALHIV:	Adolescents Living with HIV
ART:	Anti-retroviral Therapy
ARV:	Anti-retroviral
BIPAI:	Baylor International Pediatric AIDS Initiative
CDC:	Centers for Disease Control and Prevention
ECHO:	Enhancing Children's HIV Outcomes
EGPAF:	Elizabeth Glaser Paediatric AIDS Foundation
GNP+:	Global Network of People Living with HIV/AIDS
GYCA:	Global Youth Coalition on HIV/AIDS
HAART:	Highly Active Anti-retroviral Therapy
HIV:	Human Immunodeficiency Virus
IATT:	Inter-Agency Task Team
IDI:	Infectious Disease Institute
IEC:	Information, Education and Communication
IUD:	Intrauterine Device
JCRC:	Joint Clinical Research Centre
OVC:	Orphans and Vulnerable Children
PEP:	Post Exposure Prophylaxis
PEPFAR:	President's Emergency Plan For AIDS Relief
PHRU:	Perinatal HIV Research Unit
PING:	Positive Innovation for the Next Generation
PMTCT:	Prevention of Mother to Child Transmission (of HIV)
RHRU:	Reproductive Health & HIV Research Unit
RUTF:	Ready to Use Therapeutic Feeding Packets
SCOT:	Strengthening HIV/AIDS Counselor Training in Uganda
SRH:	Sexual and Reproductive Health
SSA:	Sub-Saharan Africa
STI:	Sexually Transmitted Infection
TB:	Tuberculosis
TASO:	The AIDS Support Organization (Uganda)
UNFPA:	United Nations Population Fund
UNICEF:	United Nations Children's Fund
USAID:	United States Agency for International Development
WHO:	World Health Organization
YPLHIV:	Young People Living with HIV

NOTES ON TERMINOLOGY

“ALHIV” shall stand for “Adolescents Living with HIV” and shall include people between the ages of 10-19 who are living with HIV and AIDS. (World Health Organization, 2010)

“YPLHIV” shall stand for “Young People Living with HIV” and shall include people between the ages of 10-24 who are living with HIV and AIDS. (UNFPA, 2003)

“PLHIV” shall stand for “People Living with HIV” and shall include people of all ages who are living with HIV and AIDS.

“Youth” has been defined by the UN as people between the ages of 14 -24, but will be used interchangeably in this report when referring to children, adolescents, and young people.

The focus of this report is ALHIV, though YPLHIV and PLHIV will be used when referencing research on these populations.

“Promising practices” are strategies, activities or approaches that have been identified by our key informants as effective and/or efficient. Unless otherwise stated, these “promising practices” have not yet undergone vigorous research or evaluation.

ACKNOWLEDGEMENTS

This publication is made possible by the generous support of the American people through the United States Agency for International Development (USAID), with the research supported by the President's Emergency Plan for AIDS Relief (PEPFAR) through USAID, under the terms of Contract No. RLA-C-00-05-00065-00. The contents are the responsibility of the the Africa's Health in 2010 project, managed by FHI 360, and do not necessarily reflect the views of USAID or the United States Government.

Thanks to the members of the Technical Advisory Group, which included Matthew Barnhart, Janet Kayita, Susan Kasedde, Harry Moultrie, Refilwe Sello, Takira Stokes, and Vicki Tepper. Additional thanks to the feedback from Ian Hodgson, Rick Olson, Ed Pettitt, Mychelle Farmer, and Rena Greifinger. And finally a special thanks to United States Government colleagues who provided technical input, technical guidance, vision, and professional insight that led to this work, with particular leadership from Sara Bowsky, in addition to Jennifer Albertini, Anouk Amzel, Elizabeth Berard, Ryan Phelps, and Linda Sussman.

EXECUTIVE SUMMARY

As HIV care and treatment programs grow and improve, increasing numbers of perinatally infected children are surviving into adulthood. Treatment programs have succeeded in ushering children beyond childhood,¹ and as incidence remains high in pediatric populations, the number of HIV-positive adolescents will continue to grow, with some estimates suggesting a tripling of adolescents in treatment in the upcoming three years.² With the aging of HIV-positive pediatric cohorts and growing numbers of adolescents on treatment, there is an immediate need for appropriate guidance for policy makers, providers and community members that care for these transitioning children, in addition to support for the adolescents themselves. Further complicating the demographic profiling and guidance for this age group is that there are two sub-groups of adolescents living with HIV (ALHIV): those who acquire HIV perinatally as addressed above and those who acquire HIV horizontally i.e. via sexual transmission, injection drug use, etc.

Better information on adolescents is needed if health-care providers, community-level stakeholders, caregivers, and policy-makers are to respond effectively to the specific needs of this group. As long as this population is overlooked and their clinical, psychological and social needs remain poorly understood, adolescents (including those on ART) will remain the most vulnerable populations affected by the HIV pandemic. Failure to address this vulnerability threatens the lives of these youth and jeopardizes the successes of pediatric HIV treatment efforts to date.

To obtain the evidence that will facilitate high quality care for ALHIV in sub-Saharan Africa (SSA), the Africa's Health in 2010 project, funded by the Africa Bureau of the United States Agency for International Development, initiated a multi-phase project comprising a literature review, field assessments based on the literature review, and mobilization of key stakeholders to guide the project and the development of an overarching advocacy strategy to guide and support the initiative. The advocacy strategy is presented in a separate document.

The overall aims of the project are to address the needs of a rapidly growing population of adolescents ages 10-19 living with HIV in sub-Saharan Africa by gaining an improved understanding of: (1) HIV-positive adolescents' demographic information; (2) the unique medical, psychological, and social needs of the HIV-positive adolescent population; (3) the resources needed to provide effective guidance to healthcare workers and HIV-positive adolescents themselves; and (4) the need to strengthen evidence-based advocacy efforts at the international, regional and country levels that include active involvement of key stakeholders.

This report provides an overview of current literature and an analysis of informant interviews investigating the key challenges and successful approaches to supporting ALHIV, particularly those who are perinatally infected and living in sub-Saharan Africa. The report has been structured according to the following major themes:

1. Demographics
2. Drug Access and Availability
3. Clinical Care
4. Nutritional Care
5. Sexual and Reproductive Health
6. Psychological Support
7. Social Support
8. Transition of Care

¹ Judd et al, 2007.

² Pettit E, unpublished data, 2009

9. Resources

10. Advocacy

11. Cross-Cutting Themes

In each of these sections, a summary of the literature has been provided, along with an analysis of the gaps and promising practices identified through the key informant interviews.

The primary audiences for this report include service providers who work with ALHIV, as well as program managers and officials who oversee programming for this population. This report is also useful for policy makers, advocates and others in a position to create a more supportive environment for ALHIV to receive optimal care. Caregivers and peer educators of ALHIV will also benefit from the information provided in this report.

Findings and recommendations from this assessment focus on program implementation, research, and policy guidance that respond to the identified needs of HIV-positive adolescents, care givers and health-care providers caring for and treating ALHIV. Further research will be needed to determine the suitability of these recommendations when contemplating their implementation at the local level.

INTRODUCTION

“We all remember our teenage days. Adolescence is a very different time of life. It’s one where the soul is raring to go and explore what’s out there. We want to be independent, and we want to be recognized as people on the path to independence. So one of the things that works well is recognizing that even these adolescents, many of whom have been through near-death experiences, still feel that way. And one can’t always treat them like chronically ill individuals. You allow them to express themselves and show them that, yes, they can still lead a useful life and become successful adults.” (Country Director, EGPAF, Uganda).

Adolescents in Sub-Saharan Africa (SSA) who were perinatally infected with HIV are now surviving into young adulthood for the first time and face a host of treatment, reproductive health and psychosocial challenges that the health sector is unprepared to manage (WHO/UNICEF 2009). As treatment programs succeed in ushering HIV positive children beyond childhood (Ferrand, et al. 2009) and as incidence remains high in pediatric populations, the number of ALHIV will continue to grow. While the epidemiology of sexually acquired HIV infection amongst 15–24 year olds is well described in southern Africa, few data exist on adolescents from 10-19 years of age and information about the growing number of older children and adolescents who acquired HIV perinatally is poorly understood. Pediatric HIV programs mostly focus on diagnosing and treating illness in infants and young children, excluding adolescents and older children who are often the target for HIV prevention messages only, many of which are designed without a strong understanding of their developmental stage (UNAIDS and WHO 2009). Therefore, little guidance has been produced on how to effectively provide treatment, care and support for ALHIV as they transition to adulthood. Better demographic and transmission data on adolescents is needed if healthcare providers, community-level stakeholders, caregivers and policy-makers are to respond effectively to the specific needs of this patient group.

Further complicating the demographic profiling and guidance for this age group is that there are two sub-groups of ALHIV; those who acquire HIV perinatally, as addressed above and those who acquire HIV during adolescence through other routes (e.g. via sexual transmission, blood transfusion and injection drug use). Diversity in mode of transmission, in addition to diversity in sexuality, culture, religion, gender and age, mean that young people living with HIV are a heterogeneous group that requires tailored interventions (GNP+ 2010). However, similarities in the psychosocial impact of HIV on young people (WHO/UNICEF 2009) mean that core interventions, particularly those designed for SSA, can be standardized and then adapted for regional settings, tailoring additional services and support for the two sub-groups.

As young people transition to adolescence and young adulthood, a normative stage of “desire to fit in,” psychosocial adjustment and identity development, sexual, alcohol and drug experimentation, and issues of non-adherence to medication are more common, meaning disease progression and onward transmission of the virus become ever-more pressing (Remien and Mellins 2007). Keeping these young people alive and healthy, coupled with HIV prevention within their peer group, requires a unique service model that is based on the experiences, practices, expertise and ingenuity of ALHIV and those who work with them.

METHODS

LITERATURE REVIEW

A literature search of articles, reports and grey literature was conducted using electronic databases such as PubMed, Jstor, Popline, Eldis and Google. Key search terms included adolescents, young people, perinatally infected, vertically infected, HIV, AIDS, gaps, access, needs, barriers, services, psychological, social, medical, nutrition, transition, treatment, care, prevention, support, sexual and reproductive health, family planning, youth friendly services, sub-Saharan Africa, and additional variations/combinations thereof. Additional references were selected based on bibliographies of key articles and recommendations from technical advisory group members. Literature focused on perinatally infected adolescents ages 10-19 living in SSA, with a limited selection of articles dealing with adults, behaviorally infected adolescents and regions other than SSA. The vast majority of articles reviewed were published within the past decade.

KEY INFORMANT INTERVIEWS

Two semi-structured interview guides were developed: one for informants who work with ALHIV as project managers or service providers and one for young people living with HIV (YPLHIV) who work/volunteer with other ALHIV as peer educators. The project managers'/service providers' and YPLHIV peer educators' interview guides contained 53 and 48 open-ended questions, respectively. Questions were grouped according to the subheadings used in this report, which were determined by an analysis of the major themes evident in the literature review. A total of 34 interviews (26 program managers/service providers and eight YPLHIV peer educators ages 18-25) were conducted with a gender breakdown of 16 females and 18 males representing 29 organizations/facilities in 10 countries (Botswana, Uganda, Tanzania, Mozambique, Malawi, Zimbabwe, Kenya, Rwanda, South Africa, and Swaziland). Twenty-three respondents completed the survey by phone or in-person and nine opted to complete and return the survey manually. In addition to the primary interviewer, two additional interviewers assisted with in-person interviews in both Uganda and Botswana. A standard interview guide and coaching by the primary interviewer ensured consistency in the interviews. The interviews were conducted between February and April, 2011, and a snowball sampling approach was utilized to identify appropriate key informants. Key informants were not compensated for taking part in the study. Interviews were recorded and transcribed. Responses were evaluated using a qualitative inductive approach with key themes that emerged throughout the interviews.

STUDY LIMITATIONS

First, the study design was primarily qualitative in nature, based on the analysis of transcribed interviews with key informants. Since the analysis is based on the perceptions of respondents, subsequent findings and recommendations cannot necessarily be generalized beyond the organizations and geographic locations included in this study. Second, this report provides a snapshot in time of the perceptions and experiences of our key informants – a more longitudinal approach would be needed to assess the impact and efficacy of various interventions and promising practices over time. Third, the key informants for this study were recruited based on the positive recommendations of their peers and therefore may represent best-case scenarios of service provision and organizational support. Furthermore, the YPLHIV interviewed were those who served in some sort of leadership or peer education capacity and were therefore also likely to have had better treatment and health behaviors/outcomes themselves.

SYNTHESIS OF LITERATURE

As the first generation of long-term survivors of HIV in SSA who have carried the virus since birth, ALHIV face a host of treatment, reproductive health, psychological and social challenges that the health sector had not anticipated (WHO/UNICEF 2009, Remien and Mellins 2007). As teenagers and young adults disproportionately affected by poverty and inequality, they have lower levels of education, higher levels of unemployment and homelessness and live with tremendous anxiety about the future (WHO/UNICEF 2009). Despite improved uptake of neo-natal HIV testing and prevention of mother-to-child transmission (PMTCT), particularly in SSA, there is growing evidence of a cohort of adolescents born with HIV who have survived without diagnosis or HIV-related care. These “slow progressors” who present with symptoms of long-standing HIV infection, are a major cause of adolescent morbidity in SSA countries (Ferrand, et al. 2010).

Access to ART among children in SSA remains low, with only 23% of all people who need ART able to access it, and of those only 5-7% are children (Prendergast, et al. 2007). Numerous studies suggest that to provide quality prevention, testing, support, treatment and care for ALHIV, services should be made confidential and “youth-friendly” (WHO/UNICEF 2009, WHO 2003, Gipson and Garcia 2009). Adolescents prefer health care settings that are tailored to their age group and providers who are in touch with their needs (WHO/UNICEF 2009). The ideal model of care for adolescents is a “one-stop shop” that utilizes a multidisciplinary approach: integrating primary care with HIV, mental health, prevention, and case management services (Kunins et al. 1993, WHO/UNICEF 2009).

Adherence to medication remains one of the most pressing challenges that YPLHIV face (WHO/UNICEF 2009) and the consequent development of drug-resistance is a significant problem among HIV-positive youth. Adherence to highly active anti-retroviral therapy (HAART) has been demonstrated as the single most important factor in achieving good health in YPLHIV (Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007). Non-adherence puts PLHIV at far higher

risk of developing opportunistic infections, transmitting HIV to others and being exposed to reinfection through unprotected sex. However, access to medication and knowledge about its life-saving quality is still not enough to ensure 100% adherence to medication for adolescents who “just need a break from it all” (Ledlie, 2001). In some Ugandan cohorts, adherence levels are as low as 70-85% (Bakeera-Kitaka, McKellar, & Colebunders, 2008; Nabukeera-Barungi, Kalyesubula, Kekitiinwa, Kyakika-Tusiime, & Musoke, 2007).

The high prevalence of sexually transmitted infections among adolescents warrants the integration of STI care and routine screening for HPV, Chlamydia, gonorrhea, Herpes simplex and hepatitis B whenever possible (WHO & UNICEF 2006). SSA has the highest rates of teenage pregnancy in the world (Clark 2004, Laksi and Wong 2010), and in many cases, contraceptive messages and methods are not available. The key challenge in supporting ALHIV with sexual and reproductive health (SRH) is an overall lack of focus on SRH services targeting youth, including a lack of secondary prevention services targeting the growing number of YPLHIV (Ferrand, et al. 2009, Patel, et al. 2008, Prendergast, et al. 2007).

ALHIV face a double-edged sword of mental health challenges due to the societal stigmatization of their HIV status as well as HIV encephalopathy and other forms of organic neurological dysfunction (Bachanas, et al. 2001, Brown, Lourie and Pao 2000, Earls, Raviola and Carlson 2008, Fielden, et al. 2006, Ross and Cataldo 2010, Steele, Nelson and Cole 2007, Van Rie, et al. 2007). In SSA, many ALHIV, like their HIV-negative peers, are affected by poverty, limited access to schooling, orphanhood and limited social support structures. In addition, ALHIV often deal with issues compounded by their HIV-status, including grief and bereavement, poor future orientation, anxiety related to disclosure and concerns related to abnormal growth and development, including stunting and lipodystrophy (Gaughan, et al. 2004).

A study from Uganda noted in Petersen et al. (2010) showed participation in peer support groups led to higher levels of self-efficacy and reduced feelings of stigma. Literature strongly supports a comprehensive multidisciplinary approach that focuses on engaging the family to meet the medical, psychological and social needs of adolescents living with HIV (Bachanas, et al. 2001, Brown, Lourie and Pao 2000, Earls, Raviola and Carlson 2008, Naar-King, et al. 2009, Tolle 2009, Ross, et al. 2010). A major challenge confronting HIV-positive adolescents is deciding if, when, how and to whom they should disclose their status, as well as exercising their personal freedom to make that decision (GNP+ 2010).

Still a major challenge in caring for ALHIV is the transition from pediatric to adult health care. Transition of care is met with resistance on both the part of the patient and the provider. In many instances, though unprepared to address adult care issues, the pediatric provider is unwilling or highly resistant to letting go of a patient (Peter, et al. 2009, Gipson and Garcia 2009, Wiener, Kohrt, et al. 2009). With HIV care, the situation is exacerbated by the fact that most providers have cared for their patients from birth. Participatory approaches to self-management that promote the adolescent’s self-efficacy are essential to ensuring optimal adherence to ART and a healthy transition to adulthood (Naar-King, et al. 2009, Petersen, et al. 2010, Valenzuela, et al. 2009, While, et al. 2004, Wiener, Kohrt, et al. 2009). Young people who believe that they have a choice in healthcare decision-making are more likely to look forward to medical transition as a positive experience (Greifinger, Rosenthal and Kubicek 2010).

DEMOGRAPHICS

There are currently an estimated seven million people living with HIV worldwide who are under the age of 24 years, of which more than seventy percent are under 15 years old. High levels of late and under-diagnosis of perinatal and horizontal HIV infection in adolescents makes it difficult to estimate how many adolescents are actually living with HIV (UNAIDS and WHO 2009). We do know, however, that 45% of new transmissions take place among 15-24 year-olds (WHO & UNICEF 2008).

