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Malocho Phoso **Date**

A systematic review of the literature on psychosocial support programs for adolescents and young women living with HIV and AIDS that affect disclosure of HIV status and adherence to antiretroviral treatment in Sub-Saharan Africa.

By

Malocho Phoso

Master of Public Health

Hubert Depart of Global Health

John Blevins, Associate Research Professor

(Committee Chair)

Roger Rochat, Professor

(Committee Member)

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Malocho Phoso

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University of Malawi-Kamuzu Collegeof Nursing

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Thesis Committee Chair: John Blevins, Ph.D

An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
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Abstract

Asystematic literature review on psychosocial support programs for adolescents and young women living with HIV and AIDS that affect disclosure of HIV status and adherence to antiretroviral treatment in Sub-Saharan Africa.

By Malocho Phoso

Introduction: Globally 2.0 million adolescents in the age group 10 to 19 years were living with Human Immunodeficiency Virus (HIV) in 2014. 1.6 million Adolescents living with HIV were from sub-Saharan Africa and Asia. In the same year, 2014, 620,000 young people were newly diagnosed in the age group 15 to 24. Of this group 220,000 adolescents were of age group 15 to 19. This systematic review aimed to identify psychosocial support programs for adolescents and young women living with HIV and AIDS that affect disclosure of HIV status and adherence to antiretroviral treatment in Sub-Saharan.

Method: This systematic review identified 10 articles that fulfilled the inclusion and exclusion criteria in the years 2012 to 2015 by systematically searching from PubMed, Embase, and Google scholar databases.

Results: To meet the needs of adolescents and young women living with HIV and AIDS, the review indicates that type of communication, trust, and improved self-confidence are key elements when designing and implementing psychosocial interventions. In addition adolescents or young women,caregivers and health workers are the three critical players if these programs are to be a success . **Conclusion:** Rigorous evaluations of the interventions are required to isolate best practices and assess cost-effective interventions with maximum impact on adolescents and young women affected by HIV and AIDS. A dearth of information was an obstacle in generalizing the interventions for the whole Sub-Saharan Africa region.

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May the Almighty God bless you all.

Acronyms

AIDS: Acquired Immune Deficiency Syndrome

ALHIV: Adolescents Living with HIV

ART: Antiretroviral Treatment

CDC: Center for Disease Control

CHAMP: Collaborative HIV prevention and Adolescent Mental Health Program

DREAMS: Determined Resilient Empowered AIDS-free Mentored and Safe women

EGPAF: Elizabeth Glassier Pediatric AIDS Foundation

FMP: Families Matter! Program

HAART: Highly Active Antiretroviral Treatment

HIV: Human Immunodeficiency Virus

KMAC: Kganya Motsha Adolescent Centre

MTCT: Mother To Child Transmission

PLWHA: People Living with HIV and AIDS

PEPFAR: President's Emergency Plan for AIDS Relief

UHC: Universal Health Coverage

UNAIDS: Joint United Nations Program on HIV and AIDS

UNFPA: United Nations Population Fund

UNICEF: United Nations Children's Fund

WHO: World Health Organization

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Chapter one: Introduction

Globally 2.0 million adolescents in the age group 10 to 19 years were living with Human Immunodeficiency Virus (HIV) in 2014. 1.6 million Adolescents living with HIV were from sub-Saharan Africa and Asia. In 2014, the same year, 620,000 young people in the age group 15 to 24 were newly diagnosed. Of this group 220,000 adolescents were of age group 15 to 19, (UNICEF, 2015).

In general, the number of AIDS-related deaths has declined for adults and young children, but it has remained higher for adolescents, (UNICEF, 2015). Reports show that rates of new HIV infections among children have decreased. However, many of those who acquired HIV through mother to child transmission of HIV (MTCT) from the year, 2000, are now adolescents (Kassede et al., 2013; Porth, 2014; UNICEF, 2002; UNICEF, 2011). Almost half of today's generation is comprised of individuals less than 25 years (Bearinger et al., 2007). Therefore, investing in adolescents' health helps maximize the gains achieved during early childhood and gives room for hope during adulthood (UNICEF, 2011).

The definition of adolescence varies based on the cultural context in different studies, but these studies agree that it is the period of transition from childhood to adulthood (Adejumo et al., 2015; Munthali, 2004). The World Health Organization defines "adolescents as people between 10 to 19 years" (WHO, 2015). There are some further categorizations of adolescents in early and late adolescence which is dependent on age groups between 10 to 14 and 15 to 19 respectively. Understanding the different levels is important as it informs the designing of the targeted programs (Fleischman, J., & Peck, K., 2015).

While the needs of adolescents are similar, adolescents living with HIV face unique challenges due to their HIV status which may impact entry into adulthood, the need to disclose their HIV status to peers, making informed decisions about getting married or having boyfriends or girlfriends, and bearing children. Also, long-term medical treatment of HIV infection sometimes includes unfavorable side effects and impacts drug adherence in the long term (Mahvu, 2013; Nabukeera-Barungi1 et. al., 2015).

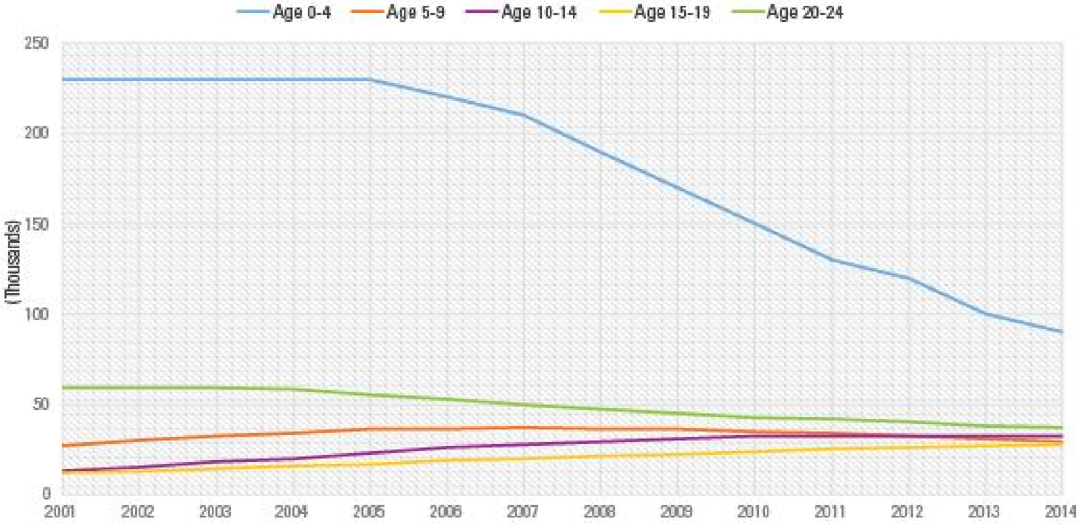
Most studies cite post-traumatic stress, anxiety, and depression as common psychological experiences among people living with HIV and AIDS, including adolescents. Inadequate integration of psychosocial support services makes it even harder to achieve holistic care (Dowshen, N., & D'Angelo, L., 2011). HIV and Acquired Immune Deficiency Syndrome (AIDS) are examples of chronic diseases, and yet unique needs accompany living with HIV and AIDS. With adolescents, HIV infection affects the transition from childhood to adulthood. While some adolescents struggle with issues such as body image and developing personal identity, those living with HIV also face unique issues such as disclosing HIV status and the need for safer sex given their HIV status. These unique issues call for proper transitional processes (Mahvu, 2013; Bakanda, C., 2011; Mavedzenge, et. al., 2011; Adejumo et.al., 2015).

