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Guiding and supporting adolescents living with HIV in sub-Saharan Africa: The development of a curriculum for family and community members

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Abstract

Although HIV-related deaths declined globally by 30% between 2005 and 2012, those among adolescents living with HIV (ALHIV) rose by 50%. This discrepancy is primarily due to failure to address the specific needs of ALHIV and resulting poor clinical outcomes related to late diagnosis and poor adherence to antiretroviral therapy. The Families Matter! Program (FMP) is an evidence-based intervention for parents and caregivers of 9–12 year-olds that promotes positive parenting practices and effective parent–child communication about sexuality and sexual risk reduction. It is delivered to groups of participants at the community level through a series of six weekly three-hour sessions. Recognizing family and community members' need for guidance on issues specific to ALHIV, we developed a seventh FMP session to address their needs. Key themes treated in the curriculum for this session include: stigma and mental health, disclosure, ART adherence and self-care, and responsible sexual relationships. In developing the curriculum, we drew on narratives about growing up with HIV contributed by young Africans to a 2013 scriptwriting competition. We describe the data-driven process of developing this curriculum with a view to informing the development of much-needed interventions to serve this vulnerable population.

Keywords

Adolescents living with HIV; Curriculum development; Parenting; ART adherence; Secondary prevention

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1. Introduction

Sub-Saharan Africa is home to over 1.7 million adolescents living with HIV (ALHIV) (UNICEF, 2013). Adolescents are becoming a more prominent sub-group among those living with HIV as increased access to antiretroviral therapy (ART) allows growing numbers of those infected perinatally to reach adolescence while new adolescent infections remain high; in addition, it is now recognized that a higher proportion of perinatally-infected children than originally believed is reaching adolescence *without* ART (Ferrand et al., 2009). However, while deaths from HIV declined globally by 30% from 2005 to 2012, HIV-related deaths among ALHIV rose by 50%. No other age group experienced a rise in HIV-related deaths between 2001 and 2012 (UNAIDS, 2013). The World Health Organization (WHO) has attributed the excess HIV-related mortality among ALHIV to their low prioritization in national HIV plans and the lack of accessible and acceptable testing and treatment services, including ART adherence support, for adolescents (WHO, 2013).

Children living with HIV, whether infected perinatally or behaviorally, have the potential to live long and healthy lives if they are able to access and adhere to ART. However, during adolescence, they have specific clinical and psychosocial needs that both pediatric and adult health services and community support systems in sub-Saharan Africa are ill-equipped to address (Ferrand et al., 2010). Living with HIV amplifies the need for guidance in navigating the physiological, social, and behavioral changes and challenges of adolescence, a time when self-exploration, risk-taking, and vulnerability to mental health problems are common. Evidence suggests that ALHIV are not receiving the age-appropriate support they need in relation not only to adherence, but also to sexuality, relationships, and lifestyles (Hodgson, Ross, Haamujompa, & Gitau-Mburu, 2012). This has implications for both treatment and prevention outcomes. ALHIV have lower rates of adherence to ART than adults in southern Africa: poor adherence can lead to drug resistance and subsequent treatment failure, which is particularly dangerous in settings with limited access to second-line ART (Nachega et al., 2009). Poor adherence also carries increased risk of HIV transmission, which is exacerbated by the failure to adequately prepare adolescents for healthy sexual decision-making (Ferrand et al., 2010). There is, then, an urgent need to develop and implement programs to support diagnosis, treatment, and care, as well as secondary prevention, for the increasing number of children and adolescents growing up with HIV in sub-Saharan Africa (Ferrand et al., 2009).

As part of a growing focus on adopting more holistic and integrated approaches to meeting the needs of ALHIV, drawing on socio-ecological perspectives (Mburu et al., 2014) and on a Social Determinants of Health framework (Skovdal & Belton, 2014), there have been repeated calls in recent years to move beyond individual-level interventions for ALHIV towards strengthening protective influences within families (Li et al., 2010; Mavhu et al., 2013) and communities (Campbell et al., 2012; Hodgson et al., 2012; Petersen et al., 2010). Stronger parental/caregiver and community support has been shown to lead to better adherence among African ALHIV (Bikaako-Kajura et al., 2006; Hodgson et al., 2012; Li et al., 2010; Petersen et al., 2010; Sharer & Fullem, 2012). More family/household centered approaches are able to address some of the broader contextual barriers to adherence, strengthen caregivers' knowledge and skills (Mavhu et al., 2013), and reinforce the

protective influence of caring and supportive caregiver–child relationships (Petersen et al., 2010). It has been suggested specifically that improving the quality of caregiver–child communication about sexuality could help reduce unmet need among ALHIV for information, guidance, and services related to sexual and reproductive health (Busza, Besana, Mapunda, & Oliveras, 2013).