There is a severe shortage of reliable data on young people and HIV, especially on adolescents (10-19 years) living with HIV. Few countries follow the United Nations General Assembly Core Indicators under which they are required to disaggregate data according to sex and age. However, the existing data is concerning. According to UNAIDS/WHO estimates based on the 2010 Global Report (UNAIDS 2010), there were 2 million adolescents living with HIV as of 2009 (Figure 1). Roughly 1.7 million ALHIV (85% of all ALHIV) live in SSA (Figure 2), of whom 64% are female (Figure 3). Only 360,000 ALHIV globally, and 290,000 in sub-Saharan Africa (Figure 4), are currently on anti-retroviral therapy. The nine

countries with highest HIV prevalence, with over one in 20 adolescents infected, are Swaziland, Lesotho, Botswana, South Africa, Namibia, Zambia, Zimbabwe, Mozambique and Malawi (UNICEF 2009).

In South Africa, while adolescents (ages 10-19) accounted for 1% of the total number of patients receiving HAART in 2008, this proportion is expected to grow to approximately 5% by 2020, mainly as a result of perinatally infected children surviving into adolescence (Jaspan, et al. 2009). A recent household survey conducted in South Africa in 2008 estimated the prevalence of HIV in children aged 2-14 years to be 2.5% (95% confidence interval 1.9-3.5) (Shisana, et al. 2008).

UNDER DIAGNOSIS OF HIV INFECTIONS

Despite widespread uptake of neo-natal HIV testing and prevention of mother-to-child transmission (PMTCT), particularly in SSA, there is growing evidence of an already existing cohort of adolescents born with HIV who have survived without diagnosis or HIV-related care. These “slow progressors” who present with symptoms of long-standing HIV infection, are a major cause of adolescent morbidity in countries such as Zimbabwe (Ferrand, et al. 2010). They present with stunting, pubertal-delay, and chronic health conditions such as lung disease (Ferrand, et al. 2009). In their investigation, Ferrand et al. (2010) found high rates of untreated pediatric HIV infection, complicated by opportunistic infections found in the adult HIV population, in hospitalized adolescents in Harare.

About one-third of infants born in SSA with HIV are “slow-progressors”. It is estimated that they will outlive their “fast-progressor” counterparts by 10-20 years, and die after the HIV epidemic in adults has peaked (Marston, et al. 2005, Stover, et al. 2006). Issues of parental consent, parental ill health and orphanhood challenge endeavors to universally test this population (Ferrand, et al. 2009). These findings set the stage for improved testing at the primary care level, with the aim to increase early infant diagnosis (EID) and prevent disease progression of this magnitude in untreated adolescents.

FINDINGS

The following sections provide an overview of the findings from our key informant interviews. Findings have been summarized using a qualitative, inductive analysis of the responses from those interviews. The authors provide recommendations based on these findings, but further research is needed to determine the strength and compatibility of these recommendations when implemented at the local level.

DRUG ACCESSIBILITY AND AVAILABILITY

Provision of ART in SSA remains fragmented, with many non-governmental organizations providing the majority of services, resulting in large unmet needs among this growing population (Ross and Cataldo 2010, Petersen, et al. 2010, Prendergast, et al. 2007). Many hospitals in and around urban areas are well supplied with first and second-line treatment, highly qualified and trained service providers, and models of clinical excellence espoused in the international community. On the other hand, hospitals and clinics located in rural districts face numerous challenges.

Medication costs are a major concern for many ALHIV. Even in countries where ALHIV have the benefit of free universal access to ART, there are a number of hidden costs connected to treatment, including transportation to clinic and lab visits and fees for certain tests, such as viral load tests (Global Youth Coalition on HIV/AIDS 2008).

While twice-daily medication regimens have been common in the past, once-daily schedules are now available for some anti-retrovirals (ARV), such as ATRIPLA (TDF, FTC, EFV). There are also fixed-dosed combination tablets like Triomune (d4T, 3TC, NVP), which can be prescribed twice a day to improve compliance (WHO & UNICEF 2006).

The majority of organizations interviewed stated that drug shortages and “stockout” pose a major threat to drug access and availability for ALHIV, particularly in rural areas. One organization in Uganda commented that most rural clinics do not have second-line therapy, so patients who require second-line drugs need to travel long distances to urban hospitals for care. Drug shortages may cause people to resist testing, as they might rather not know their status if the drugs are not available to treat it.

“The challenge, of course, is this issue of stockout, and parents not bringing them [adolescents] to test because of it. If you’re not providing ARVs, people are hesitant to test. If there are drugs, then they know life can be regained, and they move on.”
(Pediatrician, Nsambya Home Care, Uganda).

Second to drug shortages, reports one respondent, are organizational barriers that make drug access, particularly in rural settings, inconsistent.

“It all boils down to the resources available to procure these drugs at a national level. I think that’s the biggest factor. The other one is organizational, just making sure that orders are placed in time, they are accurate, and that the supplies reach the health facilities in time.” (Pediatrician, EGPAF, Uganda).

Most of the organizations interviewed provide first and second-line therapy for ALHIV. These include once-daily and twice-daily regimes, with some fixed-dosed combinations for pediatric dosing. The most common formulations are twice-daily. The large majority of organizations do not provide third-line or super HAART, though some said that a salvage therapy based on the first two lines could be offered in place of a true third line regimen. All of the organizations interviewed provide ARVs at no cost to the patient, usually subsidized by their national governments and international donor projects such as PEPFAR.

“Before September [2010], our medicines were subsidized by USAID and PEPFAR only. And [since] September, then there was [an agreement] with the government that all the PEPFAR money for HIV management needs to go through the government.”
(Adolescent Program Director, Perinatal HIV Research Unit, South Africa)

“Third-line is case by case, and it’s through consultation with other experts... we always ask advice. Luckily for us, we have access to resistance testing. With Kidzpositive, through funding from Sidaction, we’ve got a little budget, and when children fail second-line, we show that it’s not just non-adherence. We can do resistance testing, and we can base our choice on that. And then once we get resistance testing, it depends on whether we have access to the specific drugs that are indicated.” (Pediatrician, Department of Health Western Province, South Africa)

Some of the respondents reported that the need for pediatric dosing for some ALHIV complicates drug availability. Due to their diminished weight and height, many ALHIV still require pediatric dosing, but healthcare workers, particularly in rural settings, may not be trained to manage pediatric dosing, which is not as straightforward as adult dosing.

Access is also constrained by poverty. Many patients lack the money they need to attend their clinic appointments, or live with family members who are unsupportive. Some informants responded that their facilities receive support from international non-governmental organizations to address treatment gaps, but this support may not be sustainable in the long-term.

“The Clinton Foundation works closely with the government for forecasting drug needs. As international support for HIV specific programs dwindles, the Swaziland government will become more and more responsible for procuring the treatments.”
(Pediatrician, Baylor College of Medicine Children’s Foundation Swaziland).

RECOMMENDATIONS

- Train physicians, nurses and other health care providers on pediatric dosing.
- Monitor supply chain management of essential drugs and address any barriers encountered in the entire drug supplies procurement system
- Focus advocacy efforts on improving access to treatment for ALHIV living in rural settings.

CLINICAL CARE

As perinatally-infected children reach adolescence, it is important that their HIV status is disclosed to them and that they are linked to services that promote self-management of HIV independently of a pediatric provider, case manager and/or significant community/family support (Ross and Cataldo 2010, Ross and Cataldo 2010, Tolle 2009, Valenzuela, et al. 2009, WHO/UNICEF 2009). This is particularly difficult given the lack of resources and services throughout much of SSA (Andrews, Skinner and Zuma 2006, Ferrand, Corbett, et al. 2009, Petersen, et al. 2010). It is imperative that providers establish strong referral networks and communication pathways with one another, so that care remains holistic and integrated. Identifying all of the people and agencies in an adolescent's support network is important, and sometimes means having to overcome histories of working in competition or silos (WHO/UNICEF 2009).

Tuberculosis screening for ALHIV should be performed annually according to guidelines for HIV-positive adults. Appropriate immunizations for ALHIV should also be ensured in order to minimize opportunistic infections (WHO & UNICEF 2006).

ALHIV face a number of challenges in clinical care that threaten their ability to attain optimal health. A number of respondents mentioned that the ALHIV in their care are prone to various acute HIV-associated medical disorders.

“A specific problem that we’ve come across is respiratory damage from earlier years where kids might have bronchiectasis and [other] serious pulmonary specialist care requirements [that] are very difficult to treat. And then we’ve had a few renal patients with HIV-associated nephropathy (HIVAN) and... those kind of things where they need renal specialist care.” (Advisor; Former Medical Officer, Rahima Moosa Mother and Child Hospital, South Africa)

In addition, many aspects of the clinical care environment pose significant barriers to optimal care for ALHIV. Recognizing these barriers and assessing the care environment with an eye for creativity and change is paramount in the global effort to improve health outcomes and engagement in care for ALHIV.

In addition to the traditional staff of doctors, nurses and counselors, many facilities are now pushing for a greater involvement of ALHIV as expert patients and peer educators.

“We have one peer educator, at least here at Baylor’s main center, who is on salary—who is getting paid to provide peer counseling for adolescents. [She] is also one of our adolescents who was perinatally infected. So we’re really hoping that in the years to come, we can train more adolescents with HIV to be peer educators. We [also] have a lot of teen leaders, or adolescent leaders, who [assist] in finding out what adolescents living with HIV need and [serve as] advocates for their peers.” (Pediatrician, Botswana-Baylor Children’s Clinical Centre of Excellence, Botswana)

The most common clinical services provided by the organizations interviewed are primary care, anti-retroviral therapy and adherence support. Some organizations provide disclosure support, mental health counseling and peer support groups. Others provide nutrition education and nutritional support as well as treatment for opportunistic infections. This, however, is not the norm. Health providers and peer educators noted a number of challenges in clinical support, some of which can easily be rectified through improved training and guidance, a youth-centered approach, and a focus on medication adherence.

ADOLESCENT SPECIFIC TRAINING

“We have had so many clinicians who don’t have the right knowledge, the right skills, or the right techniques to handle adolescents. So in most cases, they will just prescribe the drugs and [the patient] leaves. This has been a big challenge because adolescents do not have a good relationship with our clinicians, despite the fact that they are treating them.” (Supervisor, OVC program, Reach Mbuya, Uganda)

Interviews with health providers and peer educators elicited a nearly unanimous call for training health care workers, including paraprofessionals and community health workers, in adolescent-specific treatment and care. As adolescents grow into young adulthood, they often feel less understood by counselors who they have worked with in the pediatric environment, but even more removed from those who work specifically with adults. ALHIV report feeling judged, particularly when it comes to discussions around high-risk behavior, often by pediatric counselors that they have worked with their whole lives. Other peer educators said that they are not warmly received in the clinic; they are bossed around and made to feel as if they are a burden to health care workers. These feelings can lead them to disengage from counseling and, at times, overall treatment services.

Human resource capacity is another major barrier as many institutions do not have clinicians trained in pediatrics, let alone adolescent health. Many ALHIV, particularly those living in rural settings, will see a nurse or general practitioner for all of their needs.

“In many countries in Africa, there is not pediatrician at each health facility. It is only the general practitioner and also the nurses who are treating all—children, adolescents, and the adults.” (Head of Adolescent HIV Programs, Rwanda Ministry of Health).

In order to combat some of these challenges, some institutions, like Mildmay Uganda, noted by many respondents as a promising practice model, trained all of its health care workers, both in pediatrics and adult care, to work with adolescents. Institutions and policy-makers should look to creating training courses and materials that focus specifically on adolescent development, their unique needs and priorities, and promising practices in providing adolescents with care and support. All health professionals and peer educators should have access to these resources and undergo periodic trainings to strengthen their ability to work with this complex group.

YOUTH CENTERED APPROACH

“I think what really works is [fostering] professionalism in the lives of young people living with HIV... like putting them in places of leadership so that they can deliver. Those kids have a lot to offer.” (Peer Educator, Youth Caravan, Uganda)

Numerous studies suggest that to provide quality prevention, testing, support, treatment and care for ALHIV, services should be made confidential and “youth-friendly” (WHO/UNICEF 2009, WHO 2003, Gipson and Garcia 2009). This means services must be affordable and accessible, as in flexible working hours that meet school and work schedules, drop-in centers with walk-in appointments, short waiting times and flexible payment schemes (WHO/UNICEF 2009, WHO & UNICEF 2006). Adolescents prefer health care settings that are tailored to their age group and providers who are in touch with their needs (WHO/UNICEF 2009). A needs assessment survey conducted by the Adolescent Working Group in Kampala, Uganda found that 92% of the adolescents interviewed preferred to have a separate clinic from the pediatric or adult clinics. A model adolescent HIV clinic was then started and over the course of three years, over 500 adolescents between 12 and 18 years of age were recruited (Snider 2006).

The meaningful engagement of ALHIV in the design, delivery and evaluation of treatment and support services cannot be overlooked. Their developmental stage of seeking autonomy and control, coupled with their unique expertise in growing up with HIV, makes them ideally placed to inform the development of programs and engage their peers in service delivery.

“The successes [of an adolescent-led organization] are that there’s passion and ownership of the young people; they are part and parcel of the whole process, and they feel that they cannot do without it. And we also cannot do without them.” (Peer Educator, Youth Caravan, Uganda)

“Out of our peer leaders, we are developing an ambassador program, where children who show remarkable leadership skills are brought into a program where they are taught even more leadership, and are taught to become a voice for the rest of the children—share experiences, but bring to the rest of the country and the world the attention of all these thousands of children who have overwhelming challenges, just trying to remain healthy and stay alive.” (Country Director, EGPAF, Uganda).

“Involving them in their treatment is involving them in decision making, involving them in choice making, involving them in every stage they are moving. If adolescents have come to the clinic and they have tested HIV positive, involve them in every step of the decision they are going to take.” (Supervisor, OVC Program, Reach Out Mbuya, Uganda)

Alongside youth involvement, institutions should look toward creating clinical environments that are adolescent-friendly. Many ALHIV no longer feel comfortable in a pediatric clinic, surrounded by children’s books and toys, but neither are they comfortable sitting in a waiting room alongside people thirty years their senior. In these environments, patients are often lectured about health information. However, young people, and many adults as well, do not learn well through lecture format. Utilizing creative and interactive models of health education that foster participatory learning, rather than the more traditional didactic approaches, is key.

Implementing an adolescent-only clinic or a clinic day exclusively for adolescents has been shown to be a promising practice in providing an environment where young people feel safe, active and engaged. Many facilities interviewed have specific days for adolescent patients, or have certain areas or hospital wings where adolescents can go to wait for care.

“We did a needs assessment to inform us about their [ALHIV] needs, being in a clinic where adults are and whether they needed their own clinic. They wanted their own clinic, because there were kids in the clinic with adults. They were blamed—why did they get infected at an early age? Others were sexually harassed by the adults in the clinic, trying to force them into relationships. Then there were the long-waiting times. Others felt that they were sharing the same clinic with their uncles and aunties, and it affected their clinical attendance, because they felt uncomfortable coming and meeting their aunties and uncles here. So we set up a Young Adults Clinic on Wednesdays, separate from the Adult Clinic which runs the rest of the week” (Project Coordinator, Young Adults Clinic, IDI, Uganda).

If hospitals have adolescent HIV specific services, wings or treatment days, however, they should be cognizant of the risks and stigma some ALHIV may feel in terms of disclosure. One peer educator acknowledged his discomfort in attending an adolescent-only HIV clinic that is set within a larger hospital, for fear of being seen by somebody who he knows from his school or community. Equally, even with adolescent-only clinics or days, there is a risk that some ALHIV may be excluded from services. For instance, some respondents mentioned that certain hospitals will not allow pregnant and parenting teenagers to access services on the same days as their peers for fear that they will influence their peers to get pregnant. Some peer educators acknowledged that this could leave some pregnant and parenting teenagers so isolated that they stop engaging in care altogether.

Some institutions, however, find a family-based approach to be most effective in providing clinical care and support for ALHIV.

“Because it’s a family model, we usually encourage the parents to come on the same day. So when I’m targeting this child, I’m also targeting the child with the parents. Originally, we used to provide the adult’s or the parent’s wing, but now what we basically do is if a service provider or a doctor is seeing one person and has a family, they see them as a whole. So you are basically targeting them as a family, and I think that has worked very, very well.” (Head of Field Team, Milmday, Uganda).

ADHERENCE

Working with the adolescent to facilitate self-management of HIV is key to ensure a smooth transition and strong adherence to ART and other necessary support programs (Naar-King, Petersen, et al. 2010, Valenzuela, et al. 2009, While, et al. 2004, Wiener, Kohrt, et al. 2009).

“It’s not realistic to think all healthcare workers in Malawi will do pill counts because they just don’t, but rather we should just teach that people are ALWAYS going to struggle with a drug regimen that requires nearly perfect adherence so instead of saying... ‘take your medicine every morning and evening’...say, ‘this medicine is difficult to take, what time is the biggest challenge for you, how do you remember, how can we help give you more support and more ideas on how to remember?’” (Physician, Baylor College of Medicine Children’s Foundation Malawi).

Health care providers and peer educators agree that adherence to medication is a key challenge faced by ALHIV. As ALHIV survive into adulthood, maintaining them on their lines of treatment is crucial. Availability of new lines or

combinations of treatment is limited as well as expensive. Access issues, particularly in rural areas where medication is not as readily available as it is in urban settings, are compounded by a multitude of social and environmental factors that keep young people from adhering well. Adherence at school is particularly complex, especially for those young people who attend boarding school. Many keep HIV a secret, making it difficult for them to find the privacy to take medication on time. Many young people report experiences of discrimination, on the part of peers and faculty, when their HIV status is disclosed at school. For some, the resulting psychological stress has caused them to stop taking medication, reduce productivity at school or leave school altogether.