Successful transitioning from childhood to adulthood can be supported by the existing and more supportive social systems that surround adolescents; these systems may include families, communities, schools, health services and their workplaces (Crepaz N., et. al., 2006). One way to promote transitioning from childhood to adulthood could be to provide more organized and evidence-based psychosocial interventions that would yield impact on improving the health outcomes such as quality of life.

Background information and rationale of the study

Globally, new HIV infections have declined in all age groups except for a consistent rise in rates for adolescents and young adults in the age category of 10-19 years, more than 2 million are living with HIV while many are not receiving adequate care and support to maintain their health and prevent transmission (Fleischman, J., & Peck, K. 2015;WHO, 2013).

Figure1: Estimated number of AIDS-related deaths among children (aged 0—14), younger adolescents (ages 10—14), older adolescents (ages 15—19) and young people (ages 20—24), 2001—2014 - See more at http://data.unicef.org/hiv-aids/adolescents-young-people.html#sthash.a8aZp2hi.dpuf



Source: UNAIDS, 2014 HIV and AIDS estimates, July 2015.

Figure 1 above shows how there has been a consistent rise in deaths among adolescents (10-14 and 15-19). Tailor-made interventions targeting different stages of the life course including the adolescent could be one solution to decrease the number of deaths (Fleischman, J., & Peck, K., 2015).

One way to address needs of the adolescents is to consider targeting services at different levels such as individual, community and structural (DiClemente, R. J., 2007). Internationally, global bilateral and multilateral partners advocate for integrated services to ease access for adolescents and young adults and the need to include human right based interventions.

Determined Resilient Empowered AIDS-free Mentored and Safe women (DREAMS), is one package of interventions which champions evidence-based interventions for adolescents and young women in 10 countries in Sub-Saharan Africa. The emphasis is to focus beyond the individual levels and includes other structural factors that affect adolescents and young women's risk of getting HIV (Fleischman, J., & Peck, K. 2015).

The Universal Health Coverage (UHC) framework gives an opportunity to rethink adolescent health services and programs. Some of the recommendations include widening the scope of the programs while promoting contextualized services based on adolescents as individuals (WHO, 2015). Also, programs for adolescents and young people need to be more targeted and tailored to suit adolescents' needs while avoiding hurdles such as cost, negative attitudes and lack of confidentiality (DiClemente, R. J., 2007).

Youth friendly services have been widely promoted and recommended to address the needs of the adolescents and youth. However, including the needs of adolescents living with HIV and AIDS requires special attention considering the other needs that may be particular to this group of people (Fatusi, A. O., & Hindin, M. J., 2010).

Research has also shown that participation by adolescent and young people in different programs such as sexual and reproductive health programs not only improves general health but also helps to build self-confidence, ability to cope with diversity and enrich educational and future aspirations (Fatusi, A. O., & Hindin, M. J., 2010).

Adherence to treatment and retention in care contribute to successful management of adolescents living with HIV and AIDS (Nabukeera-Barungi, N., et. al., 2015). Multiple interventions such as the use of support groups, treatment buddies, and community interventions have been reported to have a positive effect on adherence in South Africa, Namibia, Lesotho and Botswana (Adejumo e.al., 2015; Kabore, I., 2010). Despite the successes, many challenges affect adherence to treatment among adolescents. Not knowing how to approach peers and the feeling of being different from their friends may lead them not to take the drugs as expected (Fetzer, B. C.,2011; Adejumo et al., 2015).

On the other hand, disclosure is one of the important key actions to support adherence to antiretroviral treatment. In general, the stigma associated with HIV makes it difficult for individuals to talk about HIV openly (Nöstlinger, C., et. al., 2015). However, studies have also shown that adolescents who acquired HIV perinatally might have different experiences compared to adults and adolescents who acquired HIV through unprotected sex. (Adejumo et.al.,2015). The process of accepting one's HIV serostatus culminates into anger and confusion for many if they have already started taking antiretroviral medicines (ARVs) (Turissini, M. L., 2013; Remien. R., 2007). Furthermore, adolescents' feelings of blame and anger towards their parents or caretaker may affect how they take their drugs (Mutwa PR, et. al., 2013).

Age is one factor that affects adherence to treatment. Adolescents aged 15 and older are said to be less likely than younger adolescents to adhere to treatment as they juggle transfer of responsibilities from their caregivers (Adejumo et al., 2015). Despite the many challenges associated with disclosure, the act of disclosing has positive gains as this leads to developing individual coping strategies and addressing the long-term realities of life (Nöstlinger et. al., 2015).

The other main reason that disclosure is necessary for adolescents living with HIV is that as they continue to age, they are more likely to become sexually active. At this stage, disclosure may facilitate the use of appropriate measures such as abstinence and, safer sex to prevent sexually transmission infections and unwanted pregnancies (Hazra et al,2010; Turissini, M. L., 2013).

Statement of the Problem

New HIV infections among adults have declined, but for adolescents,HIV incidence has steadily risen(Fleischman, J., & Peck, K.2015). Over the last decade, several programs and policies have been drafted and implemented with successes and challenges. Replicating the successes and learning from the challenges could yield better benefits in the design and implementation of HIV and AIDS programs targeting adolescents.

HIV and AIDS is often associated with stigma and discrimination, efforts to address psychological and social concerns is key to the enhancement of the services targeting adolescents (Adejumo et al,2015). This study will review the existing literature that informs the programs and interventions that have been tried elsewhere including documented best practices and relate these to the perspectives of the adolescents and young women.

Statement of Purpose

The goal of this review is to identify psychosocial support programs for adolescents and young women living with HIV and AIDS that affect disclosure of HIV status and adherence to antiretroviral treatment in Sub-Saharan Africa. Detailing the existing programs is essential for providing information on what is already available to avoid duplicating efforts. Examining the perspectives of adolescents will help to categorize these programs based on the context, an essential element to consider in developing programs and determining what could be done to improve what is already in existence.

Systematically identifying successes and challenges in the existing literature will prevent duplication and facilitate prioritization of future research and resource allocation to address the most critical public health problems for the adolescents and young adults with greater efficiency. This study, therefore, aims to identify the psychosocial support programs for adolescents and young women living with HIV and AIDS that affect disclosure of HIV status and adherence to antiretroviral treatment in Sub-Saharan Africa.

Objectives of the study

General objective

The general aim of this review is to identify the psychosocial support programs for adolescents and young women living with HIV and AIDS that affect disclosure of HIV status and adherence to antiretroviral treatment in Sub-Saharan Africa.

Specific objectives

1. Analyze strategies/interventions for providing psychosocial support to adolescents and young women living with HIV and AIDS in Sub-Saharan Africa that affect disclosure of HIV status.
2. Explore the effects of HIV status disclosure on adherence to antiretroviral treatment by adolescents and young women living with HIV and AIDS in Sub-Saharan Africa.
3. Examine adolescents’ and young women’s perspectives on available services for adolescents and young women living with HIV and AIDS in Sub-Sahara Africa.
4. Identify documented successes and challenges on implementing psychosocial support programs for adolescents and young women living with HIV and AIDS in Sub-Saharan Africa

The study’s Theoretical conceptual framework

This study employs a socio-ecologic model to understand the individual, community and structural determinants that influence the nature of the programs for adolescents and young women living with HIV and AIDS to disclose their HIV status and adhere to treatment. The socioecological model presupposes a framework based on the social determinants of health. The World Health Organization defines those determinants as the circumstances in which people are born or live and as the systems that are available to support health care. These experiences are in turn shaped by other forces such as policies, politics and social, economic status (World Health Organization, 2016).