The Families Matter! Program (FMP) is a pre-sexual risk prevention intervention for parents and caregivers (hereafter referred to as ‘parents’) of 9–12 year-olds that promotes positive parenting practices and effective parent–child communication about sexuality and sexual risk reduction. The ultimate goal of FMP is the reduction of sexual risk behaviors among adolescents, including delayed onset of sexual debut. FMP was adapted for use in Kenya from a US evidence-based intervention in 2003–4 (Miller, Lasswell, Riley, & Poulsen, 2013). The US Centers for Disease Control and Prevention (CDC) now provides technical support for implementation of FMP in eight sub-Saharan African countries. The program has been delivered to over half a million families and is currently available in 15 languages. FMP is a community-based intervention delivered to groups of up to 18 participants by two certified local facilitators using participatory learning techniques through a series of six weekly three-hour sessions. Goals and learning objectives for Sessions 1–6 are presented in Table 1. Because the program has demonstrated effectiveness in strengthening parent–child relationships and communication about difficult sex-related topics in sub-Saharan Africa (Miller et al., 2011) and is widely accepted within communities, FMP shows promise of contributing to multi-level efforts to address the needs of ALHIV.

While a recently updated and enhanced FMP curriculum briefly addresses disclosure by parents to their child of their own or the child’s HIV status, we recognized family and community members’ need for further guidance on issues specific to ALHIV, including stigma and mental health, disclosure, ART adherence and self-care, and responsible sexual relationships. In response to reports and requests from the field, we therefore developed an additional, optional FMP session (“Session 7”) to help them provide guidance and support to ALHIV. Like the prior FMP sessions, it is a three-hour, group-level session that will be delivered by two certified facilitators using an interactive pedagogical approach. We describe the data-driven process of developing this curriculum with a view to informing the development of much-needed interventions to serve this vulnerable and underserved population. We present this not as a traditional research paper, but rather as a description of the data-driven process of developing a curriculum informed by adult learning approaches for a low-literacy population.

2. Background

2.1. Families Matter Program

FMP focuses on increasing parental awareness about the issues children face, improving parents’ ability to communicate with their children about sex, and encouraging parenting practices that increase the likelihood that children will not engage in sexual risk behaviors (Table 1). Parents are also asked to bring their child to a designated session in order to practice the communication skills learned during the intervention. The goal is that, upon completion of the program, parents have enhanced parenting skills to navigate their child’s

adolescence and will feel more competent and comfortable in addressing issues related to sex and sexuality with their children.

FMP's focus on key parenting strategies – in particular building a close relationship with the child, good communication skills, and monitoring and supervision – provides a strong foundation for a session on ALHIV. The overall curriculum is framed as a means to help parents support their children to achieve their life goals. It uses an assets-based approach, encouraging parents to build the child's sense of self-worth through positive reinforcement. FMP helps parents develop skills for communicating with their child based on attentive listening, soliciting the child's perspective, and problem-solving instead of blaming. It also helps parents develop monitoring and supervision skills which allow them to more effectively guide and protect their child. We felt that skills related to talking to preadolescents about sex and helping children to handle pressures they face would be transferable to ALHIV needs related to disclosure, handling stigma, adhering to ART regimens, and sexual and romantic decision-making.

All FMP sessions use a mixture of structured learning experiences, interactive discussion, audio narratives, role plays, and group exercises. Narratives in audio format are played on a battery-operated CD player in low-resource rural areas, while role-play exercises call on participants to improvise on a scenario and build specific skills. Adult education specialists have long recognized the power of story-based approaches such as these in teaching and learning, particularly for low-literacy audiences (Rossiter, 2002). They also provide opportunities for behavioral modeling and cognitive and behavioral rehearsal, consistent with FMP's theoretical debt to Social Cognitive Theory (Dittus, Miller, Kotchick, & Forehand, 2004; Bandura, 1986). We drew on a unique data source in the development of these narrative-based learning tools for the seventh FMP session on ALHIV: stories contributed by young Africans to the 2013 Global Dialogues (GD; known as "Scenarios from Africa" until 2012) scriptwriting competition.