“The parent went and disclosed to the head teacher, and the head teacher thought, ‘Ah-ha, we need to support this child,’ so he goes to the national assembly and announces—let me call the child Michael—that Michael here is HIV-positive, so you should support him. That kid refused to take his drugs. He says he is not positive.” (Pediatrician, Nsambya Home Care, Uganda).

Having to walk long distances to attend school also poses a challenge to adherence, for children who spend more than twelve hours outside the house, traveling to and from school.

One peer educator from Uganda reported that some church pastors discourage young people from taking their HIV medication, telling them that faith alone will heal them. Others acknowledge that they feel judged and blamed by their doctors and counselors when they are struggling to adhere, but little effort is made to develop strategies to overcome those challenges.

“In the hospital, they are threatened or blamed if they haven’t taken their meds, but it often is not looked at as to why they haven’t.” (Peer Educator, Youth Caravan, Uganda)

Nearly all of the organizations interviewed provide adherence counseling during clinic appointments and most recommend that peers take a lead role in providing that counseling. Many ALHIV report increased comfort and openness discussing issues of adherence, alongside other sensitive issues, with peers who can draw on their own experiences during counseling. Peer educators are often best equipped to address adherence from a youth perspective, tapping into an incentive structure that only adolescents will understand.

“Take your treatment well so that you can look as good as me.” We talk about adherence in that perspective—looking good so that people don’t notice that you have HIV.” (Peer Educator, Youth Caravan, Uganda)

A promising practice in this regard is Africaid’s Zvandiri project in Zimbabwe, which has trained and supported “Community Adolescent Treatment Supporters” (CATS) who work in community clinics and communities providing peer counseling and monitoring of adherence for children in their communities.

“Children and adolescents, supported by adults, take the lead in designing, implementing, monitoring and evaluating all of Africaid’s programs and activities...[such as our] Community Adolescent Treatment Support (CATS) program...in which ALHIV have been trained as adherence counselors. They work in community clinics providing adherence counseling and also follow up children and ALHIV at home to monitor pill boxes and adherence. We have found this to be an extremely powerful means of supporting adherence. ALHIV often report challenges more readily to their peers than to adults. The CATS then refer these cases to the outreach team and clinic who follow up. This has also provided the adolescents with invaluable opportunities for training and work experience and several have now progressed on to nursing training.” (Director, Africaid, Zimbabwe)

Peer educators and health providers reported that peer-led adherence support is best delivered through client-centered one-to-one counseling in the clinic setting. Supporting disclosure has also been found to be important in promoting adherence. Those adolescents who have been able to disclose their HIV status to someone in their lives that plays a supportive role, are more likely to adhere to their medications than those who have not disclosed. Support around disclosure should make up a key piece of adherence support.

“ADHERENCE is a HUGE challenge and overall not addressed in a comprehensive way with counseling or assistance. There is little understanding of the developmental stages of adolescence and that it is common for teens to struggle with adherence. There is not an understanding of the need to help teens to problem solve adherence challenges and for the most part it is often completely ignored as clinics are very, very busy.” (Physician, Baylor College of Medicine Children’s Foundation Malawi).

“I would like to suggest the best way to deal with adherence problems is to bring them peer support. First bring them peer support, and let them talk. Let them talk [about] their anger. Let them educate each other. Let them learn from one to the other.” (Supervisor, OVC program, Reach Out Mbuya, Uganda)

Some organizations provide home-based care and follow-up, particularly for those young people who are struggling to adhere. Equally important to educating young people about adherence is sensitizing key actors in the young person’s support community – teachers, school nurses, religious leaders and caregivers – in order to ensure that young people are not made vulnerable to discrimination, and receive accurate and consistent support and information from those who are most involved in their lives.

Other organizations have found pill counting to be a crucial part of their adherence program. However, providers suggest that pill counting is just one step in an ongoing conversation between the patient and the provider about adherence.

“We’ve been working hard to help them understand that a pill count can alert you of a problem, but it doesn’t end there by saying, ‘Your adherence is bad. You need to drink your medicine.’ But rather, it should trigger a conversation that starts, ‘Looks like adherence has been more challenging this month than usual. What was the biggest challenge this month? What changed this month?’” (Physician, Baylor College of Medicine Children’s Foundation Malawi).

“I must say that we’ve been doing [pill counts] since the very beginning of the clinic and certainly the beginning of the adolescent clinic. It is an integral part of the service. It gives us a reading of where the patients are at. In South Africa, viral loads are only measured [every] six months. Here at our clinic it’s [every four months]. So sometimes it can take a while for us to actually get those results, so the pill counts are really important. And I think they’re an important measure, and they’re often an important intervention. And patients coming and seeing that their pills are being counted, it makes them more cognizant of taking them.” (Project Leader, Psychosocial Division, Desmond Tutu HIV Centre, South Africa).

HOLISTIC SUPPORT

The most successful support services for ALHIV are those that look at the individual as a whole and engage the entire family in care. Treatment-only services are not adequate in the global response to improving the lives of ALHIV. Neither is the provision of different services from different locations, which prove difficult for a young person who may have to travel long distances between service locations, lack money for transport or have to miss multiple school days to meet different appointments.

Health providers and peer educators agree that services should address all of the psychosocial and environmental factors in young people’s lives. These include comprehensive information and education about sex and sexuality, family planning, mental health support, educational support and life-skills training. Many institutions advocate for the integration of HIV and SRH services into general primary care. They argue that this model is more sustainable and cost-effective for patients who only have to go to one institution for all of their care, and for the health system as a whole. Integration also removes the issue of disclosure. If an adolescent sees her neighbor at the clinic, it will not automatically be assumed that she is HIV positive.

Mildmay Uganda has seen tremendous success with its integrated approach in satellite clinics based in rural areas. Instead of setting up HIV-specific clinics, HIV services are integrated directly into the general health services provided at the district level. General health practitioners are trained to work with HIV positive patients. Since mental health workers and data technicians are not part of the general health structure, Mildmay hires them and trains them to work in rural settings. The hospital takes responsibility for delivering medication to the satellite clinics every month, and pays doctors and pharmacists to provide appropriate care.

We are providing antiretroviral drugs and treating HIV, but sometimes they have opportunistic infections that also require treatment. Yet, this treatment is not available for free.” (Adherence counselor, JCRC, Uganda)

Treatment and support programs should have a holistic educational approach addressing sexual health and hygiene to help ALHIV minimize their risk of contracting bacterial, parasitic and other co-infections. Health providers and policy-

makers should look toward subsidizing the costs of treatment for these infections, particularly STIs and TB, which are just as threatening as facilitators of HIV transmission as they are consequences of it.

EVIDENCE BASED STRATEGIES

Lastly, in order to provide effective clinical services for ALHIV, health providers should advocate that care be evidence-based. Institutions should conduct internal and external research to inform their programs. For instance, a sexual health needs assessment conducted by Baylor Uganda, showed providers that many of their patients were having unprotected sex, and often did not disclose their HIV status to partners. Baylor subsequently transitioned its support model to one that integrates comprehensive sex education, family planning and disclosure support.

Guidelines and standard operating procedures for clinical care for ALHIV are inconsistent across countries in SSA. While some respondents reported that many clinical guidelines existed, through their Ministries of Health or institutions, others said they were severely lacking.

“There are many challenges because this is a new program. The program doesn’t have the guidance—national or international guidance—and there are no standards for adolescent care in particular. So we are struggling to do our best.” (Head of Adolescent HIV Programs, Rwanda Ministry of Health).

Where guidelines are missing, service providers, policy makers and ALHIV should work together to identify and document best practices, solicit consultation and guidance from experienced programs, adopt and train practitioners in standard operating procedures that meet the capacity and remit of their organizations.

RECOMMENDATIONS

- Design and deliver training for all medical and social care providers, paraprofessionals and community health workers that work with ALHIV in adolescent development.
- Create a youth-friendly environment that is free from stigma, judgment and blame.
- Ensure that learning is participatory and interactive, rather than solely didactic.
- Meaningfully involve ALHIV in the design, delivery and evaluation of treatment and care programs.
- If possible, establish an adolescent-only clinic or an adolescent-only clinic day. Ensure that ALHIV feel safe attending this clinic and that adolescent-only services do not exclude any ALHIV from accessing care.
- Consider a family-based model where appropriate.
- Pill counts are a powerful tool for supporting medication adherence, especially when they are used to engage the patient in an ongoing conversation about adherence-related challenges and opportunities.
- Utilize peer educators in adherence counseling.
- Support disclosure to a trusted friend or family member in order to promote adherence.
- Engage the support network, such as teachers, counselors, community leaders and family members, in order to promote adherence for ALHIV.
- Provide a holistic package of services. Treatment alone is insufficient to meet the multivariate needs of ALHIV.
- Address co-infections, opportunistic infections and other STIs in addition to HIV care.
- Utilize evidence-based strategies and, if possible, conduct research to inform interventions.
- Where guidelines or standard operating procedures are missing, identify best practice models and ensure appropriate training, adoption and adaptation of those models takes place.

NUTRITIONAL CARE

Malnutrition and HIV work in tandem; while HIV can lead to malnutrition, malnutrition will worsen the impact of HIV. PLHIV need to consume up to 30% more calories than their uninfected counterparts, making nutritional support a key component of care for those living with HIV, including adolescents (Bertozzi, et al. 2006).

“Adolescence for healthy children is a time [of] higher metabolic needs and increased nutrition. Adding a chronic disease to that stage of life increases the body’s nutritional needs even more. Sadly, in most of our settings in Mozambique, poverty is so pervasive that there is rarely enough food to meet these increased needs. Chronic malnutrition is a pervasive problem in Mozambique with 40% of children having short stature.” (Pediatrician, Baylor College of Medicine Pediatric AIDS Corps, Mozambique)

In SSA, malnutrition is a major problem for ALHIV and can lead to substantial problems with medication adherence and efficacy. While many informants responded that the nutritional needs of ALHIV are similar to those of other adolescents, some noted that ALHIV have an increased caloric requirement due to their chronic illness. Others responded that ALHIV are more prone to malnutrition due to their increased likelihood of being orphaned and living in poverty. This puts them at a severe economic disadvantage, notwithstanding the oft-heard stories of losing their homes altogether when their parents die. Taking drugs on an empty stomach can greatly affect adherence, and many young people stop taking their medications completely when they do not have enough food to eat. Malnutrition will worsen their cognitive development and functioning.

Many programs have tried to curb these challenges by providing porridge or full meals during clinic appointments, and maize flour and soya for young people to take home. For those who are severely malnourished, clinics provide Plumpy Nut in the form of Ready to Use Therapeutic Feeding Packets (RUTF) and, at times, inpatient services. A few organizations are able to provide full meals for very impoverished children, particularly those that head their own households. However, financial difficulties have led many agencies to cut nutrition programs. Their ability to provide nutritional support is purely donor-based, so there is a fragmented system in which some patients receive a full meal and bag of maize to take home, while others receive nothing.

“In general, adolescents do not have a good sense of nutrition and the value of green vegetables and fruits, nor do they really like to eat them. I think more education should be done on teaching youth about WHY it is important to eat healthy during puberty and especially if one is HIV positive.” (Executive Director, Stepping Stones International, Botswana)

In order to offset their inability to feed all of their patients, many programs provide complementary services like vaccination against parasites, dietician consultations, provision of vitamins, nutrition education and income generating activities that can help young people access food. Nutrition education includes what to eat to maintain strength and energy, and how to eat on a very low budget. In rural areas, clinics have been able to partner with government agriculture programs to provide space and resources for ALHIV and their families to farm and/or develop home vegetable gardens. Many programs teach life-skills such as bead-making, creative arts and food preparation so that young people can sell their products or the institution can sell the products for them and help them generate income.

“There is an excellent service called Philani Nutritional Service. They are a tremendous resource. If I have a child in my ward who is malnourished and if the reason for malnutrition is poverty and lack of access to food, then when a child is discharged, I can write a letter and refer the child to Philani, and they will get a home visit, they will get some kind of needs assessment, they will receive education on how to do best with what [food] they have, and they will get food parcels, and they will get additional follow-up.” (Pediatrician, Kidzpositive; Department of Health Western Province, South Africa)

RECOMMENDATIONS

- Train health care workers and counselors in nutritional assessment, counseling and support.
- Provide adolescent sensitive nutrition counseling and support
- Provide nutrition education to ALHIV during clinic appointments and support group meetings.
- Train and hire dieticians and/or nutritionists when possible.
- Offer food supplements during clinic visits when possible.
- Provide Plumpy Nut and/or other nutrient dense supplements when appropriate.
- Partner with other agencies and NGOs that offer nutritional counseling and related services.
- Make appropriate referrals for nutritional counseling and related services.
- Promote the use of home-based vegetable gardens and other ways for ALHIV to supplement their diets.

SEXUAL AND REPRODUCTIVE HEALTH

As ALHIV advance into young adulthood, their focus on developing meaningful and effective relationships becomes paramount (International HIV/AIDS Alliance, 2011). Comprehensive programs that teach sexual decision-making, including abstinence and condom negotiation, are urgently needed (Kirby, 2002) in order to prevent the spread of HIV throughout SSA. Healthcare providers and society at large often assume that a person diagnosed with HIV will not want to have children, or should not have children. Service providers often forget that ALHIV are sexually active and that young women living with HIV may want to become pregnant (Global Youth Coalition on HIV/AIDS 2008, Fielden, et al. 2006). In a recently completed TASO Uganda/Population Council survey involving 732 adolescents with HIV aged 15-19 years, 90% of the boys and 87% of the girls expressed a strong desire to have children in the future (Birungi and et al. 2009).

ALHIV in SSA remain in need of supportive and confidential sexual and reproductive health services (Prendergast, et al. 2007). Added to this is the need for programs that promote healthy sexual development in ALHIV. Sexual health policies and procedures, especially those surrounding partner disclosure and family planning (Fielden, et al. 2006), should be in place before ALHIV become sexually active.

“[ALHIV have] four unique [concerns]: there is the risk of transmitting the disease to their partner, there is the stigma and trust of disclosing to their partner, the pressures of society for boys to have many girlfriends and for girls to prove their fertility, and most of our patients are physically stunted and enter puberty late. Another [concern] is that many of the ALHIV are orphans and do not have a good family unit to learn about or discuss these issues.” (Pediatrician, Baylor College of Medicine Children’s Foundation Swaziland)

While many informants responded that the sexual and reproductive health needs of ALHIV are similar to those of other adolescents, areas of particular concern for ALHIV include the added stress and complexity inherent in romantic and sexual relationships with known HIV infection as well as issues surrounding disclosure, including fear of rejection, stigma and blame.

RELATIONSHIPS

“The stigma associated with HIV in the community means many adolescents are unable to disclose or do not know how to disclose to new partners and may place themselves at risk of other STIs or wild-type HIV virus. The self-stigma of a chronic illness may also mean that an ALHIV will try even harder to be 'normal' and [be] more influenced by peer pressured [to engage in] risky behavior.” (Principal Medical Officer, Kidzpositive; Department of Health Western Province, South Africa)

If asked what is the biggest issue they are concerned about as they transition to adulthood, the majority of ALHIV will talk about relationships and sex. Questions about finding and disclosing to partners, having children, and exploring sexuality while staying safe overwhelm these young people who question daily whether or not anybody could ever love them. Some young people say that finding an HIV positive partner is important, as it reduces anxiety around disclosure and increases the partner’s ability to truly understand life with HIV. Many health providers in Uganda echo this desire, and encourage their patients to find partners within the HIV community.

Peer educators noted that health providers often dissociate sex and relationships, concentrating only on whether a young person is having sex, and rarely providing support with relationships. Further effort should be made to engage ALHIV in dynamic discussions about healthy relationships, as part of sexual and reproductive health (SRH) services and overall peer support.

SEX EDUCATION

“Though trained in youth friendly SRH, most health care workers I have encountered are still not comfortable with it as they hold very strong convictions that teens shouldn’t have sex and fear that by telling them about sex, family planning or STIs they will encourage them to have sex. It has been very difficult to change their mind about this.” (Physician, Baylor College of Medicine Children’s Foundation Malawi)

Adolescence is characterized by the desire to explore, take risks and discover oneself. This often means wanting to experiment with sex and sexuality, alongside wanting to “fit in” among a peer group that may be perceived as highly sexually active. Many young people and health providers interviewed lament that many local cultures in SSA are not conducive to talking about sex. Sex is often considered taboo and many parents/caregivers are unable to have healthy conversations about sex with their children. This means that young people often get information about sex from health care workers or their peers, though this information is not always appropriate or accurate. While health care workers are likely to have accurate information about sex, many adolescents say that the information is purely anatomical and delivered in language that is technical and difficult to understand. When coming from peers, information about sex may be inaccurate, and put ALHIV at high-risk of transmitting the virus or contracting a co-infection or STI.

“The typical information [ALHIV] receive about sex issues in our community comes from [community health workers], but again, the language they use is so technical to an ordinary child. They may discuss the whole topic but the child remains unaware of the information.” (Pediatrician, Nsambya Home Care, Uganda)

According to our informants, the most common SRH services provided include pre and post test counseling, disclosure counseling, STI treatment and basic family planning services, including the availability of condoms. Less frequently cited were comprehensive sex education, sexual violence counseling, cervical cancer screening and the provision of family planning methods other than condoms, such as contraceptive pill, injection, emergency pill, coil/IUD, etc.

YOUTH FRIENDLY SERVICES

The peer educators interviewed reported that society makes them and other ALHIV feel as though they are not supposed to have sexual feelings; that because they are HIV positive, they don't desire partners or children. This makes it even more difficult for them to have conversations with adults about their sexual needs. Many ALHIV complain that they feel blamed or judged by their health care workers when they ask questions about sex or when they ask for contraceptives. Health care providers should be encouraged to offer free, confidential and nondiscriminatory SRH services.

Those organizations providing the best SRH services are those that are youth-friendly and provide outreach to young people within their communities. Providing support around disclosure and self-efficacy is key to ensuring they remain healthy and successful throughout their lives. Providing an open and safe environment for ALHIV to talk about sex and sexuality will increase their likelihood to disclose pregnancies and access PMTCT services, contraceptive services and family planning. This environment should be separate from the adult care environment so that young people feel comfortable, and condoms should be made accessible but conspicuous so that ALHIV can retrieve them privately if needed.