Considering that HIV infection affects all the dimensions of life, psychosocial support interventions or programs that assist with addressing a person's emotional, social, mental and spiritual needs are important. Psychosocial support integration into existing programs such as HIV care and treatment, school curricula and other health services. Psychosocial support builds on internal and external resources for people and their families to cope with adversity (Lowenthal., E.D., 2014).

In this study psychosocial support refers to all programs that aim at helping adolescents and young adults living with HIV and AIDS through information sharing and discussions which are goal oriented towards maintaining the quality of life.

Understanding how the social determinants of health influences and maintains health can also lead to developing programs or interventions which resonate well with different support systems (Remien., R., 2007). One way to encourage participation of adolescents in programs is to create safe space through implementing rights-based interventions and tailor-made services to suit different levels, including individual, interpersonal, community, organizational and policy (Mburu, G., 2014).

In this study, the individual factors include being an adolescent, a period where a person is experiencing physical and mental development which affect transitioning into adult life. Besides negotiating through adolescence, the individual is HIV positive which affects some norms as expected, for instance, the taking of medications daily and frequently visiting health facilities for health care which might not be the case with other peers. It is also the time to acquire social skills in readiness for future and environment plays a role in accessing health (Fatusi, A. O., & Hindin, M. J., 2010). For adolescents and young women living with HIV, it goes beyond the built environment as they go through arranged transitions from child to adult-centered health services (Dowshen, N., & D'Angelo, L., 2011). Confidentiality and peer pressure are some of the key factors to consider if the continuity of accessing the care is to be successful. At the same time, peer pressure or influence may guide adolescent life decisions.

For safe transitioning from child care and, maintenance to achieve positive living, the community needs to be supportive by providing vital structures such as education system and other supportive structures. These could be social networks such as clubs and peer groups. To realize these support systems may require a considerable investment of different resources including money and sound leadership

The presence of psychosocial support programs may facilitate good health outcomes which could lead to adolescents living a high quality of life as they adhere to lifelong treatment and being hopeful for their future through the existing programs that impact both at individual and community levels. Understanding how the social determinants of health influence and maintains health can also lead to developing programs or interventions which resonate well with different support systems and beyond (Remien., R.,2007). One way to win participation of adolescents into programs is to create safe space through implementing rights-based interventions and tailor-made services to suit different levels such as individuals, interpersonal, communities, organizations and policy levels (Mburu, G.,2014).

Below is the graphical presentation of the application of the model to the study.

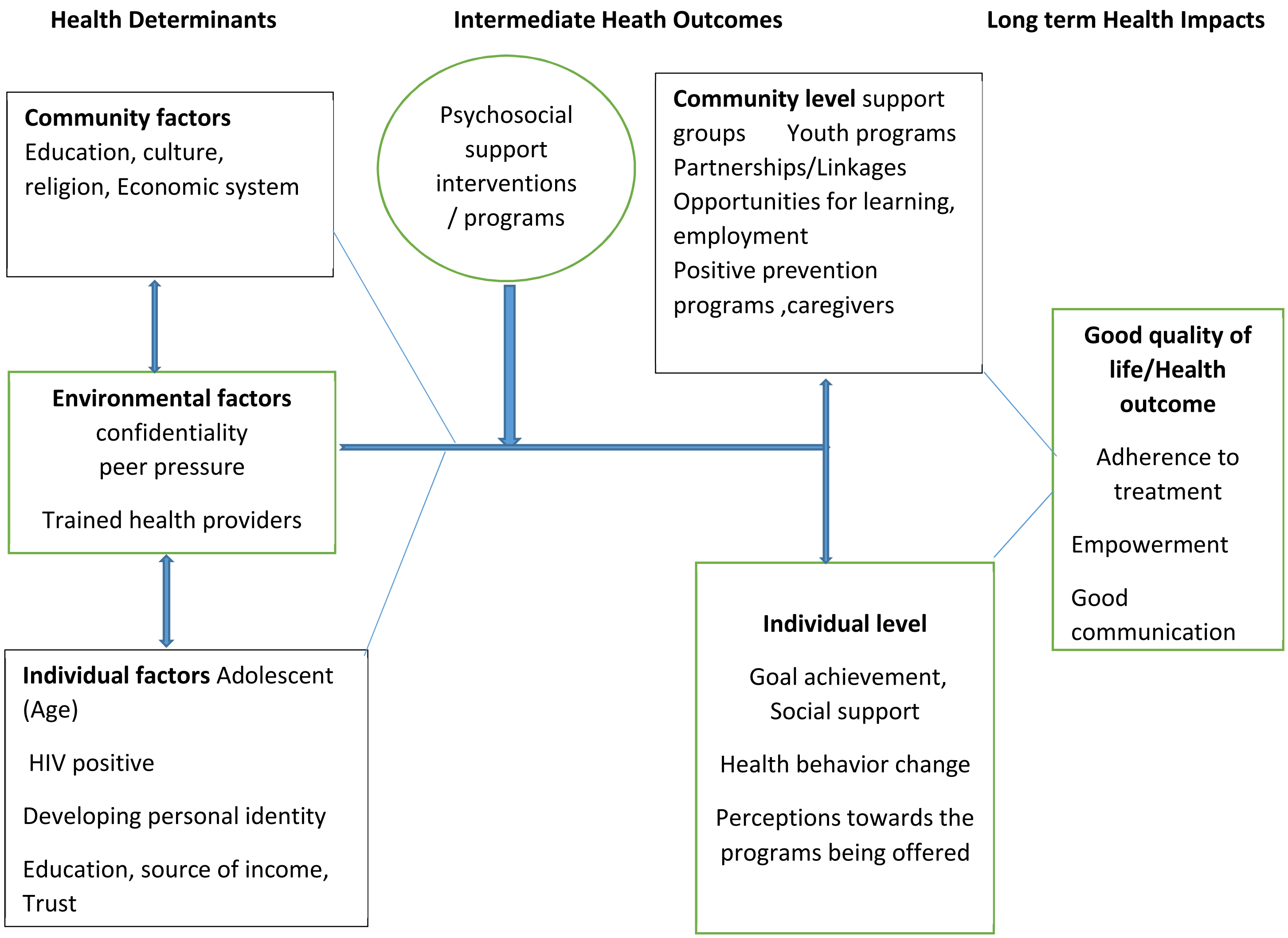


Figure 2: Application of the Socioecological model to the study, adapted from HOPE Works Conceptual Model

Definition of terms

Psychosocial support

Psychosocial support is any intervention or activity that addresses the ongoing psychological and social problems of HIV-infected individuals (adolescents and young women), their partners, families, and caregivers (WHO,2015). For the purpose of this study, this includes services or interventions that address one's psychological well-being through counseling, mentoring and activities that will reduce stress and worry related to living with HIV and AIDS and improve drug adherence (Clarke et al., 2005).

Adolescence

WHO identifies adolescence as the period of human growth and development that occurs after childhood and before adulthood, from ages 10 to19. An adolescent is anybody within this age range of 10 to 19.