2.2. Global Dialogues

Since 1997, the GD competitions have invited young Africans, up to age 24, to contribute scripts for short fiction films to educate their communities about HIV and AIDS and related themes (Winskell & Enger, 2005; Global Dialogues, 2015). The winning ideas in each contest are selected by local juries and transformed into short fiction films by leading directors (YouTube/Global Dialogues, 2013). By 2014, the process had generated an archive of over 75,000 narratives written by young people from over 70 countries worldwide. The narratives provide insight into the cultural meanings and contextual factors that surround HIV from the perspective of young Africans. These narrative data have limitations: they do not come from a representative youth sample as contest participants self-select, nor do they present a comprehensive overview of the experience of ALHIV in SSA; in addition, we do not know the extent, if any, of the young authors' personal experience of or exposure to living with HIV as the narratives may be entirely fictional. The narratives nonetheless serve to contextualize the challenges of ALHIV within the realities of youth experience and provide access to authentic voices of young Africans on the subject in a narrative form that

can be compared with existing literature and can be readily adapted to provide authentic and resonant learning tools, including audio narratives and role-play exercises.

3. Methods

Our methodologies in developing the curriculum were iterative and comprised: (a) strategic decision-making informed by the programmatic context; (b) a review of literature to identify ALHIV and parent needs; (c) review of the GD youth-authored narratives as a source both of contextual insight and of scenarios for narrative-based interactive exercises; (d) identification of session goals, learning objectives and sequence; and (e) curriculum scripting and development of interactive exercises. We focus here primarily on the review of the youth-authored narratives and their contributions to curriculum development.

The narratives were submitted in Swaziland and Kenya to the 2013 GD contest, which was held globally from 1 February to 10 April. They were in English and were written in response to a story prompt which invited competition participants to ‘Tell the story of the special challenges faced by an adolescent living with HIV’. The de-identified data were scanned to pdf format and entered into MAXQDA 2011 qualitative data analysis software (VERBI Software 1989–2011), where a summary was written for each story and the data were labeled with descriptive codes with reference to a codebook covering the following inductive and deductive themes: family, community, and social support and services; infection; diagnosis; disclosure/failure to disclose to child by caregiver and by child to others; ART (with particular focus on adherence); self-care strategies; peer pressure; responsible sexual behaviors; risky sexual behaviors; stigma; and mental health. The data belong to a larger study of young Africans’ social representations of HIV, for which our analytical methodologies – situated at the intersection of grounded theory (Corbin & Strauss, 2008) and thematic narrative analysis (Riessman, 2008) – were developed (Winskell, Obyerodhyambo, & Stephenson, 2011). We constantly compared the themes within and across narratives, all the while situating the thematically-coded segments within the context of the overall narrative to mitigate the risk of fragmentation and decontextualization of the data. The secondary analysis of the de-identified data was approved by Emory University Institutional Review Board.

Analysis of key themes found in the narratives and their intersections complemented our review of existing literature and informed the objectives and overall structure of the curriculum. We used storylines, scenes and text from the narratives both to infuse the curriculum with contextualized detail likely to resonate with participants and in the development of the interactive exercises. Specifically, we identified narratives that were representative of key themes and drew on them to develop narrative-based components of the curriculum, such as role-play exercises and audio narratives. In some cases this involved the incorporation of components of multiple storylines into a single audio narrative in pursuit of our learning objectives.

4. Results

4.1. Strategic decisions

4.1.1. Audience—FMP currently addresses parents and caregivers of all children aged 9–12. In order to avoid the risk of inadvertently disclosing the HIV status of children and adults by addressing the session specifically to parents and caregivers of ALHIV, we decided that the audience should be both family members and individuals who are likely to come into contact with ALHIV by virtue of the roles they play within their community. This approach was strongly supported by literature described earlier emphasizing the importance of family and community-centered approaches.

While the needs of younger (ages 10–14) and older (ages 15–19) ALHIV are distinct (Sharer & Fullem, 2012), we decided to create one module – Session 7 entitled ‘Guiding and Supporting Adolescents Living with HIV’ – that addressed ALHIV needs across the course of preadolescence and adolescence. We felt the opportunity to reach family and community members with this content might not recur and that it was extremely important to prepare parents of preadolescents for the challenges their children would face – and their need for progressively increased autonomy – as they move into and through their teen years. In light of the cultural diversity of sub-Saharan Africa, and of individual African countries, our objective was not to create a definitive curriculum to be used across the continent, but rather to generate a reference curriculum that could be adapted – both culturally and linguistically – to specific regions following community needs assessment and pre-testing.