FAMILY PLANNING

“We’ve realized that... kids at the clinic are getting pregnant. We want to start having focus groups to find out why they are having sex, and of ways we can [address] that.” (Teen Leader; Intern, Botswana-Baylor Teen Club; PING, Botswana)

Nearly all of the organizations interviewed provide some form of contraceptive and family planning service, but for the majority, condoms are the only form. Some faith-based organizations choose not to distribute condoms but many provide information about where to access contraceptives. All of the organizations provide PMTCT services for those young people that experience a pregnancy and education about family planning.

One informant mentioned poor availability of PAP smears as a challenge.

“Very few PAP smears [are] done... none are done routinely. You have to be referred to a [gynecologist] to get one done... a rare event.” (Pediatrician, Baylor College of Medicine Pediatric AIDS Corps, Mozambique).

Even those agencies that provide free contraception and family planning programs face challenges. Primarily, they often face supply shortages. Secondly, sexual health services that require frequent visits to the clinic may be difficult for many ALHIV to maintain.

Some peer educators report that their female peers are getting pregnant at an early age because they do not know how long they will live and they want to have children before they die. Others explain that some adolescent girls intentionally become pregnant because they think it will help them hold onto their partners.

“Maybe she just doesn’t want to lose the man. It’s actually happening a lot, with girls who want to have children without their boyfriend’s consent so that they don’t lose their boyfriends.” (Peer educator, Straight Talk, Uganda).

Interestingly, some providers report that pregnancy and parenthood lead young people to become more responsible about their care and adherent to their medications, because the baby gives them something to live for.

“We had 14 pregnancies among our adolescents last year. All of them are negative babies. All of them have improved adherence. We wonder if getting pregnant has been better for them.” (Adherence counselor, JCRC, Uganda).

“Kids want to know if it’s possible for them to have babies while HIV-positive. And kids want to know if they can have sex without a condom if they are both HIV-positive.” (Teen Leader, Botswana-Baylor Teen Club, Botswana)

If an adolescent girl expresses a desire to have a baby, some providers and peer educators have plans in place for how to counsel her.

“You sit down with this person on an individual basis, and you try to understand why they want to have a baby, and then you prepare them—the benefits of having a baby right now and the disadvantages of having a baby right now, and then the benefits of having a baby later. Then you leave the decision to the individual to decide for themselves whether they are really ready to have a baby right now or not.” (Peer educator, Youth Caravan, Uganda).

“That’s something that is very challenging to most of us, most of the peer educators, because convincing this person to change her mind—or to rethink her decision—I mean—she came to you when she has decided she wants to have a child. You have to provide real-life examples, like my own story of being a single mother. I’ve heard many stories about people going back to think, and then afterwards they come and say, ‘Wow, thank you very much. I went back and I thought about everything and I’m going to wait’.” (Peer educator, Straight Talk, Uganda).

FOCUS ON GENDER

While the majority of services can remain gender-neutral for ALHIV, it is important to identify any trends in the needs and behaviors of adolescent girls and boys, and ensure that services are adapted to meet those needs.

Most agencies report a slightly higher number of adolescent girls living with HIV than adolescent boys. They attribute this difference to a number of factors, including a) reflection of the national population, b) increased transmissibility from men to woman, c) vulnerability of adolescent girls to contracting HIV sexually, and d) greater healthcare-seeking behavior among females.

Focus should therefore be put on the increasing population of adolescent girls living with HIV and the importance of SRH and PMTCT to curb onward transmission of HIV through childbirth. Efforts should also be devoted to educating and empowering young women with information about prevention, condom negotiation and delay of sexual debut.

“We have to focus on young women living with HIV. When they talk about young people, they should set aside space for young women, because we are actually a group of people who need some attention. There have been a lot of organizations of women living with HIV, but I’ve not seen any for young women living with HIV.” (Peer educator, Straight Talk, Uganda).

Boys, however, cannot be forgotten. Service providers should concentrate on increasing the uptake of and engagement in services among male ALHIV, as well as education about preventing sexual transmission of HIV.

“Health-seeking behavior shows that females come earlier for clinical care than males. You find more males coming in wheelchairs than females.” (Project Coordinator, IDI, Uganda).

TRAINING AND GUIDANCE

“I’ve gone through a diploma course. I hardly had anything that had to do with sexual and reproductive health. I went through undergraduate. I didn’t handle anything like that. Now I’m doing the masters; still I don’t see something like that. So you can imagine, I am going to be a psychologist who doesn’t have any knowledge about sexual and reproductive health. You can only get this information in short courses or go to the Internet and search for information and then prepare yourself. But how many people are able to go to the Internet and search about sexual and reproductive health for adolescents? Very few.” (Supervisor, OVC program, Reach Out Mbuya, Uganda)

Few of our informants were able to identify efforts related to the training of healthcare providers in the areas of sexual and reproductive health counseling, including counseling related to sexual violence. Those that do address sexual violence, historically have done so on a case-by-case basis, with nearly all the cases incorporating an attack or defilement and the administration of post exposure prophylaxis (PEP). In fact, most respondents said they do not see much sexual violence or intimate partner violence in their practices, which could reflect that it is not taking place, or more likely, that it is not being reported.

“More needs to be done on sexual abuse. 20% of our 50 youth, both HIV positive and negative, reported, primarily through art therapy, that they had been raped (all girls). There is a huge issue of sexual abuse that needs to be addressed.” (Executive Director, Stepping Stones International, Botswana)

A major improvement in health worker training, guidance and policy reform around SRH is needed to adequately support ALHIV as they transition to adulthood. Healthcare workers should be trained to offer comprehensive sex and sexuality education and free contraceptive and family planning services within an environment that is non-judgmental and safe for ALHIV to access information. This training needs to be consistent and continuous, rather than a one-off event, so that health care workers remain up-to-date with promising practices in providing SRH care and services.

In addition, service providers should look toward collaborating with governmental and civil society organizations outside the HIV sector to ensure that particularly urgent issues, such as sexual violence, are handled appropriately.

“Our social welfare officers are trained to deal with sexual violence and we have an excellent relationship with the police and hospital workers to assist us. This is a best practice- training the police to learn how to deal with survivors of sexual abuse so that they do not suffer from secondary victimization.” (Executive Director, Stepping Stones International, Botswana)

Peer educators also expressed the benefits of their own training and the importance of trainers who understand the needs of ALHIV.

“[Our training] covered communications... love, sex, and dating... leadership... [and] gender violence. We covered many topics. I’ve benefited a lot from these trainings—they showed me how to behave... whether I’m here with these kids or I’m outside in my village... [One] best practice I know regarding the training of teen leaders is that the trainers know the needs of somebody who is positive, and they know how to treat them fairly and equally. So the best way to do training [is to] get the best trainers first.” (Teen Leader, Botswana-Baylor Teen Club, Botswana)

YOUTH ENGAGEMENT

ALHIV should be included in the development of curricula and resources that provide SRH education. Organizations should focus on holistic health models that promote life-skills and secondary prevention strategies. Parents, caregivers, teachers and community leaders should be empowered and equipped to deliver accurate and positive SRH messages so that ALHIV can access the information they need from multiple influential people in their lives.

“The intervention that we are adapting is called ‘Healthy Choices for a Better Future Program’. It is an intervention for young people in general that gives them skills and knowledge and how to protect themselves—skills like how to use condoms and things like that. It is an intervention that has been used in Kenya, especially in Nyanza Province. That intervention too was adapted from an intervention in the U.S. called ‘Making a Difference and Making Proud Choices.’” (Study Coordinator & Research Officer, Kenya Medical Research Institute, Kenya)

RECOMMENDATIONS

- Provide comprehensive SRH information in youth-friendly language.
- Partner with and refer to organizations and programs that provide complementary services.
- Provide support around disclosure to partners.
- Create a youth-friendly environment free from stigma and blame.
- Utilize peer educators to talk about their own SRH experiences.
- Deliver ongoing, comprehensive SRH training for all clinical and psychological/social care providers and community health workers that work with ALHIV, including training related to family planning and PMTCT.
- Provide SRH education outside the clinical setting, in rural and urban areas.
- Meaningfully involve ALHIV in the design and delivery of SRH curricula, and information, education and communication (IEC) materials.
- Educate and involve parents/caregivers, teachers, school nurses, community leaders and faith leaders in delivering positive SRH messages to ALHIV.
- Cultivate community champions who can serve as SRH advocates for ALHIV.
- Focus on PMTCT, education and prevention services for adolescent girls.
- Develop strategies to improve uptake of and engagement in treatment services for adolescent boys.
- Train providers to assess for and recognize sexual and intimate partner violence among ALHIV, including information about appropriate referral pathways for support.

PSYCHOLOGICAL SUPPORT

“They are mistreated. They are ignored. They are beaten every day, stigmatized by their community. That is how they develop mental illness. Some of them are not really born with such ailments but because of what they go through, they eventually end up developing such problems.” (Adherence Counselor, JCRC, Uganda).

In addition to elevated risks of mental illness due to having a chronic condition (Bennett 1994), additional risk factors exist for ALHIV because of their likelihood to be affected by poverty, disrupted home life, substance abuse in the home and inadequate social support. These factors are further exacerbated by fear of death, forced disclosure of HIV status and body image concerns related to HIV, such as lipodystrophy (Gaughan, et al. 2004).

Depression is significantly linked to non-adherence to medication, making its diagnosis and treatment vital in the long-term survival of ALHIV (Murphy, Durako, et al. 2001). Additionally, negative affective states, including psychiatric illness, have been linked to increased sexual risk behavior in ALHIV (McNair, Carter and Williams 1998, Ramrakha, et al. 2000) meaning diagnosis and treatment are equally important for reducing the spread of the epidemic in the wider adolescent population.

Many children living with HIV in SSA have been orphaned, losing one or both parents to HIV (Cluver, Gardner and Operario 2007, Daniel, et al. 2007, Petersen, et al. 2010), and this loss and bereavement impacts the psychosocial well-being of children as they reach adolescence (Battles and Wiener 2002, Brown, Lourie and Pao 2000, Fielden, et al. 2006, Petersen, et al. 2010).

While mental health support is sometimes seen as secondary to structural support such as food, shelter and basic living needs, ignoring the provision of mental health services in comprehensive HIV care is a severe impediment to treatment and prevention (Remien and Mellins 2007). A study from Uganda noted in Petersen et al. (2010) showed participation in peer support groups led to higher levels of self-efficacy and reduced feelings of stigma. This is echoed in Zambia, where a qualitative study of ALHIV found that immediate social networks for ongoing support had a significant impact on young people’s ability to adhere to medication and accept their HIV diagnosis (International HIV/AIDS Alliance 2011).

For the purposes of this survey, psychological support was defined as support for issues ranging from basic emotional support to more serious mental health issues such as suicidal ideation or chronic depression. Though many healthcare workers and organizations still refer to “psychosocial support,” one informant in South Africa noted the benefits of a trend to separate out the components of “psychological” and “social” care and support.

“I spoke to a guy at Sidaction, and what they’ve done in France is they’ve made a very serious division. They stopped talking about psychosocial support. They now speak of social support and psychological support, because there are some people who are good at social work, and there are other people who are good at psychological support. So I reckon that’s a very wise observation. We need to develop a really strong cohort of people who could deliver good social work and manage cases, because there are some kids whose lives are just so complicated and awful that you can’t imagine that things will ever be okay. And for most of the kids in the HIV clinic, HIV isn’t the leading set of problems. HIV and health aren’t actually what’s difficult for them. What’s difficult for them is life, and a lot of the problems are things that social workers have to help with. And then there’s a whole other group who have got problems stemming originally from family—single parent, unresolved grief—who have mainly psychological problems. And for that, for both of those, we need to be able to train our counselors to do a better job.” (Pediatrician, Kidzpositive; Department of Health Western Province, South Africa)

ALHIV face a number of psychological issues, some of which are similar to those of any adolescent growing up in SSA, and others that are directly related to HIV. Some of the unique psychological support needs of ALHIV, as identified by our informants, include counseling related to the stigma of having HIV, counseling related to orphanhood, and assistance with emotional and mental health disorders. In addition, they face neuro-cognitive delays that are often not caught early-on in life.

Many ALHIV fear disclosing their HIV status to anybody in their lives. Disclosure is one of the most pressing issues for ALHIV and providers should spend ample time helping young people think through the healthiest ways to disclose their HIV status to others.

“The best way to support a young person who is living with HIV/AIDS to disclose is to let them understand the concept of disclosure and to put simple questions on their brains. Why do I have to disclose, and to whom? What are the benefits of disclosure? What will happen for me when I disclose now and later? And when they understand all this, it makes them get prepared. And if they choose to disclose, they will be ready to face the challenges. They will be ready to face the significance of disclosure. So, for me, I would like to say it’s very important to let them get informed what is disclosure, and also encourage that choice for them. Don’t force them. Let them choose” (Supervisor, OVC program, Reach Out Mbuya)

Interview respondents spoke at length about stress. Stress is brought on by a number of factors: orphanhood, fear of death, stigma and discrimination, lack of money, lack of food and anxiety about the future. Many ALHIV suffer from depression at various points throughout their lives, and many health providers cite occurrences of attempted suicide. Peer educators report that ALHIV feel immense anger, at both themselves and at their parents. They suffer from self-stigma and self-blame, and believe that they lack the opportunities that their uninfected peers have. Moreover, many live in denial and this denial can lead to tremendously detrimental behavior such as non-adherence and unsafe sex.

“Denial is killing most young people living with HIV.” (Peer Educator, Straight Talk, Uganda).

Many ALHIV, say peer educators, live without hope for the future.

“I have reached a point in life where I think I understand my needs and [those of] other children who are in my position. I feel that the only challenge I have yet to face is of [what to say] when kids tell me that they feel they don’t want to live anymore. They will tell you, “Hey, I don’t feel like I should be living anymore, because I already know it (HIV) is going to kill me.” (Teen Leader; Intern, Botswana-Baylor Teen Club; PING, Botswana)

Physical appearance and acceptance in the community are also major concerns for ALHIV.

“Issues about self-esteem, about appearance, about teenage girls wanting to look like other teenage girls and the same for the boys—those are the kinds of questions we have. ‘Will I be able to have children? Will I be able to get married? How can I do so without infecting my partner? Will I have to disclose to my partner?’ But we also get—you know—for children who have had treatments that may change their appearance, who have scarring of the skin because of skin conditions—they’re interested in knowing how to make all that go away. They are also interested in presenting themselves in a way that will make them accepted by the community and loved like anyone else.” (Country Director, EGPAF, Uganda).

Organizations are trying to address mental health problems through individual, group and family counseling. While most organizations have social workers and/or counselors available, very few institutions have clinical psychologists or psychiatrists on staff who can accurately diagnose mental disorders and prescribe medication.

One peer educator mentioned that it is helpful for ALHIV to be mentored by HIV-positive adults since they can relate to the challenges ALHIV are facing and can serve as role models.

“We [sometimes] have an HIV-positive adult come and [talk about] the challenges [we face], because she is older than us. She has been through most of what we are going through right now, and she is helping us—[showing us] how to overcome challenges. I think bringing in people who have been through [similar] experiences or challenges that we are going through does help.” (Teen Leader; PING, Botswana-Baylor Teen Club; PING, Botswana)

SUPPORT GROUPS

“The single most important thing is the peer support group. If you can train peers to communicate the right messages to one another, that is ideal.” (Pediatrician, Nsambya Home Care, Uganda)

Nearly all of the organizations interviewed provide peer support groups for ALHIV, though the mission, structure and

activities of such groups varied widely. Some are held once a month on Saturdays at the clinic, while others are only held every three months during school holidays. Some are held outside the clinic setting, while others are held during clinic hours while patients are waiting for care. They vary widely in size and structure, with some serving children, adolescents and young adults in the same groups, and others splitting them up by age.

Topics for support group discussions often include adherence to medication, disclosure, sex and sexuality, relationships, managing stigma, and building life-skills. Most of the groups incorporate music, drama, and dance into their curriculum. Some educate about advocacy, supporting ALHIV as they make decisions to speak publicly in their communities. Some of the support group members attend summer camps and conferences.

“At Stepping Stones International we are searching for funds to train our staff and other civil society organisations’ staff in the use of art and drama therapy. From our experience with some professional therapists these are the best methods to get youth and children to express themselves and heal themselves.” (Executive Director, Stepping Stones International, Botswana)

“When we started the music, dance and drama program, we started it to improve the well-being of the child. We started it so that it can address some of the emotions of children, which they often hid. So we realized when they come and they drummed and they danced and they chanted and they laughed, there was a kind of healing. It was a kind of therapy. After two years, we asked ourselves ‘Why shouldn’t we have a professional music, dance, and drama group?’ When we realized we have the capacity to train professionally, we trained. And at the training we said, ‘Now, what are we going to do with this professional dancing?’ And then we came up with the addition of, ‘Why shouldn’t we develop this program to become an income generating activity?’ And then we started writing to people and requesting them to give us business. We started to perform at weddings and cocktail parties and national organizations’ ceremonies, in the church, and at the moment I can assure you we are really generating good money. At the moment, I can say we have contributed more than 8 million shillings (about US\$400) from this. So the purpose of this money is to enroll the sisters and the brothers of these children from their homes—those who are not in school. So we are seeing what we call peer support education: children are supporting other children.” (OVC Supervisor, Reach Out Mbuya, Uganda)

One of the most structured and widespread support groups is the network of Baylor Teen Clubs. With sites in Botswana, Uganda, Malawi, Swaziland, Lesotho and Tanzania, it is the largest global network of peer support groups for ALHIV and has been cited as a promising practice by numerous respondents.