Young women

In this study, young women are all girls aged 20 to 24

Chapter Two-Methods

This descriptive systematic review will follow the general Cochrane methods by including a research question, specific population, and clear outcome of interest. Interventions and comparison groups will not be applied as they are not applicable to the research question as such will not conduct a meta-analysis (Abalos et al., 2001).

Specific inclusion and exclusion criteria were developed and applied to the published peer-reviewed articles.

Inclusion Criteria

Studies included in the review are based on the following criteria:

i. Studies conducted in Sub-Saharan Africa
ii. Population targeted: adolescents and young women aged 10-24 years living with HIV/AIDS
iii. Articles published between the years 2000 and 2016
iv. Published in English
v. Full article available through Emory Library

Exclusion criteria

Studies excluded from this review are based on the following criteria:

i. Studies not conducted in Sub-Saharan Africa
ii. Population targeted was not adolescents and young women aged 10-24 years living with HIV/AIDS
iii. Articles published before the year 2000
iv. Articles published in languages other than English
v. Full article not available through Emory Library

Also, the search terms in this review were based on the four objectives of the study, which focused on psychosocial interventions or strategies, disclosure and adherence to treatment, adolescents and young women perspectives, challenges, and successes of the psychosocial programs. In some instances, articles and reports which had general information for adolescents and young women were used if they had relevant information to inform the study.

Literature search strategy

Electronic sources on PubMed, Embase and Google Scholar were searched. The first search was done in PubMed followed by Embase and Google Scholar.

This study involved a review of the literature of articles published with the first search in the PubMed database regarding the psychosocial support programs for adolescents and young women living with HIV and AIDS that affect disclosure of HIV status and adherence to antiretroviral treatment in Sub-Saharan Africa. All searches included (Africa and combinations of search terms related to (((((("Africa South of the Sahara"[Mesh]) AND hiv infections)) AND (social support OR psychosocial)) AND ("last 10 years" AND (young adult[MeSH] OR adolescent[MeSH])))) AND "Antiretroviral Therapy, Highly Active"[Mesh]

((("Africa South of the Sahara"[Mesh]) AND hiv infections)) AND (social support OR psychosocial) AND ("last 10 years"[PDat] AND (young adult [MeSH] OR adolescent [MeSH]))

The author conducted the searches from January to May 2016, and the search strategy was adapted accordingly based on the key objectives of the study. A manual check of unpublished articles or reports and searched in websites of different national and international organizations such as UNAIDS and UNICEF for relevant information was also conducted. No restrictions on time and location of publication were applied.

Most citations were exported to Endnote. Title and abstracts were reviewed for all the studies that met the established inclusion and exclusion criteria. The full text was obtained for all studies that met the inclusion criteria. The reference sections of abstracted articles were also skimmed to identify additional articles of interest, and identified references were then manually located in PubMed. Relevant data were extracted from articles and managed using a Microsoft Excel spreadsheet. Abstracted information included reference, region, and country the study was conducted in, as well as the topic, studied, study design, sample size, and key findings. Quantitative studies were categorized based on the outcomes, and the qualitative studies were reviewed based on the thematic areas discussed.

Study Selection

The methodology followed in this study combined quantitative and qualitative systematic review of studies from the Sub-Saharan Africa countries. Integration of the two types of studies can identify ways to improve interventions and their implementation (Thomas et al., 2004).
The lead author first reviewed the articles based on a title, abstract, and content. Duplicates were removed and the remaining articles were reviewed by the two Senior Authors who independently screened the remaining articles using the agreed inclusion criteria outlined above and read through the content in all the articles. Following this process of review, the results were shared and the final studies to include were agreed on. The independent reviews were conducted as a way to reduce bias. The studies were further reviewed for quality focusing on the population and outcome, which was adherence to treatment, and for qualitative studies, the findings were aligned with the perspectives of the adolescents and young women living with HIV/AIDS.

Data extraction

Each article meeting the inclusion criteria was entered into an Excel form, which outlined the study design, population, and outcome or results. The first author collected information on general study information. In cases where the title and abstract passed the first screening phase, and the full article could not be accessed, the study was dropped.

Ethical considerations

The study did not involve human subjects it only involved the review of documents and studies from different countries. As such, it did not require ethical review or submission to Emory's Institutional Review Board.

Chapter 3: Results

Description of studies

The literature search yielded 950 articles of which 234 articles were duplicates, 370 articles were removed because they did not meet the criteria of being published between 2000 and 2015 or they were not done in the Sub-Saharan Africa. 314 articles were removed after the title and abstract review because they were not targeting adolescents living with HIV and AIDS and or the content did not match the objectives of the study. The full-text articles for the remaining 32 were assessed for eligibility, and 23 articles were ineligible as they did not focus on any one of the four objectives of the study. A snowballing method was used to identify additional articles which yielded one article. Ten studies met the set criteria and were published between years 2010 and 2015 (Figure1).

Characteristics of the ten studies are summarized in Table 1. The ten studies were from the following countries: South Africa=2, Zambia=3, Botswana=1 Uganda =2 Malawi=1 and both Zimbabwe and Uganda=1.

All the ten studies' participants included adolescents or young people living with HIV and AIDS from 10-24 years of age. Some studies included participants younger than 10 years (Lowenthal et al., 2014), or health care workers and caregivers as part of the participants (Mburu et al.,2013; Hodgeson et al,2012, 2014; Bernays et al., 2015; Mellins et al., 2014) and adults as participants (Gama et al., 2011).