4.1.2. Needs, goals and objectives—A growing body of literature seeks to identify the specific needs of ALHIV in sub-Saharan Africa from the perspectives of health workers, parents and caregivers, and adolescents (e.g., Bakeera-Kitaka, Nabukeera-Barungi, Nostlinger, Addy, & Colebunders, 2008; Beyeza-Kashesya et al., 2011; Birungi, Obare, Mugisha, Evelia, & Nyombi, 2009; Ferrand et al., 2010; Hodgson et al., 2012; Li et al., 2010; Loos et al., 2012; Mavhu et al., 2013; Petersen et al., 2010). From our review of the literature and the GD narratives, four interrelated themes emerged as central to the session on ALHIV: stigma and mental health; disclosure of the child’s status to the child and disclosure by the child to others; adherence to medication and other aspects of self-care; and sex and romantic relationships. Goals and learning objectives for Session 7, which are presented in Table 2, address needs related to these thematic areas.

The speed of recent technical and programmatic developments in the field of HIV leaves parents feeling ill-equipped to support adolescent adherence and ill-informed on ARVs, safety of romantic and sexual relationships, and possibility of future aspirations (Mavhu et al., 2013). There is also unmet demand for information and skills to support disclosure (Midtbø, Shirima, Skovdal, & Daniel, 2012; O’Malley et al., 2015) and communication around sexuality (Busza et al., 2013). The curriculum is intended to increase the motivation, knowledge and skills of family and community members to offer guidance and support to ALHIV. It seeks to interface with community mechanisms and to promote linkages to local services, including clinical and mental health services and peer support groups, where they exist.

4.2. GD data

Thirty-one narratives on the challenges faced by ALHIV were submitted to the 2013 GD competition by young people in Kenya (n = 9) and Swaziland (n = 22). Participants ranged in age from 10 to 25 (average 17); half were female and roughly half came from rural areas. We have no way of knowing the extent to which the narratives are based on personal experience. We treat them as creative stories which are likely to draw on – and therefore provide insight into – situations of which the young authors are aware within their own communities, as well as normative understandings of the experience of ALHIV in these communities. The contest is framed as an opportunity for young people to speak out and be heard on issues that affect them; participants are aware that their stories may be adapted and published in the context of health promotion or research activities.

The narratives were consonant with existing qualitative literature and complemented it by situating ALHIV needs and experiences within specific contexts and storylines. This made them particularly valuable in the development of narrative-based interactive exercises.

4.3. Family, community, and social support

Around half of the narratives refer to the importance of community support for ALHIV and how this enables them to feel accepted and make healthy decisions, such as adhering to ART. Conversely, the lack of support from family, school, or society at large is cited in some narratives as a barrier to feelings of acceptance, physical survival, and hope. While support from family members is mentioned rarely in the narratives, sources of support external to the family include the police, health care providers, schoolmates and teachers, church, counselors, and PLHIV community groups. A poem by a female author from Swaziland (no age given), for example, describes a teacher and the transformative role she played in her life, ‘A good Samaritan/a good teacher called and talked to me/I told her, they said I’m HIV positive/...She told me to focus on my work/For she will forever be by my side/Now I am always smiling, I’ve achieved my dreams.’ While some of the support mentioned is service-oriented, such as the government’s provision of free ART and health care providers’ work, much is emotional support in the lives of ALHIV and advocacy on their behalf.

The narratives thus further support the strategic decision to address the curriculum to both family and community members. This is a departure from earlier FMP sessions and shapes the content, activities, audio narratives, and role plays. For example, role plays not only address disclosure by parents or caregivers, but also disclosure-related exchanges taking place with health workers, teachers, religious leaders, boarding school dormitory managers, etc., drawing directly on concrete, contextualized examples provided in the narratives.

4.4. Diverse needs of all ALHIV

While the majority of narratives discuss the experiences of ALHIV who were infected with HIV perinatally, several address behavioral transmission, including through child sexual abuse. Children and adolescent characters become infected as a result of rape, forced marriage, abuse by a teacher, commercial sex work, the infidelity of a partner, and peer pressure to abuse alcohol and other substances and then have unprotected sex. The

curriculum addresses the diverse needs of all ALHIV, drawing on this diversity of experience represented in the narratives.

4.5. Stigma and mental health

The narratives highlight the centrality of mental health to ALHIV well-being, not least in the context of pervasive HIV-related stigma. They document stigma, neglect and mistreatment at the household, school and community levels; struggles to make sense of bereavement, displacement, and prospects for survival; isolation, humiliation, and loneliness, leading to depression and suicidal thoughts; and repeated illness and declining school performance. A 14-year-old male author from Swaziland describes being ‘born crying’ and ‘not knowing who to blame, my parents or God,’ while a poem by a female Swazi author (no age) describes a liminal state of being sick but never cured, ‘a walking tomb.’ In several cases, a protagonist’s HIV status is publicly revealed at school without his/her permission, leading to avoidance by class mates. ALHIV responses to learning their status include self-blame among behaviorally-infected characters and anger and rejection of treatment among those who feel their trust has been violated through violence or non-disclosure. One narrative speaks of suicide attempts after diagnosis, and another speaks of attempting to intentionally infect others with HIV out of anger. However, there are also stories of resilience and overcoming stigma, and several narratives depict ALHIV making future plans and playing important social roles.

