Children and Youth Services Review 61 (2016) 253–260

Contents lists available at ScienceDirect

Children and Youth Services Review

journal homepage: www.elsevier.com/locate/childyouth

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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ARTICLE INFO

Article history:
Received 23 March 2015
Received in revised form 15 December 2015
Accepted 15 December 2015
Available online 23 December 2015

Keywords:
Adolescents living with HIV
Curriculum development
Parenting
ART adherence
Secondary prevention

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.

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).

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http://dx.doi.org/10.1016/j.childyouth.2015.12.017
0190-7409/

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;