Figure 3: Flow of articles through the systematic review process

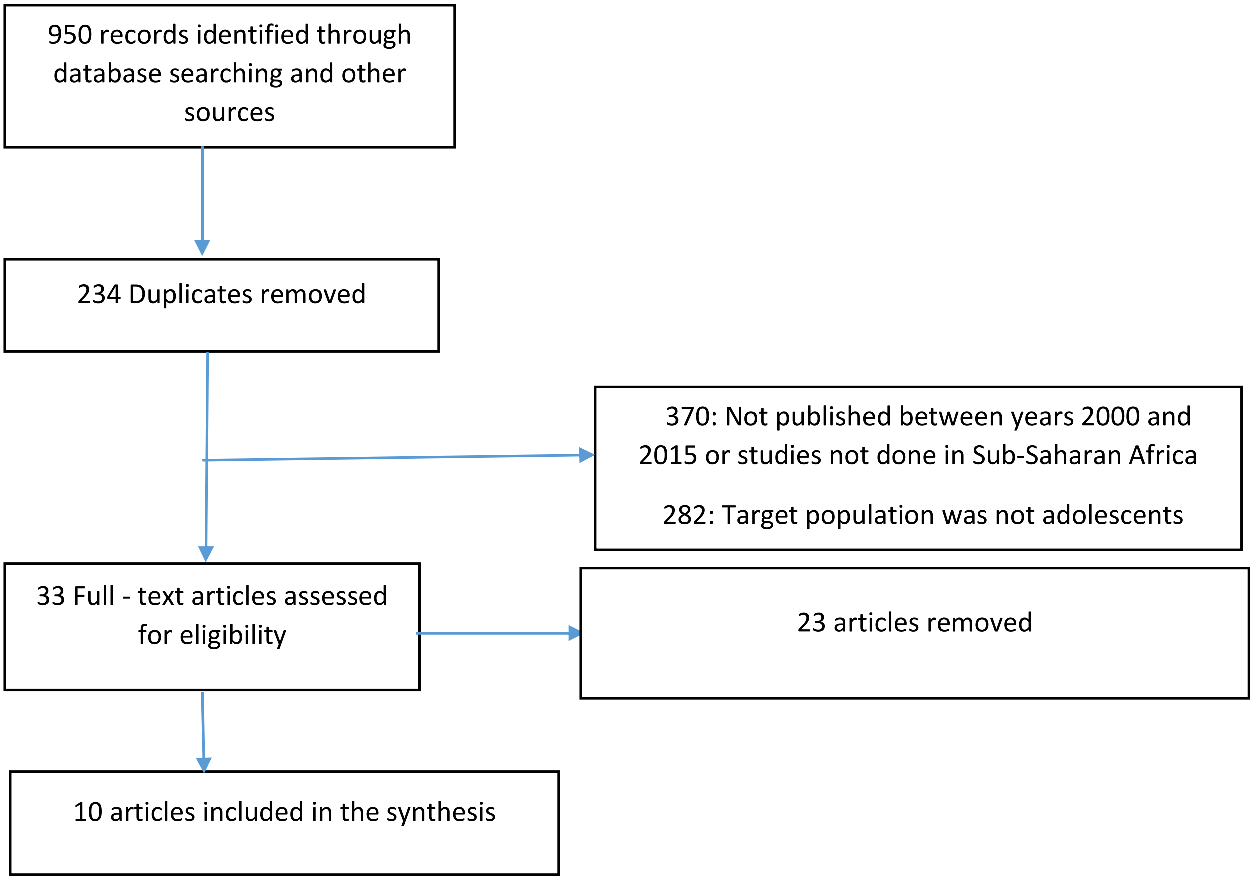


Table 1**:** Description of the articles included in the systematic review about psychosocial interventions/activities

Authors and study location	**Study Type**	**Target population and primary study objective**	**Study Setting**	**Description of activities/ intervention**	**Key results / Limitations**
1. Nkala et al. 2015 Republic of South Africa	Retrospective Cross-sectional	14 -24 years To describe the proportions of HIV testing and prevalence among young people accessing KMAC from 2008 to 2012 and describe the cascade of care among adolescents testing HIV positive	Clinical	Having identified the need to improve sexually and reproductive health services for young people, Kganya Motsha Adolescent Centre (KMAC) was established in Soweto, South Africa. The center offered comprehensive	A total of 11,522 young people (14-24 years) and 25+ years tested for HIV 410(3.6%) tested positive 109 out of the 410 tested (27%)positive had CD4 cell count ranging from 5 to 983 cells/mm^3

		in KMAC Soweto, South Africa		HIV management for adolescents and operated as a standalone center. The center aimed at providing HIV testing, identifying adolescents who required access to HIV care and treatment and providing HIV management services.	12 out of 410(11%) had CD4 count of-$^{<}$ 200 cells/mm^{3}making them qualify for ART treatment as per 2010 RSA ART guidelines 25%(N=41) did not return for the CD4 count results **Limitations** The program did not have a specific system of follow-up for participants and relied on the adolescents to provide contact information which may have been unreliable.
2. Mellins et al.,2014 Republic of South Africa	Randomized Controlled Trial(RCT)	14-16years (25 adolescents) 15 Caregivers To describe the VUKA intervention and explore lessons learned from the process of adaptation A pilot RCT of VUKA was conducted to examine the (1) development, feasibility, and acceptability of VUKA for health care settings in South Africa and (2) short-term impact of the VUKA family program on a range of psychosocial variables for YLWPHIV	Community	Collaborative HIV Prevention and Adolescent Mental Health Program (CHAMP)," is one of the interventions developed for PLHIV that targets families with pre- and early adolescents To promote mental health and prevent sexually and drug risk behaviors before problems emerge. Multiple families come together for an average of 10 sessions including communication within families, HIV knowledge, and parental supervision and monitoring, puberty, and social	Generalized Linear model was used to compare VUKA families and the control group in RCT. Key outcome included increased youth adherence to medications (Reported as change scores VUKA=1.10; Control=-0.43 at baseline and follow-up $p<0.05$) strengthened social support for caregivers, and their children. This was one key finding which was associated with diffusion of the program with other family members and caregivers being comfortable to discuss

		moreover, their caregivers		support. The sessions involve adolescents and caregivers with both separate and combined discussions. In South, Africa CHAMP has been adapted and is called VUKA. Health workers from different backgrounds including physicians, nurses, psychologists lay counselors, and researchers, together with patients, South African artists, and Educators/curriculum developers, reviewed existing materials and facilitated interviews with adolescents, youth, and caregivers as to inform the adaptation process.	sensitive issues with adolescents Limitations of the study included self-reported adherence measures and small sample used
3. Strasser S&Gibbons,2014 Zambia	Zambia Services review	12-22 years To document lessons learned as EGPAF responded to expressed needs for child-centered HIV support in Zambia	Clinical	Zambia identified a need for child-centered HIV support services. As a result, EGPAF responded through implementing learning by doing. Collaborating with Zambia Ministry of Health and support from donors such as PEPFAR and they implemented different programs of which among them were the “Psychosocial Care and Counseling for HIV-Infected	440 trained in HIV counseling Pediatric ART enrollment increased from 13.7 to 18.8 children(p<0.01) Adult enrollment increased from 165.6 to 208.1(p<0.01) In general, over one year the pediatric attrition rate was lower in sites with counselors than in sites without counselors 7.1% versus 10.7% (p=0.02). 13 HIVpositive youth

				Children and Adolescents” (2008) and *Tisamala* Teen Mentors Program (2012) The objectives of the programs were: to equip counselors with practical skills to support disclosure, adherence, and basic counseling for HIV-positive children and adolescents using a family-centered approach and through the T*isamala* Teen Mentors Program (2012)	and nine adult mentors trained 66 HIV positive teens aged 12–22 years reached 13 session life skills program covering topics including healthy relationships, seeking support, drugs **Limitations** Data used routinely collected and did not control for other variables such as other initiatives available to improve pediatric enrollment and retention into care
4. Lowenthal et al. 2014 Botswana	Botswana Services review	19 years and below To describe a comprehensive clinic-based disclosure support process, implemented in a large outpatient pediatric HIV care and treatment center in Botswana	Clinical	Clinic-based program for support of HIV status disclosure to children that has been adapted for use nationally in Botswana.	There are individual differences in readiness to learn early concepts leading to disclosure. Healthcare workers training play a major role to support disclosure With this disclosure model, there is high adherence rate of 92% based on pill count.