We were able to infuse these perspectives and contextual details throughout the curriculum. At the start of FMP session, participants are reminded of the changes and challenges of adolescence (addressed in earlier FMP sessions) and invited to consider the additional challenges that ALHIV face. The intent is for participants to identify with the experience of ALHIV and specifically with challenges to their mental wellbeing. Participants are invited to reflect on potential effects of HIV-related stigma and discrimination, including self-isolation, poor adherence, poor health, and poor school performance. They then propose ways they can counteract stigma and discrimination in their communities. Recognizing that children are less likely to internalize stigma if they feel good about themselves, they are encouraged to apply positive reinforcement not only to their own children, but also to ALHIV in their families and communities. Earlier FMP sessions introduce the ‘3-Step Parenting Plan for Handling Pressure’, a tool that encourages parents and caregivers to help children identify, plan, and role-play together situations where they may be pressured to have sex by peers, partners or adults. In Session 7, this tool is re-introduced as a way for family and community members to help ALHIV anticipate situations where they may face stigma and discrimination and to prepare their responses. This process provides an opportunity for cognitive and behavioral rehearsal by the child and for modeling and feedback by the adult.

4.6. Disclosure to ALHIV

Disclosure to the ALHIV of his/her status in the narratives is frequently delayed until it is overheard by the ALHIV (e.g. at the doctor’s office or school) or until necessitated by circumstances. This avoidance is motivated by fear or stigma. In all such situations, the ALHIV feel distressed, and some feel betrayed. None of the narratives discusses a disclosure situation that leaves the young person feeling secure, cared for, or empowered to live

positively with HIV. The narratives evoke potentially dangerous consequences of failure to disclose. In one narrative, a young boy gives his ARVs to his friend who is feeling ill because his mother had told him that they were pills to give people superpowers. In another, a young man, furious at overhearing his status after years of believing his ARVs were vitamins, asks ‘what if I had met someone and had sex without protection?’ (male Swazi author, age 19).

The Disclosure section of the curriculum opens with an audio of an aunt and a father explaining why they have not yet disclosed to their children and why the time has come when it is crucial to do so: increasing struggles to persuade one child to take his medication and another child’s imminent puberty and anticipated sexual awakening. Adolescents describe their feelings following inadvertent disclosure of their status in another audio, inspired by the GD narratives. These children are left wondering whether they will die soon, whether they are at risk of infecting others, and feeling like they have no one to trust. In contrast, a third audio models a positive progressive disclosure process and the foundation it lays for ongoing parental support and the child’s long-term wellbeing. While there is no positive example of disclosure in the GD data, the narratives identify disclosure needs that are addressed in the model audio narrative.

Recent research by O’Malley et al. (2015) suggests that how the child is informed she or he has HIV may be as important as whether a child is told. Parallels are drawn in the curriculum between disclosure and talking with a child about sex – both are best viewed as a process that ideally starts when the child is young and unfolds in a progressive, age-appropriate way (Lowenthal et al., 2014; WHO, 2011). The mother in the audio both anticipates and responds to the child’s informational, emotional, social, and clinical needs. She also encourages goal-setting and hope for the future: ‘She helps me to think about love and marriage and how I can keep my future husband and children safe and healthy. She helps me look forward to a happy future!’

Key features of effective disclosure modeled in the audio are also parsed out in a hand-out, extending their relevance beyond parents and caregivers to other stakeholders in the community. We chose to cover both initial/partial disclosure of HIV status and ongoing disclosure, notably ALHIV’s emerging information needs over time. This allowed us to address the disclosure-related needs of both family and community members. As evident from the GD narratives, ALHIV may direct their questions to nurses, teachers, dormitory managers, church and youth group leaders, and so on, in addition to parents, caregivers and other family members. Role-play examples thus include: a child asking her grandmother why her younger brother isn’t infected with HIV, but she is; a child telling a religious leader he has heard only bad people get HIV — how come he and his mother are infected; and a child telling his teacher that the pills he is taking will soon cure him of HIV.

4.7. Disclosure by ALHIV

In the narratives, disclosure by ALHIV to others is primarily represented as happening inadvertently or being avoided. One narrative discusses an ALHIV having a health incident at school which leads to the whole school knowing about her status; in another, a character discontinues ART for fear that people will be able to identify her medication and discover

her serostatus. In one narrative, an ALHIV's boyfriend learns her status after she is hospitalized; in another, disclosure in a romantic relationship occurs in anger. Two narratives are distinctive because they show ALHIV characters actively preparing for disclosure at school or to their romantic partner and disclosing in a positive and thoughtful way. In the majority of the narratives, disclosure is a stressful and nerve-racking experience.