“The mission of Teen Club is to empower HIV-positive adolescents to live positively and successfully transition into adulthood. We offer emotional and educational support through structured activities designed to teach life skills, foster relationships, and build confidence. We provide a forum for adolescents to constructively express themselves and discuss issues regarding their condition without the threat of stigma.” (Pediatrician, Baylor College of Medicine Children’s Foundation Swaziland)

“[Teen Club] is a place where you can find smiles all over these kids [faces], where tears are wiped away. Nobody [can] tell me when they come to Teen Club they are here to cry. No—Teen Club is a support group which provides happiness [to] HIV-positive kids who need to find happiness in life. You are home at Teen Club; you find happiness at Teen Club. You get to know that you are not the only one who is affected by this disease.” (Teen Leader, Botswana-Baylor Teen Club, Botswana)

“It’s a club for them, by them, using their ideas. It’s a forum for a voice for young people living with HIV/AIDS. There’s a lot of bonding among them and increased knowledge to prevent further transmission of HIV/AIDS. We also have a curriculum—and several people have managed to use it to develop their peer support clubs. For instance, Straight Talk, the AIDS support organization TASO, other Baylor Centers in Botswana—they manage to borrow our curriculum and then modify it to their setting.” (HIV Prevention Officer, Baylor College of Medicine Children’s Foundation Uganda)

The Teen Club program also follows a model of decentralizing psychosocial support at the country level through the establishment of satellite support groups in partnership with local ARV hospitals and community-based organizations.

“[Our] satellite Teen Clubs came about because we realized that we can not only provide psychosocial support for teenagers in [the capital city]. There are also teenagers across the country who need psychosocial treatment. And then we partnered with different NGOs and ARV sites in their respective satellite areas, and up to date, we have about five satellite Teen Clubs across the country. We have a memorandum of understanding [that details how] they’re involved, like NGOs and ARV sites, and then we provide a model for all the Teen Club activities that we do at the main center and then try to [replicate] it [and] modify [it] for the

different areas. And then, we provide funding for the teen support and we train the adult volunteers and the administrative [staff] over time. And we also teach them how to raise funds so that they can be able to raise funds for themselves and how to run the Teen Clubs on their own.” (Pediatrician, Botswana-Baylor Children’s Clinical Centre of Excellence, Botswana)

The majority of organizations provide support groups for HIV positive adolescents only, though some include young people who are closely affected by HIV as well. Three key reasons that organizations limit their support groups to those adolescents living with HIV are: 1) organizations can only cater to ALHIV because they lack resources to cover a wider range of youth who are just affected; 2) the mission of many organizations is to work with HIV positive people, so the support group needs to fit within their remit; and 3) there is a fear that those who are affected could disclose the HIV status of their peers to the outside community, a risk many ALHIV are not willing to take.

“The degree of stigma in Swaziland and the nature of the meetings dictate that we keep the support group meetings closed. We are exploring opportunities to bring HIV negative and positive adolescents together. The biggest issue is that an adolescent may not have the capacity to make an informed decision [about whether] to disclose their status.” (Pediatrician, Baylor College of Medicine Children’s Foundation Swaziland)

“The youth who are HIV positive have stated clearly that they do not want ‘other’ youth in the program because they do not want them to know their status. They like the fact that they are all the same [and] can talk openly about their issues and share ideas. They feel if there are HIV negative youth in the group then the dynamics would be different.” (Executive Director, Stepping Stones International, Botswana)

“Teen Club is open to HIV-positive kids only. But we are beginning to [consider] including the HIV-negative kids who are willing to support these HIV-positive kids.” (Peer Educator, Botswana-Baylor Teen Club, Botswana)

Those few agencies that bring ALHIV and adolescents closely affected by HIV together, however, also report numerous benefits. For instance, those young people that are closely affected become mobilizers within their communities to end stigma, and are able to access the support they need to support those in their families who are living with HIV.

“We don’t segregate those who are affected by HIV because many young people in Uganda lost their parents and relatives to HIV and AIDS. They also need that information. They need the support. We need them, and they also need us, so that’s why we bring everyone on board.” (Peer educator, Youth Caravan, Uganda)

Some organizations provide peer support groups for both populations concurrently.

“We have [a support group] that is open, and that’s both for disclosed and non-disclosed kids. Issues that we speak about there are just the issues that face adolescents in general. Then we have a closed support group for kids who have been disclosed [to] here, and [for this support group] our mission is around the particular health needs of adolescents living with HIV, and particularly perinatally-infected kids because I think their issues are different [than our] behaviorally-infected kids.” (Head of Counseling and Prevention, ECHO/RHRU, South Africa)

“[Having a group for affected youth] has helped us to fight what we call stigma, what we call discrimination, within our society. Because all the adolescents are trying to get informed. They know what HIV/AIDS is. It’s not something they need to fear. It’s something they can protect themselves from. It’s something they know if someone is HIV positive, needs care and support.” (Supervisor, OVC program, Reach Out Mbuya, Uganda)

Lay counselors or social workers usually provide leadership of support group meetings, though some programs have dedicated staff for their support groups. A few programs have also trained adolescent leaders who have taken over many of the leadership responsibilities and many agree that this is the gold standard.

“Most of our adolescents, they are tired of adults. From Monday to Friday someone is standing in front of them, and then you come on Saturday and another adult is standing in front of them. The model we have is a teaching model or pedantic model where someone just stands there and teaches. And adolescents are tired of this model” (Supervisor, OVC program, Reach Out Mbuya, Uganda).

“The meetings are coordinated by a specific Teen Club Coordinator, an employee of Peace Corps and Baylor Clinic. We are about to hire a Swazi national via Baylor to coordinate the meetings. The lessons are conducted by Teen Leaders who live with HIV and have received special training. There are [also] contributions made by the clinic’s social worker, nurses, expert clients, and doctors.” (Pediatrician, Baylor College of Medicine Children’s Foundation Swaziland)

“We have a lot of young lay counselors that have been trained to run [one] group that are young men. We have more girls than boys at the clinic, but I think that the group is particularly attractive to boys because they have fewer male role models in their lives, and we offer that with the support group.” (Head of Counseling and Prevention, ECHO/RHRU, South Africa)

Average attendance at the support group meetings varies widely between programs, with estimates given between 10-15 adolescents per meeting to over 200.

The challenges that health providers face in the provision of support groups include the lack of resources to provide services for all of the ALHIV that need support; youth growing too old for their support groups but struggle to transition to adult services; and a wide age ranges within the groups mean that some ALHIV are sexually active and others are not, making conversations about sex and other complex topics difficult.

“Challenges encountered in having the group itself are mostly due to its size and the HUGE amount of need out there. It is difficult to find adequate staff for good ratios with the kids to ensure good impact, yet we do the meeting on Saturday and staff do not want to work another weekend per month so we’ve continued with one group every month.” (Physician, Baylor College of Medicine Children’s Foundation Malawi).

In order to meet some of these challenges, organizations are beginning to establish separate support groups for younger adolescents and older adolescents, respectively. Some organizations have even created a separate support group for young adults. Baylor and JCRC in Uganda, for example, hold one peer support group for 12-18 year olds and another for 19-24 year olds.

“We have two groups here in Teen Club. A group [of] kids aged between 13 to 15 years, and another group from 16 to 19 years. They get to shift every month. If the younger group of 13 to 15 years do a recreational activity, [then the] next [month] they will do an educational activity.” (Peer Educator, Botswana-Baylor Teen Club, Botswana)

Despite their challenges, respondents overwhelmingly encourage the establishment of peer support groups for ALHIV citing numerous benefits such as improved adherence; promotion of income-generating activities that help young people earn money, leadership skills, improved confidence to disclose HIV status to others, increased confidence to speak publicly about HIV and educate others to raise awareness and reduce HIV stigma, and a sense of self-acceptance and belonging that leads to all kinds of improvements in health and well-being.

“[Teen Club has] three major benefits: Knowing that as an adolescent with HIV, you are not alone, and you have the opportunity to build relationships during the support groups and camps; addressing issues that our patients are facing and empower our Teens to live positively; and [the creation of] a generation of future leaders to fight the HIV epidemic.” (Pediatrician, Baylor College of Medicine Children’s Foundation Swaziland)

“What the group provides is you get to hear what different people have to say like when you think you’re the only person who is going through a particular situation and you hear some others sharing, you kind of get stronger and say you’re not alone. And actually you can even go to that person for assistance on how to go about a particular situation you’re going through.” (Peer educator, Youth Caravan, Uganda).

“The benefits/successes of the [support] group are many. Most importantly it allows ALHIV to know that there are other kids JUST LIKE THEM. Often before attending teen club, teens knew NO ONE else in the world who was taking medicine and living with HIV so that alone is a success that they know they are not alone. The fellowship and strength of the group is amazing. They support one another and give each other good ideas of how to deal with the challenges of stigma, disclosure, adherence, etc in their lives.” (Physician, Baylor College of Medicine Children’s Foundation Malawi)

“They can express themselves. They are very receptive. They have high levels of self-esteem. They are people who can stand and

say, 'This is what I want, and I want it because 1-2-3,' and they receive it. They are people who can advocate for themselves and also advocate for their peers. They are people who have a future, not unlike when they came and they were not thinking of having a future. They are people who are saying, 'You know? Me, I'm going to live, and because I'm going to live, I have to achieve this and I have to achieve that.'" (OVC Supervisor, Reach Out Mbuya, Uganda)

Informants mentioned a number of ways in which the support groups can be improved, including the expansion and decentralization of the groups and more community outreach.

"Overall, we need to have more activities; more camp, more support groups, more leadership training. However, our imagination is much further ahead of our logistical or financial abilities. We have found that our Teen Leaders and teens are enthusiastic to tackle new projects. Overall, we need to expand to reach all children in Swaziland. With 8 support groups, we can operate on a more fundamental community level with more intimate meetings. We want to get our Teen Leaders involved in supporting our adolescents at the clinic with poor adherence and difficult social situations. Finally, we want to get our teens to communicate with HIV negative adolescents in a constructive, anonymous forum. Ideas have included health pamphlets written in SiSwati that educate adolescents about HIV and what it is like to live with HIV." (Pediatrician, Baylor College of Medicine Children's Foundation Swaziland)

INDIVIDUAL SUPPORT

Support groups provide a space for young people to learn from one another, share experiences and devise collective solutions to the issues that they face. One-to-one counseling support, however is equally important. It allows ALHIV to dig deeper into the issues that they face and get individualized support for their problems.

Some informants wished that they had more time and resources to conduct one-on-one support.

"I wish we had more capacity to do more in depth one-on-ones with kids. They get their general needs met within the group, but we don't have enough time, space, resources, or qualified people to do more of the in depth counseling because I think we're actually missing lots of kids who do need psychiatric referrals, and they don't get it." (Head of Counseling and Prevention, ECHO/RHRU, South Africa).

Most informants indicated that referral-making and acceptance of outside referrals is a regular part of the care they provide.

"At our clinic, referral/permission forms are available to the clinicians and expert clients. We have also extended invitations to children outside of the Baylor clinics, specifically through local and international organizations like Cabrini Ministries (local) and Elizabeth Glaser Pediatric AIDS Foundation (international). If an adolescent shows up at a support group meeting without a referral/permission form, we ask to see the child's "green book" which is given to all patients who have HIV by the government. The child then brings the permission form to the next meeting." (Pediatrician, Baylor College of Medicine Children's Foundation Swaziland)

"When a more serious psychological issue comes up (recent death, social circumstances preventing good adherence etc), we refer our patients to the psychologist. She is available 2-3 times a week." (Pediatrician, Baylor College of Medicine Pediatric AIDS Corps, Mozambique)

Peer educators mentioned that they often refer other youth to adult counselors and professionals when they don't feel capable or comfortable assisting their peers.

"I answer all [the] questions they ask me to my best knowledge. But if they keep on asking questions deeper and deeper about these things and I don't know answers, I contact my adult leaders." (Teen Leader, Botswana-Baylor Teen Club, Botswana)

SAFETY AND SECURITY

One important issue that arose during interviews was the safety and security outside the support setting. When peer and individual support models are effective, participants in the programs feel empowered and equipped. An effective

support group setting is one that is safe, nurturing and encouraging, helping ALHIV realize their potential and their skills. However, the peer support environment does not usually represent reality, and ALHIV have to return to their homes, schools and communities in between meetings. There are situations in which a young person feels empowered to disclose his/her HIV status to a partner, directly, after accessing peer support, but without appropriate time and counseling to critically think about the consequences of this decision. Health providers and peer educators should remain aware of these circumstances, and implement adequate training, counseling and prevention schemes to ensure that ALHIV make healthy and informed decisions.

“All the members of the peer support club feel comfortable coming out from the setting where there's stigma, into an area where they feel more comfortable to discuss and feel free. But at the end of it they have to go back to the community where they live. They need support within the community. We need to look at developing a peer support network in the community, such that individuals can continue to support each other while in that setting.” (Prevention Officer, Baylor College of Medicine Children's Foundation Uganda).

GAPS IN PSYCHOLOGICAL SUPPORT

“There is a lack of adolescent training in the country. There are few psychologists in the country and it is pretty much inaccessible to most teens except those in big cities and specialized centers. Health care workers in Malawi are not trained in how to support ALHIV.” (Physician, Baylor College of Medicine Children's Foundation Malawi)

Numerous gaps still exist in regard to psychological care across SSA. Primarily, there are very few trained psychologists and psychiatrists, so the majority of people providing mental health support are counselors. These counselors range tremendously in their qualifications and training. Many are not qualified to manage trauma in HIV positive patients. Others are not trained to deal with issues concerning sex and sexuality. Very few counselors, especially those based in rural settings, are trained to work specifically with adolescents. Counselors are invaluable in the creation of strong systems of support for ALHIV. Increased funding and attention should be given to comprehensive and ongoing training.

“If you speak to anybody in South Africa, you'll discover that the plans are wonderful but the resources, basically human resources, are very scarce. And people keep hinting that they're going to start training clinical nurses, but it doesn't really materialize. And counseling has been subcontracted to NGOs who allegedly train counselors but in fact only give them about 30 days of training. And they come to us and they really can't cope with the sort of load that you would expect a psychosocial counselor to be able to handle.” (Pediatrician, Kidzpositive; Department of Health Western Province, South Africa)

Secondly, many medical providers do not screen for psychiatric illness or psychological problems during consultations, so many mental health issues remain unaddressed. Informants noted gaps in the referral system, including poor identification of when a referral is needed. Institutions should focus on developing guidelines for medical providers and community health workers to screen for mental health problems during their interviews, and establish clear referral pathways to mental health support, especially for the more common diagnoses of depression and anxiety.

“We refer to the psychiatric department, but that's normally only for kids with very pervasive mental health problems. Those kids that are suffering from major depressive disorder, post-traumatic stress disorder, those kinds of things, which are very pervasive. This population doesn't necessarily get a good referral—A, because it's not screened well, so people don't recognize the symptoms, or [B], the symptoms have been so normalized in the populations that even the providers that are providing the service themselves sometimes don't recognize it.” (Head of Counseling and Prevention, ECHO/RHRU, South Africa)

Informants also identified stigma surrounding emotional and mental health issues as a gap in the provision of psychological support.

“There is A LOT of stigma surrounding mental health issues, maybe even more than around HIV if you can believe that....” (Physician, Baylor College of Medicine Children's Foundation Malawi)

Lastly, respondents identified a significant gap in the utilization of rights-based approaches when providing psychological support for ALHIV.

“I think people don’t take a rights-based approach. I think we need to help adolescents become empowered health care users and demand better treatment from health care service providers.” (Head of Counseling and Prevention, ECHO/RHRU, South Africa)

Some of the current efforts underway to address gaps in the provision of psychological support for ALHIV, as identified by our informants, include the development of counseling training programs, including materials specifically related to the needs of ALHIV, and increased recruitment of mental health professionals.

“What we’re doing at the moment is we are now developing what we call an advanced counselors training curriculum. We want to register [the curriculum] with the University of Cape Town as an adult education qualification.” (Pediatrician, Kidzpositive; Department of Health Western Province, South Africa)

“I’ve created [psychological] screening tools for people, but also backed it up with very intensive training, which looks at bereavement, trauma, . . . intimate partner violence and domestic violence because these are bigger issues in our clinic.” (Head of Counseling and Prevention, ECHO/RHRU, South Africa)

Peer educators suggested the establishment of drop-in centers for counseling and support. They also suggested that institutions create programs that integrate ALHIV from many different agencies and institutions within a regional setting so that they can share their experiences more broadly and create a wider community of ALHIV for support and guidance. More broadly, utilizing peer educators in the provision of psychological support was lauded by many of those interviewed.

“The sort of people who normally come to us are those people who have gone through situations we’ve gone through in the past and we’re in a better position to help them try to become better people because of our own experiences. So we use our experiences to better their lives.” (Peer educator, Youth Caravan, Uganda)

Employing peer educators in the clinical setting does have its challenges, warn two young respondents. There are situations in which youth peer educators who have been attending the pediatric clinic for many years, get hired on as staff in the clinic to provide peer education and adherence support. Veteran employees, such as counselors who have been caring for these young people most of their lives, sometimes feel threatened or uncomfortable working alongside their patients, creating a tense work environment.

CAREGIVER SUPPORT

“Caregivers do not understand how to parent these children because of their own issues. I think that you have to work really closely with caregivers of these children and adolescents for everybody’s health to be improved on multiple levels—physical health, social health, emotional health.” (Head of Counseling and Prevention, ECHO/RHRU, South Africa)

Even as adolescents grow older and become increasingly independent, parents and caregivers have an important role to play in the education and support of ALHIV. However, at times, they themselves need support and information in order to adequately support their child. Issues surrounding sexuality and relationships, transition of care, and developing independence can be just as overwhelming and confusing for a caregiver as for the adolescent. Disclosure, often the responsibility of the parent/caregiver, can be especially difficult. Providing the caregiver with adequate information, support and empowerment is crucial to ensuring that the disclosure experience will not be damaging for the adolescent.