Table 2: Studies included in the review targeting objectives 2 to 4

Author/ Place where study was done	**Type of study**	**Study population and purpose**	**Main results and limitations**
Hodgson et al., 2012, Zambia	Cross-Sectional	10-19 years(N=111) In-depth Interviews with 53 adolescents	Emerging themes included availability of HIV information, SRH needs of adolescents and health

		Key Informant Interviews with Caregivers Key Informant Interviews with Health workers(N=38) The aims of this study were to explore and document the informational, psychosocial, sexual and reproductive health (SRH)needs of adolescents (aged 10_19 years)living with HIV in Zambia, and identify gaps between these needs and existing services	services' capacity Local norms, fear of stigma and underlying presumptions that adolescents will not comprehend disclosure results
Nabukeera-Barungi,2015 Uganda	Cross-sectional study(Convergent design)	10-19 years (1824 adolescents) 69 Key Informants In-depth interviews 40 In-depth interviews The purpose of the study was to describe the level and factors associated with adherence to antiretroviral therapy(ART) as well as the one-year retention in care among adolescents in 10 representative districts in Uganda and explore the barriers and facilitators of adherence to ART among adolescents	Good adherence to treatment 87.1%(N=1588 out of 1824) Location of the facility remained statistically significant with rural facilities associated with poor adherence (Adjusted Odds Ratio 2.64[1.28 5.43] and a p-value of 0.008. **Qualitative results** 33 Focus Group Discussions(FGDs) involving 227 ALHIV and 5FGDs with caregivers of ALHIV Barriers to adherence included Stigma, discrimination laxity, poverty, side effects, pill burden and disclosure associated with barriers to adherence. Key limitation was gaps in the data for retrospective records for reviews
Mburu et al. 2013 Zambia	Cross-sectional study	8 FGDs with adolescents 10-19 years 2FGDs with 21 Parents 3FGDs with 24 Healthcare providers To explore how the evolving capacity of adolescents living with HIV is shaping their ability to express their needs and how the health services should respond	Adolescents expressed the need for a range of information and support which is locally available and relevant. Five key findings were as follows: use participatory approaches to define adolescent services; 2) identifying Health care providers to facilitate the safer transition from pediatric to adult services. 3) strengthening adolescent friendly

			services through well-trained health care workers.; 4) responding to individual circumstances as well as the wider social the context of adolescents living with HIV i.e. in relation to social, economic, stigma and other cultural barriers and 5) empowering adolescents living with HIV to become agents of change.
Bernays et al., 2015 Zimbabwe and Uganda	Prospective qualitative study	11-13 years' adolescents, Health workers, Caregivers 104 baseline interviews (58 were girls) 60(25 boys,35 girls) Followed for 16 months 40 adult caregivers interviewed 20Healthworkers interviewed To examine the children's experiences of living with HIV on ART, where HIV is relatively common and yet these experiences are also silenced, as well as surrounded by uncertainty, and to describe how children articulate 'living with' and 'growing up' with HIV and how this is shaped by their relationships with the adults around them.	Children experiences of HIV are largely constructed about a language of sickness. Differences in how children feel about themselves about sickness with the caregivers Symbiotic relationships contribute to lived experiences of children
Gama et al.,2011 Malawi	Cross-sectional study	15-24 years old and adults To explore how HAART rationing and access mechanisms impact on youth's utilization of HAART in Malawi	Malawi Demographic Health Survey 2004, 11.6% of young people aged 15-24 years had HIV. It was however observed that while 3.92% of the population who are HIV positive are those aged 15-19 years, only 1.47% of the people with HIV using HAART are from the ages ranging from 15-19 years. Similarly, while 19.42% of the people with HIV are those aged 20-24 years old, only 6.55% of

			the people living with HIV on HAART are from the age bracket of 20-24 years. **Limitations** These data are the best estimates available but suffer from non-response bias in that about one-third of those sampled refused to be tested for HIV.
Siu et al., 2011 Uganda	Retrospective Qualitative study	20 In-depth interviews To explore a broad range of experiences relating to ARV and HIV serostatus disclosure and social	The main themes identified included meaning of HIV serostatus, disclosure strategies, how much to disclose, and positive and negative aspects of disclosure

Strategies/Interventions for providing psychosocial support to adolescents and young women living with HIV and AIDS in Sub-Saharan Africa that affect adherence to treatment.

While there is no single intervention recommended for meeting the needs of adolescents and young women living with HIV and AIDS, the literature challenges a singular focus on biomedical interventions alone since the health needs are beyond the individual (McMillan, A. S., & Simkiss, D. 2009). However, there is a need for evidence-based interventions to support families in promoting health and psychosocial wellbeing of adolescents and young women. The interventions need to be further tailored and or adapted to suit the needs of the adolescents and young women in low and middle-income countries such as Sub-Saharan Africa (Parkhurst, J. O. 2012).

A pilot Randomized Controlled Trial was conducted in South Africa to examine development and feasibility of Collaborative HIV Prevention and Adolescent Mental Health Program (CHAMPS) designed for the general promotion of mental health and to prevent risky behaviors among the uninfected youth (Mellins et al., 2014).

The strategy called for families to come together for an average of 10 sessions focusing on social support, communication, HIV knowledge and general puberty issues (Small et al., 2014). The intervention has been tested in South Africa and other countries such as Argentina on managing adolescents living with HIV.

In South Africa, the strategy has a local name VUKA meaning wake up, and results showed an increase in youth adherence to Antiretroviral treatment with a mean baseline score of 3.71 to 4.81 follow-ups compared to 4.79 mean baselines score to 4.36 follow-up in the control group. There was an increase in youth HIV treatment knowledge with a mean score 4.18 baseline to 4.45 follow up for the VUKA compared to mean score of 4.88 to 4.14 and a follow-up for the control group, (Bhana et al.,2014)

The results also showed significantly higher proportion of females testing HIV positive compared to males in 2008 ($p=0.0371$), 2009 ($p<0.0001$), 2010 ($p= 0.0006$), 2011 ($p= 0.0287$), and 2012 ($p= 0.0103$). The number of young females accessing the program was three times higher than that of males throughout the years. Uptake increased every year with less than 500 males in the first year and above 1000 in the fifth year. These findings agree with other studies across Sub -Saharan Africa who have reported similar trends in HIV testing where women continue to test more for HIV than males (Ramirez-Avila et al., 2012; Van Rooyen et al., 2013; Mellins et al., 2015).

Structure of VUKA

The intervention was developed to help with management of adolescents living with HIV and AIDS. In its development, key consumers and stakeholders included adolescents living with

HIV aged 14-16years and caregivers responsible for adolescents aged 9-14. The consumers were selected to provide historical insights of care for adolescents living with HIV and AIDS.

Ten consumer consultants (Five caregivers and Five adolescents living with HIV) formed the working groups. Also, the set up strengthened the bonding of the participants who came to the table from different cultural backgrounds. During the discussions, each party needed safe time and space, for instance, adolescents needed their own time to discuss issues with each other related to peer pressure and relationships crushes without fear of negative consequences from the caregivers. The safe space offered an opportunity for peer support (Mellins et al., 2014).

For the caregivers, they also needed space to ask questions without feeling guilty to share their frustrations or being interfered with the presence of the adolescents. The VUKA inclusion of caregivers opened up a learning space of the caregivers from the adolescents under their custody. Qualitative interviews were conducted with the youth and caregivers (25 adolescents and 15 caregivers) to give the context of the psychosocial challenges according to the South African families (Mellins et al., 2014)

VUKA manual and storyline

The ten sessions followed a cartoon character by the name Themba, a 12-year-old boy in the South African context who lost his mother to AIDS and moved to a new community with his aunt, uncle, and his baby sister and eventually found out he was HIV positive. The story depicts the common scenario for most youths living with HIV in South Africa which might also apply to the Sub-Saharan Africa region.

Alongside the cartoon, there was a facilitator's manual which designed as an easy reference guide to people such as lay counselor who are always taking the role of professional counselor given the shortage of skilled personnel. The manual facilitated the review of a part of the story line in the cartoons and provided activities, discussion questions, probes, and tips for engaging participants in each topic/session.

Curriculum content

The original topics have maintained the initial design from the United States of America. However, new sessions which were deemed necessary for the South African context were included such as a new focus on identity, acceptance, and coping mechanisms. Other topics such as communication within families, HIV knowledge, stigma and feelings about HIV had small tweaks made.