The FMP session helps participants develop skills to support ALHIV as they disclose to others. The topic of ALHIV's disclosure decisions is approached in the curriculum via consideration of the risk–benefit analysis that accompanies parents' and caregivers' decisions about whether to disclose their child's serostatus to a teacher. The advantages of disclosure in terms of adherence, social support, information sharing, stress reduction, and mental health, as well as public health considerations (Petersen et al., 2010; Sharer & Fullem, 2012), are stressed, but not without acknowledgement of the attendant risks.

In view of the need for ALHIV to progressively develop autonomy for self-management of treatment, we introduced simple approaches that draw on the spirit of motivational interviewing to help family or community members guide and support the child through his or her own decision-making process. There is promising evidence that brief interventions based on motivational interviewing principles can support treatment adherence and other issues (Sharer & Fullem, 2012). The four key principles of motivational interviewing are: express empathy; support self-efficacy; roll with resistance (i.e. avoid confrontation); and develop discrepancy (i.e. help the adolescent perceive a mismatch between his or her future goals and current behaviors) (Suarez & Mullins, 2008). Motivation to change and strategies to achieve change are most likely to be successful if the adolescent discovers them him or herself.

The motivational interviewing techniques are introduced in an audio in which a counselor, Mr. Adam, helps George – an ALHIV who has recently moved home to live with his uncle – as he thinks through whether, when, and how to disclose to his close friend Thomas. Participants are invited to reflect on this audio and parse out the ways in which Mr. Adam guides and supports George in his decision-making. The result is three simple steps: 1. be warm and listen (Greet them; Listen to them); 2. focus on what's important and how to get there (Help them focus on what matters most; Focus on strengths); and 3. support their plan (Support them in coming up with their own plan; Do not tell them what to do). These approaches are extended to adherence and sexual decision-making in the remainder of Session 7.

4.8. Adherence

The narratives present a variety of reasons why ALHIV may have difficulties adhering to ART. In several narratives, ART non-adherence is attributed to barriers such as not having food to take ARVs with, fear of side effects such as losing weight, and inability to schedule doctors' appointments. This echoes literature on ALHIV's need for material, psychosocial and logistical support as they transition to increased autonomy in managing their own care (Sharer & Fullem, 2012). In other narratives, non-adherence is a result of disclosure issues or mental health issues post-diagnosis. Community, family, and medical staff support are the

overarching facilitators of ART adherence in the narratives, while the desire to live a 'normal' life is a major motivating factor.

The FMP session builds on information about ART provided earlier in the FMP curriculum to increase understanding of resistance and the critical importance of adherence for long-term health and survival. While it stresses the need to progressively increase ALHIV's responsibility for their adherence, it also advocates a pragmatic approach incorporating adult monitoring and supervision to minimize the risk of long-term adverse effects on health. Recognizing that not all ALHIV will be taking ART or prophylactic antibiotics, the session also extends discussion of health maintenance behaviors to other forms of self-care, including healthy eating, regular clinic visits, and avoidance of drugs, alcohol, and smoking.

Participants are invited to identify challenges to adherence, for example: forgetting; side-effects; fear of being seen collecting or taking meds; treatment fatigue; or depression. These situations are both discussed in a group setting and serve as prompts for role-plays in pairs. The facilitators role-play a scripted dialog between George and Mr. Adam after George reveals that he has forgotten to take his medication for a couple of days, and participants are invited to provide their input. Having discovered that George forgot his ARVs because he studied late and overslept, Mr. Adam prompts him to come up with a solution, namely setting his alarm clock and avoiding working late, as sleep is also important to his health and preserving his health is essential to achieving his academic goals.

The interactive session activities continue as participants are invited to propose questions Mr. Adam could ask George to prompt problem-solving around each of the challenges to ART adherence identified earlier. Of course, many challenges to adherence are outside of the control of ALHIV and their caregivers, including structural constraints such as stock-outs or lack of bus fare. However, raising awareness of these issues among family and community members can generate awareness and potentially motivation within the community to address them. The intent in helping family and community members to develop skills to support adherence is not to obviate the need for specialist support: participants are actively encouraged to seek support from local specialists and provided with a hand-out of local 'Community Resources for Adolescents Living with HIV', including peer support groups, where they exist.