“We assess the existing environment where this child comes from. Do they live with a foster parent, in an orphanage or with the real parents. We work with the parents to determine what are their fears of disclosing. We work through their fears, inform them of the potential benefits and the likely challenges that they will face as a result of the young person in their care knowing they have HIV. We prepare them to respond to the detachment that might come, but also for the freedom good that it will do in their ability to be there for the young person.” (Prevention Officer, Baylor College of Medicine Children’s Foundation Uganda).

RECOMMENDATIONS

- Create referral pathways to institutions that have clinical psychiatrists or psychologists on staff for severe mental health cases.
- Conduct periodic needs assessments and evaluations among ALHIV in your care system to find out which types of support groups will work best (e.g. age limits, infected only vs. infected and affected) and what topics to cover.
- Ensure that support group content is culturally, age and patient appropriate.
- Utilize peer educators to lead support groups and make sure that peer educators are provided with appropriate oversight and support.
- Look toward rolling out peer support models to wider, and more rural settings.
- Provide more time and resources for individual support.
- Provide on-going disclosure support by helping ALHIV think through all the reasons and consequences for disclosure.
- Train medical providers, psychosocial support and community health workers on mental health screening, support and referral-making.
- Provide support for parents and caregivers.
- Create trainings, campaigns and educational materials that de-stigmatize mental health problems and encourage ALHIV and their families to seek mental health support.
- Provide guidance and training for health care providers to recognize, screen and refer for adolescent-specific mental health problems.
- Provide a drop-in center where ALHIV can access informal counseling and peer support.
- Build programs that integrate ALHIV from many agencies so that they can expand their support community and share promising practices between organizations.

SOCIAL SUPPORT

For the purposes of our survey, we defined social support to include a range of informal to formal social support including material, food and economic support from a range of public, private and community-based entities, as well as instrumental support such as assistance with getting to clinic appointments.

According to 2008 report by GYCA, the financial liabilities of living with HIV are a major concern for YPLHIV. Young people, as compared to adults or their HIV-negative counterparts, are less likely to enjoy financial stability, have less access to credit, and are more likely to experience discrimination in the workplace. In certain situations, YLPHIV are excluded from employment due to their status, such as when they are required to take a blood test during the job application process, when they miss work due to sickness and hospital stays, or when they are dismissed from work upon disclosure of their status.

Studies from Zimbabwe have found that ALHIV are unable to afford transportation and food, resulting in malnutrition, the cessation of treatment due to hunger and their inability to attend clinic appointments (Ferrand, et al. 2010). The role of stigma in the psychological and social support of ALHIV cannot be overlooked. Whether real or perceived, stigma lies at the heart of every challenge that the health sector faces in supporting ALHIV through their transition to adulthood. Stigma is associated with concepts of fear, secrecy, trust, disclosure and isolation (Fielden, et al. 2006).

“The majority of ALHIV in South Africa come from very poor socio-economic backgrounds. They may have been living with grandparents in rural areas where conditions are very poor. ALHIV in our service are often living in very cramped informal accommodation with very little money or access to food and transport. The death of family members may remove the only income from the home, increasing the financial difficulties.” (Principal Medical Officer, Kidzpositive; Department of Health Western Province, South Africa)

“It’s a very competitive world, and if one grows up with one form of disadvantage or another, there is a high likelihood that they won’t be as competitive once they come out into the world. So I just think we haven’t invested as much in trying to prepare youth for this developing economy.” (Country Director, EGPAF, Uganda).

ALHIV face a number of challenges related to their basic needs, putting them at increased risk of non-adherence, disengagement from health care, and high-risk behavior. ALHIV often lack the money they need to buy enough food, pay school fees, purchase necessary scholastic materials, travel to and from health services and support family members if they are heads of households. Stigma, unsupportive school staff and fear of discrimination, coupled with cognitive delays, make academic performance very difficult for many ALHIV. In some families, parents will stop paying school fees and remove a child from school if he/she is not performing well. Others drop out of school completely, and lack the skills necessary to find employment. School drop-out then leads to high-risk behaviors such as substance use, unprotected and cross-generational sex, putting ALHIV at risk of acquiring STIs and transmitting HIV to others.

Economic empowerment and the development of life-skills are crucial in the effort to improve health outcomes, longevity and quality of life for ALHIV.

“Definitely, the challenge is that most of the young people are out of school. Meaning that they are unemployed, and they have no economic empowerment, which affects their decision making in terms of sex” (Project Coordinator, Young Adults Clinic, IDI, Uganda).

“ALHIV are often single and double orphans so they often move from home to home and struggle with school fees and transport to clinic. These are the biggest needs of our kids. They are often fed last in their homes and many times made to eat separately from the rest of the family due to misunderstandings of HIV transmission.” (Physician, Baylor College of Medicine Children’s Foundation Malawi)

Some organizations provide outreach in schools, with the aim of sensitizing school students and staff to create a more nurturing environment for ALHIV. They try to provide training and education for teachers so that teachers will incorporate HIV/AIDS curriculum into their health lessons, but this model is still fragmented. There are some teachers who are eager and willing to learn, while others are not.

Some providers do warn, however, that extra care and attention be paid to keeping young people's HIV status confidential if the organization is working in schools. One respondent mentioned, for instance, that when his organization comes to a school to provide outreach or resources, those ALHIV that access support at his organization will shy away or disengage for fear of accidentally disclosing their HIV status to their peers.

Peer educators talked about lack of housing and shelter for ALHIV, particularly those that are orphans. When no other resources are available, some of these peer educators take homeless youth into their own homes.

“When their parents died, their relatives grabbed their property. So they sleep on the streets. And actually that has predisposed very many young women living with HIV to relationships which they really wouldn't have gone into at all if they had a home.” (Peer educator, Youth Caravan, Uganda).

Though many of our informants responded that their facilities have access to social workers and liaise with government social welfare departments, other forms of social support are severely limited, mostly due to low funding. Some hospitals and clinics are able to provide meals during clinic visits and a stipend to subsidize young people's travel to and from services. Some agencies have programs that support the very needy with school fees, but the majority of ALHIV who are not attending school do not have access to such funds. Nsambya Home Care in Uganda supports ALHIV through vocational training programs in areas such as hairdressing, mechanics and hotel management, as well as some capital so that they can start small businesses. Reach Out Mbuya not only provides scholastic materials (e.g. books, pens, pencils, sanitary towels) but also bedding and mattresses for those ALHIV who are in boarding school and cannot afford them. They are even able to provide school fees through university and equipment for those starting up their own businesses.

Those that are able to provide transportation assistance have seen tremendous results.

“We have a grant to pay for transport for all teens to teen club meetings and have seen nearly perfect attendance at all meetings when we added the transport assistance. Social work also assists with transport if the family has need for other visits. We support school fees for some kids. Sometimes we have donations of clothing.” (Physician, Baylor College of Medicine Children's Foundation Malawi)

“The main reason that we started offering [transport money] wasn't because attendance was low. It was because we found that the 10- and 11-year-olds and those kids were coming on their own. And when we asked why they were coming on their own, they said because their families didn't have the transportation money, which in their community is about a dollar. So it just felt like something we could help with.” (Project Leader, Psychosocial Division, Desmond Tutu HIV Centre, South Africa)

Some organizations have tried to partner with one another to provide social support, but even this can cause problems for young people who have to travel long distances between organizations to access support. The travel itself becomes too much of an expense. Another challenge for organizations is that they may be able to provide ALHIV with some instrumental support and materials such as bedding and school fees, but they are unable to support all of the children in the family. So the ALHIV gets a benefit that his/her uninfected sisters and brothers do not. This can cause extreme tension in the family environment.

Often, those organizations that do provide some instrumental support can only provide it to those young people that live within a certain catchment area, so, inevitably, some ALHIV fall through the cracks. In order to provide better social support services for ALHIV, providers suggest holding inter-agency networking meetings within regional settings, so that non-governmental organizations and relevant ministries can create a better understanding of what each is doing and forge stronger referral networks. In addition, agencies should look toward working with local communities and districts for funding to support basic needs such as food, transportation and school fees. Partnering with governmental and non-

governmental organizations outside the HIV community might be beneficial, as most of these ALHIV will qualify for support under grants that support orphans and vulnerable children (OVC).

“If communities could support young people with HIV rather than isolate them, it will help them gain confidence and improve their adherence. This needs to be implemented nationally.” (Adherence counselor, JCRC, Uganda)

RECOMMENDATIONS

- Focus efforts on supporting ALHIV to generate income through skills-based activities (e.g. bead making and selling) and career support (e.g. resume writing and interviewing)
- Train and engage social workers in all areas of social support, including: counseling, livelihoods support and referral-making, as well as areas of particular concern to ALHIV, such as adherence and disclosure counseling.
- Establish referral pathways with agencies that provide social support, particularly those that support school fees and the purchase of scholastic materials.
- Develop criteria to provide food and/or transportation assistance for ALHIV who need it most.
- Hold inter-agency networking meetings to increase collaborative work, resource sharing, joint grant proposals and referral pathways for support.
- Partner with governmental and non-governmental organizations outside the HIV community, especially those that offer support to orphans and vulnerable children/adolescents.
- Consider whether social support adds tension to the family environment if uninfected children are not receiving support. Have a strategy in place to deal with this.

TRANSITION OF CARE

“I think if we can have a clear transition plan that is supported financially by the program, I think that’s the best that we can do for these kids. Because ultimately, I believe most of the young people, the adolescents, are going to grow up into adults, and that is what we hope and plan for them—that they grow up into healthy adults who are recognized, who are able to cope on their own. So a transition plan is urgent. We need it.” (Pediatrician, Baylor College of Medicine Children’s Foundation Uganda)

The loss of parents and important caregivers to AIDS-related illnesses, coupled with the perception of non-survival, means many ALHIV are unprepared for social and economic independence, self-management of HIV (Petersen, et al. 2010), and the transition to adult health care. Many perinatally infected young people have already suffered the loss of important caregivers in their lives (Remien and Mellins 2007, Wiener, Kohrt, et al. 2009, Gipson and Garcia 2009), so leaving a pediatric provider who has been there from the start is particularly traumatic (Gipson and Garcia 2009, Hauser and Dorn 1999, Wiener, Kohrt, et al. 2009). In response, many adolescent HIV programs have expanded their upper age limit from 21 to 24 years (WHO & UNICEF 2006).

Careful consideration, planning and practice are essential for a seamless and effective transition experience (Gipson and Garcia 2009). Continuity of care, not only through medical transition but straight through to adulthood is important to adolescents, who recognize that their psychosocial, mental health, sexual and reproductive health needs will change through their young adult years (GNP+ 2010).

Training HIV positive young people to plan ahead, as in preparing questions for their providers and checklists for their responsibilities, has been found to improve long-term health and adherence to medication (Gipson and Garcia 2009). Equally important is teaching decision-making skills to YPLHIV, not only so that they are able to make informed decisions around high-risk behavior, but also so they can make important decisions about their healthcare.

Few of the organizations interviewed have a clear strategy in place to transition their ALHIV from pediatric to adult health care. This issue remains a major challenge for health providers across the world, and requires a joint effort on the part of health providers, patients, families and policy makers, in order to be effective. Agencies vary in terms of when they think ALHIV should transition. Some attempt to transition them at age 18 while others wait until they are 24.

“The problem is at Harriet Shezi: our oldest pediatric patient is 23. So I don’t think we’re [transitioning] well, but mainly because the barriers are so great, we end up offering services for way longer than we should be. They’ve been coming to the clinic for so many years to pick up their ARVs, they don’t want to leave. It’s a real problem.” (Head of Counseling and Prevention, ECHO/RHRU, South Africa)

“Almost all of these teens have been infected since birth and are some of the most medically complicated patients in the country so we have maintained them in our care for now while we continue to build capacity related to their needs. We continue to build this capacity at outreach clinics.” (Physician, Baylor College of Medicine Children’s Foundation Malawi)

Respondents listed a number of reasons why transition is such a challenge. They note that ALHIV do not want to go to the adult clinic, and often when they do transition, they boomerang back to pediatric services soon after. Sometimes, they stop engaging in health care altogether. As mentioned, many providers, particularly those based in rural settings, are not trained to work with adolescents, so when they transition to adult care, the adolescents feel misunderstood and unwelcome. In many parts of SSA, HIV treatment and counseling services are provided free of charge in the pediatric setting, but at a cost for adult care. In addition, many hospitals that provide food during clinic visits for children do not provide food for adults. These are very clear barriers for ALHIV who may not have a source of income or consistent food supply.

Peer educators interviewed talked about not wanting to have to start all over with providers, particularly with counselors to whom they will have to retell their stories and experiences. On the other hand, pediatric providers do not want to let go of their patients either.

“This child has a good relationship with this person for the last 10 years or the last 5 years, but now, without any preparation—without any transitional preparation—the child is just shifted, like magic, to the next person. And then, it will take time for that child to build a relationship. It can affect the child’s health. It can affect the child’s adherence. It can affect a lot of issues to do with the child.” (Supervisor, OVC program, Reach Out Mbuya, Uganda).

PROMISING PRACTICES

“As you know, children have been a neglected group for a long time, and adolescents even more. We don’t really have [a transition protocol] in place right now but we’re working on an adolescent transition program which will hopefully have specific guidelines for [transitioning] perinatally infected adolescents [to adult care].” (Pediatrician, Botswana-Baylor Children’s Clinical Centre of Excellence, Botswana)

Those informants whose facilities did have a transition plan in place often advocated for skills-based transitioning, continuity of care, and the promotion of youth friendly services at the adult care level. Respondents agreed that training be provided for providers in the adult care environment to understand and manage the specific needs of adolescents.

“From a clinical perspective, just having adolescents in our clinic really requires us to have continuity of care for them, because they are a very special group, and they [should not] have a different [healthcare provider] to tell their story every time. So we have a continuity clinic which we are still trying to improve on, where a healthcare provider or doctor sees the same patients every visit.” (Pediatrician, Botswana-Baylor Children’s Clinical Centre of Excellence, Botswana)

“Our model is we train all our service providers to know the adolescent kind of treatment and management. By the time you are having this adolescent transitioning to the adult wing, there is that clear understanding by the provider that, okay, this is what an adolescent would want.” (Head of Field Team, Mildmay, Uganda)

They stressed the importance of including ALHIV so that they feel empowered and equipped to transition.

“They should design them [transition programs], they should get involved, they should own these programs, and they should bring change to themselves if they want.” (Supervisor, OVC program, Reach Out Mbuya, Uganda)

Others suggested the implementation of an adolescent-only transition clinic.

“Our clinic has been very successful in transitioning ALHIV into our adolescent clinic and has been in place since 2006. The doctors working in the adolescent clinic are the same as those in our pediatric clinics. This allows us to provide continuity of care and a smooth transition into adolescent care. As the decision to enter our adolescent clinic ultimately lies with the ALHIV and their care gives the plan is usually fully adhered to. Health care providers are encouraged to identify patients who would benefit from the adolescent clinic.” (Principal Medical Officer, Kidzpositive; Department of Health Western Province, South Africa)

The Infectious Disease Institute in Uganda runs a weekly young adults clinic that serves as a transition clinic between pediatric and adult health care.

“First we identified the clinicians who were willing to work with these young people. They went for training on how to be youth friendly and deal with the young adults. Pediatricians came in as consultants but these were mainly physicians who were seeing adults at IDI. However, eventually, time came that management felt that everyone—every physician, nurse, counselor—should know how to work with the young people.” (Project Coordinator, Young Adults Clinic, IDI, Uganda).

Still, others suggest a more incremental approach to transition. For instance, providing adherence and mental health counseling from the adult clinic, but maintaining them in pediatrics for their medical care. Of course, this will only work if ALHIV are transitioning within the same institution. Similarly, if institutions provide adolescent services on a particular day of the week, transitioning adolescents could be invited to attend the adult clinic from time to time, but still see their

pediatric providers. At Mildmay, Uganda, adolescents maintain the same mental health counselor, before and after they switch medical providers. At IDI's Young Adults Clinic, they see adult providers all the way through.

"We have so far transitioned 65 young adults into the adult clinic, and we have a procedure—a standard operation procedure—that we follow. The first entry point is age. When you turn 25 we start preparing you. And one of the things we look at is knowledge in terms of sexual and reproductive health issues. We look at adherence. How are you faring? And if we see there is a gap, the counselors address it. Eventually we decide when to give you a clinic appointment at the Adult Clinic. But you continue seeing the same clinicians and counselors that you've been seeing in the Young Adults Clinic. Definitely, the challenge is most of them feel they don't want to go into Adult Clinic, but we keep on encouraging them—continue ensuring them that everything is going to be okay." (Project Coordinator, Young Adults Clinic, IDI, Uganda).

Many providers stressed the importance of looking at transition holistically, as a set of life transitions rather than medical transition alone. Medical transition is just one aspect of the ongoing life changes that ALHIV face – questions of sex and sexuality, relationships, starting families, having children, having negative partners, transition in education, housing and income. All of these life transitions are happening at the same time and can be addressed simultaneously to transition of care.

Equally, providers stress that institutions must work together in order to provide better information about and access to services for ALHIV as they begin to transition to adult care. While many pediatric providers are hesitant to let go of their patients, it is imperative that they do so, thoughtfully and intentionally, in order to ensure that their patients get the highest quality of care and do not slip through the net.

"I think the institutions need to work together to give them [ALHIV] as much information as possible about the availability of services, care for the fears or threats they may be having, and enable them to come out of their comfort zones and know that the time is coming for them to grow." (Project Coordinator, Young Adults Clinic, IDI, Uganda).

RECOMMENDATIONS

- Put a transition strategy or standard operating procedure in place at your institution.
- Include ALHIV in the development of your transition strategy.
- Consider a step-by-step skills- and knowledge-based approach to transitioning in which adolescents graduate to adult care only after achieving certain milestones.
- Consider an adolescent-only or transition clinic.
- Train adult health providers to work with adolescents.
- Sensitize the adult patient population to welcome young adults into the clinic.
- Approach transition as a process, not an outcome.
- Start preparing ALHIV for transition early.
- Assess patient readiness before transitioning.
- Provide continuous counseling and mental health support before, during and after transition.
- Collaborate with other organizations and share best practices around effective transition for ALHIV.
- Address clinical transition as part of all the transitions ALHIV are facing.
- Involve parents and caregivers at all steps of the transition process.