Despite that the sample size of the families assigned to the VUKA arm was small (33 families) 100 percent completed at least one session, and 94% attended at least five of the required six days with fifty-five percent attending all the six days. Reasons for failing to attend were sicknesses and family time conflicts.

The VUKA arm revealed significant differences in the major outcomes which were ART adherence, HIV treatment knowledge, and caregiver-child communication. In general, the following were the key improvements based on the intervention:

Diffusion of the program to other family members

The story books were reported to assist promoting support from the family members after reading them which impacted in caring for the HIV positive child in the household.

Talking about sensitive topics

With the help of story books, caregivers found a way of initiating discussions on sensitive topics which they never mentioned before VUKA.

Improved social support

Through realizing that other people shared the same experience of being HIV positive, the caregivers and adolescents made new friends who they were comfortable.

Improved self-concept and future orientation

Using the positive approach in Themba story line where he talked about not being sick this gave the caregivers and children a new meaning of life.

Adherence to medication

Caregivers reported that VUKA improved adherence as children realized they were not the only ones on medication which made them hopeful for their future.

The results show that the CHAMP strategy is feasible and can be adapted to suit the needs of the targeted community. Paruk et al., 2009 conducted a post-intervention qualitative evaluation of the CHAMP model on family-based prevention program where it also showed a great sense of individual empowerment and improved communication.

Kganya Motsha Adolescent Centre (KMAC)

In South Africa, a retrospective cross-sectional study conducted which reviewed clinic records of young people attending the KMAC from 2008 to 2012, which was initially designed for adolescents 14-19 years. The KMAC was a standalone clinic which referred to as "*Motsha*" meaning shine young one in their local language Sesotho (Nkala et al., 2015). *Motsha* clinic 's aim was to provide HIV testing, identify adolescents who required access to HIV care and treatment and provided HIV management services. The results showed that proportion of males and females testing for HIV was higher in the age group the age group ≥25 years (70%), followed by those in the age group 16–25 years old (22%). HIV testing was lowest among adolescents' ≤15 years (8%).

Despite the successes associated with the KMAC, there were some challenges such as failure to link the adolescents to ART and to retain them into care, despite the established networks with local clinics and health facilities (Nkala et al., 2015). Some studies have attributed adolescents lower adherence to cultural differences which might influence age at first marriage (Kim et al.,2014).

In Africa and South America, older adolescents were most likely to get married at the age between 16 and 24 years which makes them easily associate with adults as they all share the status of being married despite the age differences. This culture differs from European countries where marriage may occur later in life which makes it difficult for the adolescent to relate with adults in the clinics hence the need for more adolescent friendly HIV management clinics (Kim et al., 2014).

A longitudinal cohort study conducted in the United States identified individual and extra-familial factors which affect adherence by the adolescents (Naar-king et al., 2013). Individual factors included awareness of the HIV status which was discussed alongside the adolescents' age to explain readiness for disclosure of HIV status. For the extra-familial factors, social support from the caregivers and engagement with the medical team had an impact on adherence to treatment. The results further showed that the definition of the individual of a good caregiver has an effect on adherence to treatment.

The study suggested that caregiver responsibility should match with adolescents' perceptions of a good caregiver (Naar-king et al.,2013). These results are in agreement with the study conducted by Gross et al.,2015 who found out that quality communication between adolescent and caregiver results in optimal adherence to treatment. The study further reported that the group that adhered more to treatment received additional support such as a reminder through telephone call or short message system from the health care provider if they missed a visit.

Attending to additional group activities such as discussions promoted adherence to treatment. However, there was a distinction between those led by professionals and peers. Professionally led group activities were more associated with adherence compared to the peer-driven activities. These results are in support of the VUKA model which recommends for formally tested interventions to yield maximum potential considering that professionals are not adequate to do the non-clinical interventions (Gross et al., 2015; Mellins et al., 2014).

Much as there is no usual cadre to address adherence, continuous and persistent assessment during every encounter with the adolescent should assess readiness for disclosure and adherence to treatment. Use of multidisciplinary approach and paying attention to age and cognitive appropriateness and readiness (Agwu, A. L., & Fairlie, L. 2013).

Previous evidence has shown that social support is key to successful parenting interventions even in low-income countries like Sub-Saharan Africa who are hard hit by HIV. The role of the caregiver may have direct effects on the behavior and conduct of the adolescents which extended family or community social network can further support (Casale et al., 2015; Dotse, J. E. & Mensah, K. A. 2014).

Similarly, Bearinger et al. 2007, suggested providing young people with protective factors such as strengths or assets in their social and environmental context and not only focusing on risk reduction to promote youth development.

Learning by doing approach

Elizabeth Glassier Pediatric AIDS Foundation in Zambia adopted a learning by doing approach. The approach is founded on the two child developmental theories by Piaget and

Inhelder (1969) and Erickson (1950).Also, the approach focuses on the expressed needs, clinical observations and the lessons learned from the nursing and medical practices during their implementation.

The learning by doing approach is an incremental model of learning to evidence-based interventions and allows for innovations to suit the different context given the diverse culture and resources availability (Strasser, S. & Gibbons, S.,2014).

Learning by doing approach consisted of six interventions of which only two were relevant to this review. These interventions were the psychosocial care and counseling for HIV-infected children and adolescents and “Tisamala” teen mentor program. The psychosocial care and counseling for HIV-infected children and adolescents is a 14 module curriculum endorsed in Zambia in 2008.

The curriculum equips counselors to support disclosure, adherence and offer basic counseling. Also, the counselors use educational videos with actual counseling sessions recorded in Uganda which reinforces on issues of child development, adherence, and common communication challenges. A variety of job aids such as feeling books, charts and drawings were also used (Strasser, S. & Gibbons, S., 2014**).**

The lesson learned from this intervention is that it increases the counselor's' scope to address challenging psychosocial issues by working closely with children and caregivers through the learned skills and practical steps acquired during the training. The study further identified the need for multisector collaborations in managing psychosocial issues presented by the adolescents as well as their caregivers (Strasser, S. & Gibbons, S., 2014).

Some of the suggested referral networks include the clinicians, community liaison officers, the legal system, trauma therapist and institutions that purport safety of individuals.

With the strong collaborations, the culture of learning by doing is much stronger. By reinforcing adolescents care, adult enrollment into ART also increased.

"*Tisamale*" team mentor program was one of the interventions targeting teens from 12 to 22 years. This intervention involved young people in discussion and exploration of topics affecting their lives through storytelling. The intervention showed improved self-confidence, decreased stigma and increased adherence. The study involved the existing support groups, and the response was positive from those adolescents who patronized the services (Strasser, S., & Gibbons, S. 2014).

HIV disclosure model

Lowenthal et al., 2014 conducted a post-intervention review and described an HIV disclosure model to HIV-infected children in a large African treatment center in Botswana. The model is based on developmentally appropriate ways that support the entire family and always embraces truth-telling at all stages. The review echoes many writers acknowledging the WHO guidelines on HIV disclosure and counseling to school-aged children that it should be incremental and appropriate to age, but it questions the absence of the practical guide on how to do the process (WHO, 2011; Lowenthal et al., 2014).

The disclosure model developed through Botswana-Baylor Children's Clinical Center of Excellence which supports Botswana National Antiretroviral Therapy Program with a goal to catalyze the provision of high-quality care to HIV-infected children. In this model before children initiation to ART, caregivers attend adherence classes which focus on introducing basic HIV concepts to young ones.