4.9. Romantic relationships

ART is repeatedly represented in the GD narratives as a means to allow ALHIV to lead healthy lives, make plans for the future, and envisage healthy romantic relationships. In one story, for example, a perinatally-infected woman says that ART made it possible for her to have a healthy marriage with an HIV-negative man and four HIV-negative children. However, there are also examples of unprotected sex in the context of non-disclosure to a romantic partner, leading to potential HIV infection and pregnancy. These highlight the need for support for ALHIV to develop skills for healthy sexual behaviors, including negotiation of and access to contraception and condoms and disclosure to partners.

The opening exercise in Session 7 invites participants to reflect on the goals and dreams for the future that ALHIV in their community may have. It concludes that their dreams may not

be very different from those of other children their age: they want to have what they see as ‘normal’ lives and healthy romantic relationships. The session stresses that ALHIV need the same information about reproduction and family planning as other adolescents; they also need to understand that alcohol and drugs and harmful gender norms may lead them to make unhealthy choices. They face the same risks of pressure to have sex from peers, partners, and adults, and need help to prepare them to face these pressures too.

While acknowledging commonalities with non-infected youth, the session also recognizes the complexities of sexual decision-making for ALHIV and the need to address information needs. These include: the risks that unprotected sex represents for the health of an ALHIV, including unplanned pregnancy, STIs, and the risk of re-infection or contracting a resistant strain from an HIV-positive partner; the importance of condom use to protect the health both of ALHIV and their partner; and the added benefits of ART adherence in terms of reduced risk of transmission to partner and children.

Having addressed informational needs, a scenario introduces some of the complexities of romantic and sexual decision-making for ALHIV through the persona of Emma, an 18-year-old ALHIV who is on ART, and her boyfriend of three months, Frank. Emma’s scenario is based on a GD narrative describing the fears and considerations associated with disclosure to a romantic partner. Building on previous discussions of stigma, disclosure, and ART, participants are encouraged to use the simplified MI steps and the ‘3-point Parenting Plan for Handling Pressure’ to guide and support ALHIV through complex decisions like those faced by Emma as she considers when to disclose to Frank.

In the final exercise of the curriculum, family and community members role-play a range of challenging scenarios situated at the intersection of several of the thematic areas addressed in the curriculum — stigma and mental health, disclosure, ART adherence and self-care, and sex and relationships. For example, a child asks her dormitory manager at boarding school how she should respond to her dorm-mates when they ask about her medicine; a child tells her mother that she hasn’t been taking her pills because she is tired of being ‘different’ from other kids; a child approaches his church group leader to ask if he will ever be able to get married and have children if he is HIV positive; and a girl approaches her aunt to say that her boyfriend is pressuring her to have sex and she hasn’t told him about her serostatus yet. One participant plays the adult, while the other plays the ALHIV to further reinforce identification and empathy.

5. Discussion

Based on research in Zimbabwe, Campbell et al. (2012) have described an ‘adherence competent community’ as ‘a social landscape where local community members, nurses, NGOs, guardians, and children themselves are able to optimize opportunities... to promote optimal child health’ (p. 130). Factors contributing to the adherence competent community include enhancement of the caregiver’s agency, commitment, confidence, competence, and solidarity with the child, and also the enhanced agency and competence of the child. Programs are increasingly acknowledging and seeking to address a range of determinants of ALHIV wellbeing (Skovdal & Belton, 2014). These include broad-based interventions to

support caregivers of HIV-positive children with the purpose of increasing children's retention in care (Busza, Dauya, Bandason, Mujuru, & Ferrand, 2014). There are clearly limitations to what can be achieved in the three-hour FMP group session. However, as a community-level intervention that addresses ALHIV needs within the context of parent-child communication around sexuality and sexual risk-reduction, FMP is well-placed to support such multi-level efforts.

Resources for children and adolescents living with HIV exist and were valuable in the development of the FMP curriculum (Clayton et al., 2012; Wiener, Wood, & Pettitt, 2013). While few informational or skills-building resources are widely available to family and community members who are in a position to provide guidance and support to ALHIV, their number is nonetheless growing (Lowenthal et al., 2014; O'Malley et al., 2015). Although some such studies have indicated benefits of certain disclosure, support, and adherence counseling techniques, the majority of evidence is currently based on interventions in adult populations. There is a considerable need for further research on ALHIV and effective means of addressing their needs related to disclosure, care, and adherence support (WHO, 2013).