RESOURCES

“I think we need a toolkit which any service provider can use when they are reaching out to young people living with HIV, especially those perinatally infected. I think it should even be given first priority because there’s nothing at the moment for them.”
(Peer educator, Youth Caravan, Uganda).

Informants mentioned a number of resources that they use to provide effective guidance related to adolescent HIV treatment, care and support to healthcare workers and ALHIV themselves. These include resources from:

- AIDS Information Center, Uganda
- Auntie Stella Life Skills Program
- Baylor College of Medicine International Pediatric AIDS Initiative (BIPAI)
- Centers for Disease Control and Prevention (CDC)
- Guttmacher Institute
- Global Youth Coalition on HIV/AIDS (GYCA)
- Ibis Reproductive Health
- Integrated Management of Adolescent Illnesses (IMAI)
- International HIV/AIDS Alliance
- International Planned Parenthood Federation
- Love Life: South Africa
- Ministry of Gender, Uganda
- Ministry of Health, Uganda
- Regional Quality Center for Health Education, Mulago Hospital, Uganda
- Strengthening HIV/AIDS Counsellor Training in Uganda (SCOT)
- Soul City
- Southern Africa AIDS Information Dissemination Service (SAfAIDS)
- Stepping Stones International: Botswana
- United Nations Children’s Fund (UNICEF)
- World Health Organization (WHO)
- Youth Health Organization (YOHO): Botswana

Some organizations have produced their own resources and have disseminated them widely. These include “Our Story Book”, a compilation of testimonies from children and adolescents living with HIV in Zimbabwe, as well as question and answer guides for ALHIV, such as ‘Teen Talk’ by the Botswana-Baylor Children’s Clinical Centre of Excellence and ‘HIV Positive? Thinking About Sex? Read This First’ by JCRC in Uganda.

“We have a whole bunch of things that I know about because I’ve helped develop them, [such as] a DVD training on how to run support groups for children and adolescents who are HIV positive for lay counselors to help capacitate them, specifically around

identifying and treating trauma and traumatic bereavement. We've also created curriculums around how to run 12-week groups with children and [also one for] adolescents.” (Head of Counseling and Prevention, ECHO/RHRU, South Africa).

Youth Caravan, in Uganda, will soon launch an adolescent-friendly website for YPLHIV. Other organizations develop their own guidelines for treatment and care. The Botswana Teen Club program has created a website containing a blog as well as a portal of suggested resources, some of which are created in-house.

Some informants also mentioned that they adapt resources for their specific country context.

“Resources we use include WHO publications on care of adolescents; 1 day orientation to care of ALHIV; Alliance [also] has several good publications; we have created some of our own materials that we share with partners in Malawi; we have referenced some of the material from other African countries, but sometimes they do not exactly address the cultural context here in Malawi so we have adapted them.” (Physician, Baylor College of Medicine Children’s Foundation Malawi).

However, informants also felt that certain resources are lacking. These included resources on SRH education and services, addressing the needs of HIV positive women, youth-friendly services, clinical transitioning and adolescent specific training modules and guidelines. One informant mentioned the need for further research on the needs of ALHIV in order to produce evidence-based resources.

“SRH training that gets to the heart of why many healthcare workers refuse to provide SRH services to adolescents would be critical. A very basic introduction to mental health issues that adolescents experience (NOT schizophrenia), but basics of depression and anxiety and basic skills of how to address these issues and when to refer, i.e. danger signs. Basic curriculum to help health care workers understand and work with ALHIV on issues relevant to them in an interactive way, requiring very little preparation.” (Physician, Baylor College of Medicine Children’s Foundation Malawi)

“If we had resources, training guides, programs, adolescent-friendly games, things around disclosure, family planning, sexual risk behavior, substance abuse, adherence as the main topic, if we had a little training tool kit that we could use, things that we could give the kids to take home, that kind of thing, it would be really helpful.” (Project Leader, Psychosocial Division, Desmond Tutu HIV Centre, South Africa)

It is also important, however, that those resources that are produced are culturally-sensitive and user-friendly.

“It’s important for people who are very aware of the cultural context as well as the reality of the working environment. Many curriculums have been developed and remain on the shelf not used because people don’t have enough time in the day to sit down, read it all and then use it. Must be very simple and user friendly.” (Physician, Baylor College of Medicine Children’s Foundation Malawi)

RECOMMENDATIONS

- Conduct research on the needs of adolescents in your program so that you can produce evidence-based resources.
- Adapt existing resources for specific country contexts.
- Develop resources that are culturally-sensitive and user-friendly.
- Document any innovative intervention from your program

ADVOCACY

“Meaningful involvement of young people [is needed] because we don’t have youth voices in the national AIDS response. We would love to see a new generation of young leaders [because] things have been the same over and over, and... if the young people’s leadership is tapped into, we could really have great results. We could even reverse transmission by maybe 35% or 40% and reach the universal access target.” (Peer Educator, Youth Caravan, Uganda)

In its report on the needs, challenges and priorities for ALHIV in Zambia, the International HIV/AIDS Alliance and Alliance Zambia state that, on the policy level, funding for services for ALHIV and SRH, in urban and rural settings, should be a key priority. Equally, advocacy efforts should focus on providing health workers with the support they need, through clinical consultation and guidance, in order to adequately support this patient group (International HIV/AIDS Alliance, 2011).

At the international level, the Global Network of People living with HIV/AIDS (GNP+) advocates for improved quality of life for all PLHIV. GNP+ works with independent and autonomous regional and national networks of PLHIV worldwide. Under the central theme “Reclaiming our Lives!”, GNP+ implements an evidence-informed advocacy program focused on: empowerment; human rights; positive health, dignity and prevention; and sexual and reproductive health and rights of people living with HIV. GNP+ has also established the Y+ Program to address specific gaps in the HIV response and address the specific needs of YPLHIV, ages 15-30.

Another international body that has begun advocating on behalf of ALHIV is the Inter-Agency Task Team (IATT) on PMTCT and Pediatric HIV Care and Treatment. The overall purpose of the IATT is to strengthen partnerships that address the broader health concerns and survival of women, infants and children within the context of HIV. The IATT on PMTCT and Pediatric HIV is co-convened by UNICEF and the WHO.

Furthermore, recent gatherings of healthcare professionals, service providers, policy makers, and ALHIV themselves, have resulted in strong calls for action to address the gaps in service provision for YPLHIV.

Currently, there are a number of advocacy initiatives across SSA that deal with issues related to adolescent HIV, though few exist for ALHIV specifically. Respondents talked about policies surrounding rights of the child and workplace protection for all PLHIV. In Uganda, there is a pediatric subcommittee that is developing national ART guidelines, which includes adolescent-focused physicians. In Botswana, there is an Adolescent Technical Working Group that advises the Ministry of Health on an array of issues related to the treatment, care and support of ALHIV.

In Zimbabwe, ALHIV from Africaid produced an exhibition of art titled “Audacity of Hope” in commemoration of World AIDS Day 2010. The exhibition was held at the National Gallery and was launched by the Minister of Health and Child Welfare. The adolescents developed powerful works of art through which they shared their hopes for the future and advocated for the rights of ALHIV including access to ART and stigma-free communities.

Indeed, the need for ALHIV-specific advocacy efforts is great.

“Any advocacy would be great! Just getting the word out that children and adolescents living with HIV have been infected by no fault of their own and that they deserve equal rights as everyone else and helping [to educate people] about how HIV is transmitted so there is less stigma.” (Physician, Baylor College of Medicine Children’s Foundation Malawi)

“I think [advocacy around] youth friendliness and youth-friendly services [is needed]. I think that’s a great starting point. People see children in this country and then they see grown-ups. They don’t see adolescents. That’s why in terms of policy, 12-years-old is the cutoff age. That’s it. After 12 you’re a grown-up and your needs are like adults’ needs. You’re treated that way. And we’re just missing that entire developmental group. We’re just missing them entirely. Our policy sets us up against that, so I think policy needs to change ... in terms of [South Africa], the constitution is great, but it’s not practiced on [the] ground. And so I think there

needs to be a shift not only with policy but with the way that it's implemented and more awareness around that. And in addition to that [we must]empower youth to demand better services for themselves.” (Head of Counseling and Prevention, ECHO/RHRU, South Africa)

Child rights were a huge theme in discussions about advocacy. In many countries, when a child becomes orphaned, he/she loses the right to his/her parents' property.

“It's a big problem here in Uganda—very big problem—because they assume that these children are at a tender age; they can't do anything. They just chase them away, and then they take their land, they take their house, they take everything that belongs to their family. People need to grow from that level. People need to respect children, regardless of whether they are orphans or whether they are vulnerable.” (Supervisor of OVC program, Reach Out Mbuya, Uganda)

Some respondents also expressed the need for increased advocacy for young people who identify as sexual minorities, who, in many countries, are not recognized legally or institutionally.

DISSEMINATION

The greatest challenge to advocacy, however, is not whether the policies are written, but whether they are implemented.

“Policies are there; dissemination is the challenge” (Head of Field Team, Mildmay, Uganda)

“I think that sensitization is more important than policies. There are so many policies but without creating awareness in society, the policies do not work.” (Adherence counselor, JCRC, Uganda)

“I perceive a massive disconnect between the written and [practiced] law.”(Pediatrician, Baylor College of Medicine Children's Foundation Swaziland)

“Sometimes guidelines remain in the books. We might have these people with bright ideas and very good expertise and they develop these tools and they disseminate them at the conferences, but they remain at the conferences. That is the biggest challenge.” (Supervisor, OVC program, Reach Out Mbuya, Uganda)

In order to combat some of these challenges, health providers recommended that bringing policy makers into services, to meet ALHIV and learn about their unique issues first-hand, is important in the success of advocacy efforts. Equally, providers suggested that national policies be written that can be adapted for both urban and rural settings, since many policies are not written with rural settings in mind.

“In the city, we are seeing more adolescents who are aware of their environment. They know what they are doing. In the districts, some of them—it's by chance that they get on board to recognize that they have HIV, because access to services is quite difficult.” (Head of Field Team, Mildmay, Uganda)

RECOMMENDATIONS

- Spearhead advocacy campaigns that focus specifically on ALHIV.
- Advocate for youth-friendly services and youth-friendly clinical and support environments.
- Advocacy and protection policies should be inclusive of minority populations and marginalized groups.
- Advocate for stronger and more comprehensive SRH education, family planning services and related policies within the clinical environment, school system and wider society.
- Meaningfully involve ALHIV in all advocacy efforts while respecting their confidentiality.
- Develop advisory groups and technical working groups to address the needs of ALHIV and involve ALHIV in such efforts.
- Invite policy-makers to visit your services/facilities so that they can witness your work first-hand.
- Disseminate and implement policy. Don't leave it sitting on a shelf.
- Ensure policies are adaptable for urban and rural settings.

CROSS-CUTTING THEMES

Throughout the interviews, a number of cross-cutting themes emerged that merit attention.

COLLABORATION

Throughout interviews with health providers and peer educators in SSA, a reoccurring theme was the need to increase collaboration and sharing of best practices among organizations working with ALHIV. Respondents called for increased communication and referral pathways, inter-agency networks and meetings, and platforms to bring ALHIV from different institutions and countries together so that they can share their experiences and work toward creating a unified voice for ALHIV across the world.

“There are a few people doing wonderful things. We don’t meet enough so you’re left to feel like you’re the only ones that are taking this as a focus and you’re constantly hit with resistance around the issue. So more collaboration would be great.... and coming together with best practice models, because many of us have tried and failed at a bunch of things and we keep reinventing the wheel.” (Head of Counseling and Prevention, ECHO/RHRU, South Africa)

“A lot of people are doing a lot of things, but they’re doing them in silos. The Desmond Tutu Foundation, I don’t know what they are doing. I know that they really are leaders in the peer support group side of things. Our efforts to train our counselors are probably pioneering. But any meeting you go to, you discover these guys are developing a training DVD, those guys have discovered such and such, and everybody is frantically busy to try and do things, but we don’t get together and work on a comprehensive plan to put everything into place. What we actually need is some kind of inter-organizational meeting to work out what our priorities ought to be.” (Pediatrician, Kidzpositive; Department of Health Western Province, South Africa).

A useful approach is to conduct a mapping exercise of local organizations, their remits and programs, in order to better understand who is doing what and how organizations can collaborate. Collaborating with these organizations, whether they provide specific support for ALHIV or more generalized support for OVCs, could provide tremendous results for organizations that are struggling to meet all of the needs of ALHIV.

“As one moves out into rural areas, many times it’s not very clear whom to refer to. There are not so many groups providing services. So it’s kind of—it’s difficult. But right now we’ve just completed a mapping of service providers in each of these districts so that we can have a referral directory that’s up to date. And that will help us refer and connect adolescents to providers who complement what we’re doing.” (Country Director, EGPAF, Uganda).

EMERGING TECHNOLOGIES

“The management of adolescents changes so rapidly that we need to try and keep up. Currently, most adolescents are so technologically advanced, and [yet] we are trying to provide the services using the old model where we want to sit with them and give information. I’m thinking we need to advance [to the point] where they can just... get on to the computer, look at the information, and come up and ask questions where they are not clear. We are not moving with the times. It might be just me, that I’m of another generation, but I can see I’m running behind them.” (Adolescent Program Director, Perinatal HIV Research Unit, South Africa)

Other informants have also advocated for a greater utilization of emerging technologies to provide care for adolescents. Such interventions may be difficult to offer, however, in resource-limited settings.

“More interactive [smart phone] and computer activities should be designed to attract the interest of the youth... We use an interactive video produced with Stanford [University], approved by the Ministry of Education called ‘Teach AIDS’. Highly recommended as it is interactive and has been adapted specifically for Botswana.” (Executive Director, Stepping Stones International, Botswana)

One promising practice cited by a peer educator working in Botswana is the Kgakololo Project, which is overseen by a youth-run organization called Positive Innovation for the Next Generation (PING). The Kgakololo Project is a cellphone-based support, reminder and information system for Botswana Ministry of Health patients living with HIV/AIDS. Using a web interface, the system sends out text message reminders to patients for doctor appointments, prescription refills, individualized pill reminders, and lab test results and allows appointment rescheduling via text messages. All the messages can be delivered in English or the local language of Setswana and are personalized to patient's interests. Patients can also program in their own codes for reminders so that they can protect their privacy and knowledge of their status. The program is completely free for all patients enrolled and there is no cost for text messages into or out of the system, or for calling their toll-free helpline.

“[A] unique intervention currently being tried in Botswana through an organization called PING is sending a text message of your choice to your phone that reminds you to take your medication. The message you choose might be “Meet me at the shop” but you know this means take your drugs which cuts down on stigma if anybody other than yourself reads the message.” (Executive Director, Stepping Stones International, Botswana)

“[The Kgakololo Project] reminds people to take their medication on time and provides them with messages that do not just say, “Hey, it’s time up. You have to take your medicine,” but also gives a lot of information like [motivational] verses or [messages from] local celebrities.” (Teen Leader; Programs Department Intern, Botswana-Baylor Teen Club; PING, Botswana)

Some informants mentioned that they are using social media to reach their target audiences. One peer educator in Botswana has even made Facebook account using a pseudonym that he uses to chronicle and share his experiences living as an HIV-positive adolescent.

“I have a [pseudonym] Facebook account for myself, open to the public, telling them who I am and that I’m this HIV-positive guy who is happy with his life and enjoying it to the fullest. It seems to be going well. Though I [sometimes] get negative comments, I manage to get my message across to those people who want to be my friend. Overall, it’s going according to my plan.” (Teen Leader; Intern, Botswana-Baylor Teen Club; PING, Botswana)

In Uganda, EGPAF is starting an SMS –based platform that will utilize “community chatrooms” to answer the community’s questions about HIV and sexual health. Community champions will be identified, provided with phones and airtime, and trained to solicit questions from the community and feed them back to EGPAF using SMS. They will then receive an accurate and up-to-date answer from EGPAF, which they will deliver to the people asking the question.

“Amongst HIV-positive youth, within their peer community, we shall have champions there. But it’s going to be a wide platform and there will be people from all walks of life – men, women, infected, non-infected, village health team members. But we’ll use this as a sounding board to be able to reach out to communities, but also to try and get communities access to information. We hope it will be a window into their lives and into their aspirations and expectations.” (Country Director, EGPAF, Uganda).

CONCLUSION

“Some [ALHIV] are determined to take control of their lives – indeed, a number state they seek normality, to be like other young people. Others are more reactive, less willing or able to influence their lives. Perhaps as an illustration, HIV is a force leading to deviation from a routine trajectory, into a world dominated by treatment, altered social interaction, and a consideration of sexuality requiring awareness of ‘real’ danger to self or others (rather than imagined danger, which underpins education around sexual health).

In spite of this, many respondents are planning for future times – indeed their hopes and dreams are similar to many other young people; marriage; children; and employment. They steer towards a goal that in spite of their diagnosis is still very much in their sight.” (International HIV/AIDS Alliance, 2011, p. 28).

This report captures genuine voices from those in the frontline of the fight against HIV and AIDS, telling us the story of a rapidly increasing population of ALHIV that are transitioning into adulthood. Innovative strategies and additional resources are needed if health-care providers, community-level stakeholders, caregivers, and policy-makers are to respond effectively to the specific needs of this group. As long as ALHIV and their unique clinical, psychological and social needs are overlooked, adolescents will remain one of the most vulnerable populations affected by the HIV pandemic. Our failure to address this vulnerability threatens the lives of these youth and jeopardizes the successes of pediatric HIV treatment efforts to date.

Efforts to mobilize and strategically advocate for pediatric and adolescent HIV care, support and treatment have not been commensurate with the magnitude of the problem. Organizational and political inertia, coupled with a dearth in patient voice, have stifled the response to this urgent problem. However, the findings of this report point to a number of concrete actions that can be taken to improve service provision for ALHIV. These include:

- providing adolescent-specific training for health care workers;
- developing holistic treatment, care and family planning services for ALHIV utilizing evidence-based strategies; meaningfully involving ALHIV in all aspects of their care and support, including assessments, design, delivery and evaluation of services;
- identifying, training, and utilizing peer educators, as well as providing them with ongoing support;
- developing youth-friendly services and facilities that are easily accessible;
- providing comprehensive sex education and reproductive health services, including family planning;
- creating and monitoring appropriate referral pathways; developing clear and holistic strategies/protocols for transition of care;
- providing psychological counseling and mental health support by trained psychologists, psychiatrists and paraprofessionals;
- providing support to parents and caregivers;
- sharing best practices between organizations;
- holding inter-agency network forums to improve collaboration;
- developing resources that are culturally appropriate, age appropriate and user-friendly;

- and advocating for and with ALHIV, especially in regards to stigma reduction and improved access to services.

These strategies will require improved collaboration between service providers and a greater commitment by policy makers, development partners and public leaders to address the unique needs of ALHIV.

Though the information provided by key informants in this report provides a broad overview of the gaps and opportunities for service provision for ALHIV, more research is needed on the following:

1. The extent to which ALHIV overlap with most-at-risk populations, such as injection drug users and sex workers, and/or are children of those who are.
2. The gender dynamics and gender-specific needs of ALHIV.
3. The cost-effectiveness/benefit of specific interventions.
4. The other chronic diseases impacting adolescents that have significant social dimensions and how linkages and lessons from programs designed to address these other chronic illnesses can be formed/shared with interventions for ALHIV and vice versa.

REFERENCES

Bachanas, P J, et al. "Predictors of psychosocial adjustment in school-age children infected with HIV." *Journal of Pediatric Psychology* 26, no. 6 (2001): 343-352.

Battles, H B, and L S Wiener. "From adolescence through young adulthood: Psychosocial adjustment associated with long-term survival of HIV." *Journal of Adolescent Health* 30, no. 3 (2002): 161-168.

Bennett, D S. "Depression among children with chronic medical problems: a meta-analysis." *Journal of Pediatric Psychology* 19 (1994): 149-169.

Bertozi, S, et al. "HIV/AIDS Prevention and Treatment." In *Disease control priorities in developing countries*, by D T Jamison, J G Breman, A R Measham and et al., 331-369. New York: Oxford University Press, 2006.

Birungi, H, and et al. "Sexual behavior and desires among adolescents perinatally infected with human immunodeficiency virus in Uganda: implications for programming." *Journal of Adolescent Health* 44, no. 2 (2009): 184-187.

Brown, L K, K J Lourie, and M Pao. "Children and adolescents living with HIV and AIDS: A review." *Journal of Child Psychology and Psychiatry, and Allied Disciplines* 41, no. 1 (2000): 81-96.

Clark, S. "Early marriage and HIV risks in sub-Saharan Africa." *Studies in Family Planning* 35, no. 3 (2004): 149-160.

Cluver, L, F Gardner, and D Operario. "Psychosocial distress amongst AIDS-orphaned children in urban South Africa." *Journal of Child Psychology and Psychiatry* 48 (2007): 755-763.

Daniel, M, H Apila, R Bjorgo, and G T Lie. "Breaching cultural silence: Enhancing resilience among Ugandan children." *African Journal of AIDS Research* 6, no. 2 (2007): 109-120.

Earls, F, G J Raviola, and M Carlson. "Promoting child and adolescent mental health in the context of the HIV/AIDS pandemic with a focus on sub-Saharan Africa." *Journal of Child Psychology and Psychiatry, and Allied Disciplines* 49, no. 3 (2008): 295-312.

Ferrand, R A, et al. "AIDS among older children and adolescents in Southern Africa: projecting the time course and magnitude of the epidemic." *AIDS* 23 (2009): 2039-2046.

Ferrand, R A, et al. "A primary care level algorithm for identifying HIV-infected adolescents in populations at high risk through mother-to-child transmission." *Tropical Medicine & International Health*, 2010.

Fielden, S J, et al. "Growing up: Perspectives of children, families and service providers regarding the needs of older children with perinatally-acquired HIV." *AIDS Care* 18, no. 8 (2006): 1050-1053.

Gaughan, D M, M D Hughes, J M Oleske, K Malee, C A Gore, and S Nachman. "Psychiatric hospitalizations among children and youths with human immunodeficiency virus." *Pediatrics* 113, no. 6 (2004): e544-e551.

Gipson, L M, and G C Garcia. *Transitioning HIV positive youth into adult care*. Camp Sunrise and Ohio AIDS Coalition, 2009.

Global Youth Coalition on HIV/AIDS. *Living positively: young people living with HIV and the health sector response*. GYCA, 2008.

GNP+. *Statement from the global network of young people living with HIV consultation*. Statement, Amsterdam: Global Network of Young People Living with HIV, 2010.

Greifinger, R, Rosenthal, E, & Kubicek, W. "Medical transition for young people living with HIV: Challenges and solutions." 2010 Unpublished Next Step, Cambridge.

Hauser, E, and L Dorn. "Transitioning adolescents with sickle cell disease to adult centered care." *Pediatric Nursing* 25, no. 5 (1999): 479-488.

Jaspan, HB, Li, R, Johnson, L, & Bekker, LG. "The emerging need for adolescent-focused HIV care in South Africa." *The Southern African Journal of HIV Medicine*, (2009): 9-11.

Kirby, D. "Effective approaches to reducing adolescent unprotected sex, pregnancy, and childbearing." *Journal of Sex Research* 39 no. 1 (2002): 51-57.

Kunins, H, and et al. "Guide to adolescent HIV/AIDS program development." *Journal of Adolescent Health* 14 (1993): 1S-140S.

Laksi, L, and S Wong. "Addressing diversity in adolescent sexual and reproductive health services." *International Journal of Gynecology and Obstetrics* 110 (2010): S10-S12.

Marston, M., Zaba, B., Salomon, J. A., Brahmbhatt, H., & Bagenda, D. (2005). Estimating the net effect of HIV on child mortality in African populations affected by generalized HIV epidemics. *Journal of Acquired Immune Deficiency Syndrome*, 38, 219-227.

McNair, L D, J A Carter, and M K Williams. "Self-esteem, gender, and alcohol use; relationships with HIV risk perception and behaviors among college students." *Journal of Sex and Marital Therapy* 24 (1998): 29-36.

Murphy, D A, C M Wilson, S J Durako, L R Muenz, and M Belzer. "Antiretroviral medication adherence among the REACH HIV infected adolescent cohort in the USA." *AIDS Care* 13, no. 1 (2001): 27-40.

Naar-King, S, et al. "Allocation of family responsibility for illness management in pediatric HIV." *Journal of Pediatric Psychology* 34, no. 2 (2009): 187-194.

Patel, K, et al. "Long-term effectiveness of highly active antiretroviral therapy on the survival of children and adolescents with HIV infection: A 10-year follow-up study." *Clinical Infectious Diseases* 46, no. 4 (2008): 507-515.

Peter, N G, C M Forke, K R Ginsburg, and D F Schwarz. "Transition from pediatric to adult care: internists' perspectives." *Pediatrics* 123 (2009): 417-423.

Petersen, I, et al. "Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: A qualitative investigation." *AIDS Care* 1 (2010): 1-9.

Prendergast, A, G Tudor-William, P Jeena, S Burchett, and P Goulder. "International perspectives, progress, and future challenges of paediatric HIV infection." *Lancet* 370 (2007): 68-80.

Ramrakha, S, A Caspi, N Dickson, T E Moffitt, and C Paul. "Psychiatric disorders and risky sexual behavior in young adulthood: cross sectional study in birth cohort." *British Medical Journal* 321 (2000): 263-266.

Remien, R H, and C A Mellins. "Long-term psychosocial challenges for people living with HIV: let's not forget the individual in our global response to the pandemic." *AIDS* 21, no. 5 (2007): 55-63.

Ross, A, A Camacho-Gonzales, S Henderson, F Abanyie, and R Chakraborty. "The HIV-infected adolescent." *Current Infectious Disease Report* 12 (2010): 63-70.

Ross, J, and F Cataldo. "Adolescents living with HIV in low-income settings: A review of the evidence on gaps in HIV services." *Poster session presented at the XVIII International AIDS Conference*. Vienna: International AIDS Society, July 2010.

Shisana, O., Rehle, T., Simbayi, L. C., Zuma, K., Jooste, S., Pillay-van-Wyk, V., et al. (2008). *South African national HIV prevalence, incidence, behaviour and communication survey 2008: A turning tide among teenagers?* Cape Town: HSRC Press.

Snider, C et al. Children with perinatally-acquired HIV surviving into adolescence in Uganda: prevalence of physical, social and emotional challenges. Bangkok: International AIDS Society, 2006.

Steele, R, T Nelson, and B Cole. "Psychosocial functioning of children with AIDS and HIV infection: Review of the literature from a socioecological framework." *Journal of Development and Behavioral Pediatrics* 28 (2007): 58-69.

Stover, J., Walker, N., Grassly, N. C., & Marston, M. (2006). Projecting the demographic impact of AIDS and the number of people in need of treatment: updates to the Spectrum projection package. *Sex Transm Infect*, 82(3), iii45-iii50.

Tolle, A M. "A package of primary health care services for comprehensive family-centered HIV/AIDS care and treatment programs in low-income settings." *Tropical Medicine & International Health* 14 (2009): 663-672.

UNAIDS. (2010). *Global Report: UNAIDS Report on the Global AIDS Epidemic 2010*. Geneva.

UNAIDS and WHO. (2009). *AIDS Epidemic Update*. Report, Geneva.

UNICEF. (2009). *Children and AIDS 4th Stocktaking Report*. Geneva: UNICEF and WHO.

Wiener, L, B Kohrt, M Haven, B Battles , and M Pao. "The HIV experience: Youth identified barriers for transitioning from pediatric to adult care." *Journal of Pediatric Psychology*, 2009: 1-14.

While, A, A Fobes, R Ullman, S Lewis, L Mathes, and P Griffiths. "Good practices that address continuity during transition from child to adult care: Synthesis of the evidence." *Child: Care, Health & Development* 30, no. 5 (2004): 439-452.

WHO. *Adolescent friendly health services. An agenda for change*. Report, Geneva: WHO, 2003.

WHO & UNICEF. *Global consultation on strengthening the health sector response to care, support, treatment and prevention for young people living with HIV*. Report, Blantyre: WHO, 2006.

WHO/UNICEF. *A Qualitative Review of Psychosocial Support Interventions for Young People Living with HIV*. Review, Geneva: World Health Organization, 2009.

Valenzuela, J, C Buchanan, J Radcliffe, C Ambrose, L Hawkins, and M Tanney. "Transition to adult services among behaviorally infected adolescents with HIV. A qualitative study." *Journal of Pediatric Psychology*, 2009: 1-7.

Van Rie, A, P Harrington, A Dow, and K Robertson. "Neurologic and neurodevelopmental manifestations of pediatric HIV/AIDS: A global perspective." *European Journal of Paediatric Neurology* 11 (2007): 1-9.

APPENDIX I FIGURES

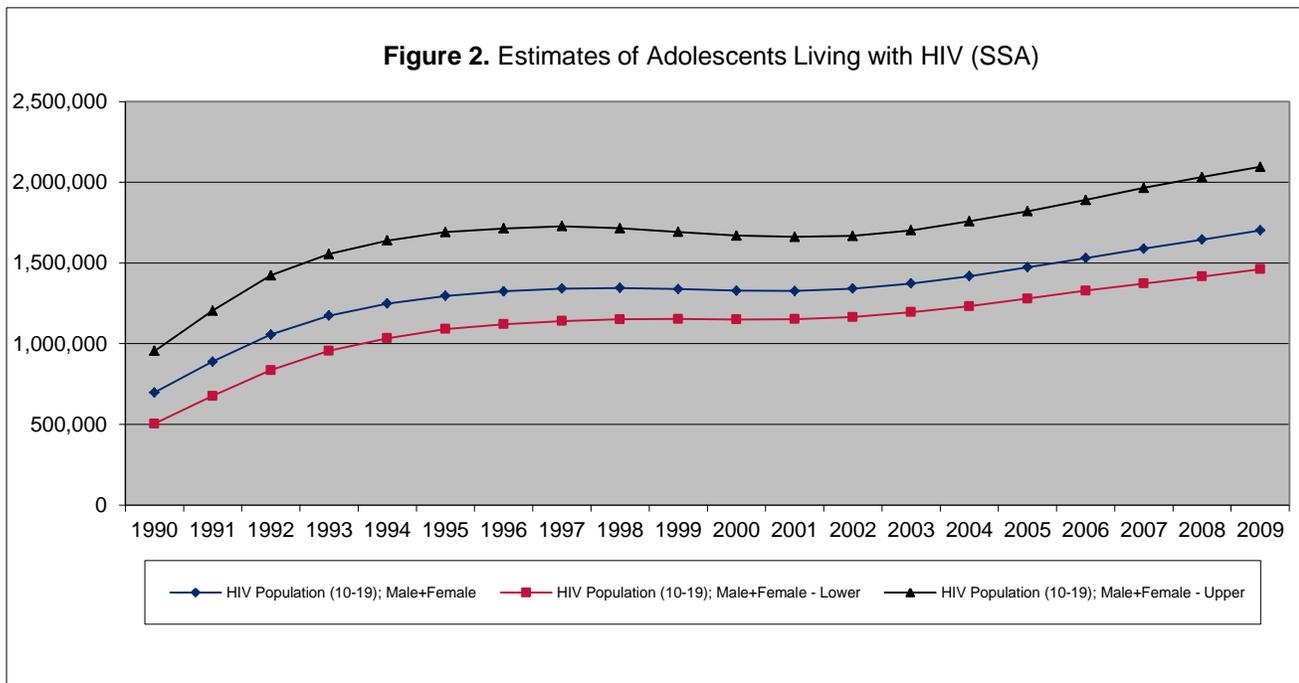
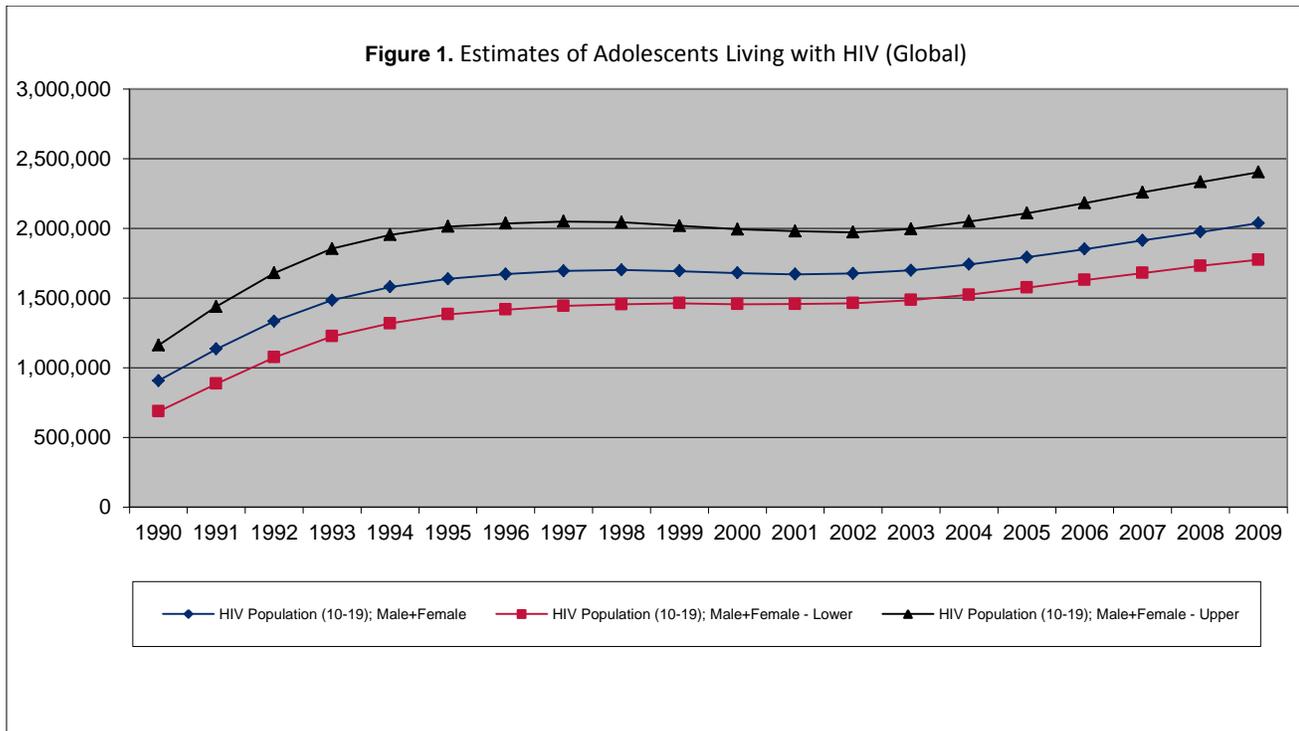


Figure 3. Gender Breakdown of Adolescents Living with HIV in SSA (2009)

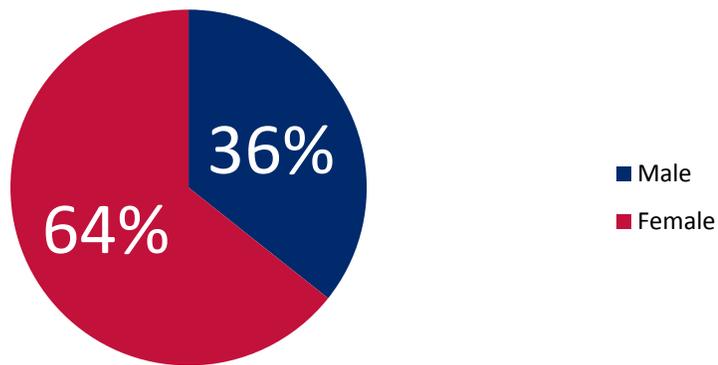


Figure 4. ALHIV on ART (SSA)