Using a competency-based approach, we drew on existing literature and youth-authored narratives in developing our curriculum. Although a self-selected sample, the GD narratives both supported and supplemented the existing literature on ALHIV needs and experience. They served a dual purpose as both a needs identification tool and a valuable resource in the actual scripting of the curriculum, pointing to promising new avenues for curriculum development that are applicable to a range of issues and contexts. Findings from our thematic analysis thus informed the objectives and overall structure of the curriculum, while the narrative data allowed us to pepper the curriculum with concrete and contextualized examples likely to resonate with participants. By situating ALHIV needs and experiences within specific contexts and storylines, the narratives lend themselves most distinctively to use in the development of the narrative-based components of the curriculum, such as role-plays and audio narratives.

We built on parenting skills strengthened throughout FMP and introduced simplified motivational interviewing approaches to support ALHIV's incremental transition to greater autonomy in decision-making and self-management of treatment. The narrative-based approach we employed in the audios and scripted and unscripted role-plays allowed us to convey the complexity of the challenges faced by ALHIV, while also fostering empathy and identification by situating them within emotionally-compelling stories that, we anticipate, will resonate with participants.

Although evidence of the curriculum's effectiveness must await formal evaluation, feedback from the field provides strong indication that the curriculum – developed in response to requests from the field – is valued and considered important and relevant by public health colleagues and community members. Field adaptation of the ALHIV module in Zambia has been completed and its roll-out to 30,000 households as part of a 7-module FMP curriculum will begin there in early 2016. We share our experiences in the data-driven process of developing this curriculum in the hope that it may be helpful to others seeking to develop

much-needed interventions at the family and community level to serve this vulnerable and underserved population.

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Table 1

FMP Sessions 1–6 goals.

1: Introduction to FMP and Steps to Understanding Your Child

Session 1 Goals:

- To provide parents and caregivers with an understanding of the purpose and goals of the *Families Matter! Program*
- To increase parents' and caregivers' awareness of the situations their children face that may put them at risk and the important role they play in keeping their children safe and healthy.
- To introduce parents and caregivers to the physical, emotional and social changes their preadolescents are going through and the need to provide guidance and support to children during this important period

2. Good Parenting Skills

Session 2 Goals:

- To help parents and caregivers understand that their children need and value their guidance and support during this difficult period of adolescence
- To provide parents and caregivers with information and strategies to protect and guide their children through this important period
- To help parents and caregivers practice general parenting skills that support their children and protect them from risky situations

3. Parents' Role in Educating their Children about Sexuality

Session 3 Goals:

- To make parents and caregivers more aware of the need for them to be sex educators for their children
- To increase parents' and caregivers' understanding of the physical and reproductive changes their children will be going through during puberty and adolescence
- To help parents and caregivers to define their values about sex and to learn ways to communicate their values to their children
- To provide parents and caregivers with tools and strategies for communicating with their children about sex

4. Information to Increase Comfort and Skills in Discussing Sex and Sexuality

Session 4 Goals:

- To provide parents and caregivers with information on family planning, STIs, HIV and AIDS and other sexual health issues
- To provide parents and caregivers with direct linkages to community health resources
- To increase parents' and caregivers' comfort and skills in discussing difficult sex-related issues with their children, including HIV stigma and disclosure

5. Discussing Sexuality and Pressures Children Face

Session 5 Goals:

- To continue improving parents' and caregivers' comfort in discussing sex and sexuality with their child
- To give parents and caregivers an opportunity to work on their communication skills with their child
- To introduce parents and caregivers to pressures their children face from peers, partners and adults, such as pressure to have sex, that could keep their children from reaching their life goals

6. Understanding Child Sexual Abuse

Session 6 Goals:

- To raise parents' and caregivers' awareness about child sexual abuse
 - To increase parents' and caregivers' understanding of their role in preventing child sexual abuse
 - To increase parents' and caregivers' awareness of their role in protecting and supporting their children when responding to child sexual abuse
-

Table 2**Goals and learning objectives for Session 7: Guiding and Supporting Adolescents Living with HIV.**

Session 7 Goals

- To increase family and community members' understanding of challenges facing adolescents living with HIV including those related to stigma, disclosure, adherence, and healthy relationships
- To help family and community members strengthen their skills to provide guidance and support to adolescents living with HIV around issues of stigma, disclosure, adherence, and healthy relationships
- To provide family and community members with information about living with HIV, Anti-Retroviral Therapy, and resources in their community to help adolescents living with HIV

Session 7 Learning Objectives

After completing this session, participants will be able to:

- Disclose an adolescent's HIV status to him/her
 - Prepare adolescents living with HIV to face stigma
 - Guide and support adolescents living with HIV as they make decisions about disclosing their status to friends
 - Support ART adherence among adolescents living with HIV and anticipate and help them address challenges with adherence
 - Guide and support adolescents living with HIV to avoid risky sexual behavior and enter into responsible sexual relationships
-