During each clinic visit the provider assesses the knowledge of the children on HIV and ends the session with one positive message to leave with the child, and give the child verbal praises. An example of the negative message could be a strong myth in the community. Stickers and dances are used to reinforce and facilitate recall of key things such as the names of the drugs the child takes (Lowenthal et al., 2014)

One key reinforcement is to help the children and caregivers transition from negative messaging to positive messages while upholding the truth always. At all times, the clinic staff avoids using blame words like" your mother infected you "instead they would say some children are born with HIV, and we think you are one of those."

Household visits are done to psychologically challenging cases but the review identified inadequate resources as the limiting factors to implementing this strategy. Teens participate in the teen's clubs who continuously provide a safe environment through social support and education during the monthly meetings on the weekend (Lowenthal et al., 2014). Of the many lessons learned from implementing this model is that its success is dependent on the consultative process that included suggestions from patients, families, and staff through informal discussions and focus groups (Lowenthal et al., 2014).

Bearinger et al., 2007 noted that there is no single approach to sexual health promotion that would work universally but that there is the high promise of success in multisector approaches. The study further outlined three key strategies to be considered when implementing adolescent health programs which were high quality and accessible clinical services, evidence-based curricula that speak to developmental process and youth strategies that enhance development and life skills with connections other support systems such as adults, education, and economic empowerment.

The Families Matter! Program (FMP)

FMP is an evidence-based intervention for parents and caregivers of 9-12 year-olds to promote effective communication between parent and child about sexuality and sexual risk reduction. The intervention originated from a US evidence-based intervention and has technical support from the US Centers for Disease Control and Prevention(CDC)which supports eight Sub-Saharan African countries on the similar intervention (Miller et al.,2011; Winskell et al.,2016). The FMP is a six, weekly three hours' session delivered to communities. Specifically, for ALHIV, an additional module was included to address their specific needs. The discussions in this module center around topics on stigma and mental health, disclosure, ART adherence and self-care, and responsible sexual relationships.

Two certified local facilitators lead the discussions with a group of 18 participants using participatory learning techniques (Winskell et al., 2016). Global dialogues narratives competitions also assisted in putting in the context of ALHIV perspectives in developing the curriculum. To avoid inadvertent disclosure participants to the sessions were mixed to include family members, community members who promote community-centered approach.

The effects of HIV status disclosure on adherence to antiretroviral treatment by the adolescents and young women living with HIV and AIDS in Sub-Saharan Africa.

Disclosure is considered a delicate topic in HIV management considering the negative consequences that may arise if the process is not well done. WHO recommends a step by step approach to building on of information about HIV status (WHO, 2011; Mburu et al., 2014).

A study in Zambia by Mburu et al., 2014, looked at barriers, facilitators, and outcomes of adolescent HIV disclosure. The study targeted adolescents aged 10-19 and included caregivers to these children. The results showed that disclosure had an association with emotional well-being, sexual relationships and adherence. The study also pointed out that delayed disclosure could lead to unintentional disclosure as the more the adolescents grow up, the more inquisitive they become which could lead to discovering why they are taking the drugs.

The uncles' approach, where a close relative such as an uncle, casually asks and discusses with the adolescent what they will do if found HIV positive and suggest if they can test together was explained as one way of promoting disclosure. The study further suggests targeting disclosure before the onset of sexual relationships and being incorporated into community-based interventions that challenge adverse social norms and cultural values and practices (Mburu et al., 2014).

The most frequently stated reason for disclosure was the hope that disclosure would improve medication adherence while the belief that the child was too young to understand his or her illness was the main reason for non-disclosure. Atwiine et al., 2014, suggested that gradual disclosure starting at younger ages maximizes the benefits to the child and caregiver as it is not overwhelming. However, the effects of disclosure had an association with both positive and adverse effects on adherence to treatment.

In a cross-sectional study conducted in Uganda by Nabukeera-Barungi et., al 2015 which looked at the factors associated with adherence to treatment at different places such as home and school. The results showed that adolescents are challenged to adhere to treatment because of inadequate support from the caregivers especially if they are not their biological parents.

Insensitivity by openly discussing their HIV serostatus with other people was discouraging and affected them continuing taking the drugs. Older caregivers usually forget the appointment dates which contributed to the adolescents missing the doses. Previous hospitalizations and transfer of responsibility for medication administration are the other factors that also affect adherence to treatment (Hudelson, C., & Cluver, L. 2015).

For the school going adolescents, lack of disclosure made it difficult to ask for permission during the appointment days, and the boarding facilities lacked privacy to take drugs when one did not disclose to peers. In general, the study reported very good adherence of over 90% for the one-year period. The study noted the limitation to generalizing the results given the shorter period of assessment, therefore, recommended future studies to consider longer duration on ART (Nabukeera-Barungi et al., 2015).

Adolescents and young women perspectives on the available services for adolescents and young women living with HIV and AIDS in Sub-Sahara Africa.

Most HIV and AIDS programs for adolescents' origins are either pediatric or adult and yet the needs of adolescents may sometimes not match the expectations and needs of the two groups (Mburu et al., 2013). In the same vein, advocacy for reproductive health services for the adolescents living with HIV and AIDS is mostly driven by adults or networks of people living with HIV and other Stakeholders with no or little adolescent representation (Mburu et al., 2013).

In general, adolescents prefer to have services offered in one room and where possible by the same health provider as they may also lack experience in navigating the healthcare systems (Baryamutuma, R., & Baingana, F. 2012; Ferrand et al., 2010; Tanner et al., 2014).

Other studies have noted that adolescents social environment which include their individual factors, home setting, school, community and society as a whole shape their experiences (Mburu et al., 2014; Fatusi et al., 2010). While there are no differences in the sexual and reproductive health needs of the adolescents and young women living with HIV and those that tested negative, HIV brings additional demands and expectations.

Right based interventions and expectations

Rights-based approaches significantly contributed to increasing the uptake of services among adults during the first decade of HIV and AIDS among adults and yet much has not been promoted for adolescents' services (Berkman et al., 2005). Adolescents, on the other hand, find mainstream primary health services unacceptable because of lack of respect, privacy and confidentiality and sometimes health care providers impose moral values on them.

The United Nations Conventions on the rights of the child and HIV/AIDS advocates for treatment of children with respect and protection. There is a call to shift from biomedical approaches to understanding other determinants of health such as social, cultural and economic factors and making human rights to be taken as prerequisites to human wellbeing (McMillan, A. S., & Simkiss, D. 2009).

A cross-sectional study in Zambia conducted on the right based services for adolescents living with HIV. Forty-six adolescents aged 10-19 and 14 care providers were involved. The majority of the adolescents expressed the need for them to have the rights to sexual and reproductive choices such as relationships, marriage and having children (Mburu et al.,2013).

Fifty percent of the study participants were in a sexual relationship, and this was common among older adolescents. Six participants were married while two of the sexually active participants did not disclose their HIV status is fearing rejection. In general, they all acknowledged the right to control disclosure of their HIV status.

The study further explored the expressed unmet needs which affected the right based services for adolescents. The weak health system hampered the adolescents meeting their HIV, sexual and psychosocial needs and because of the inadequate information on topics like family planning which the adolescents were in need of to help them make informed choices.

Family planning information is critical to adolescents living with HIV and AIDS as the timing of first sexual intercourse is the same to the general adult population. Promoting access to high-quality contraceptive services is also essential to reducing the number of unintended pregnancies and new infections and re-infections (Landolt et al., 2011)

Long queuing time was one of the biggest challenges to accessing the services and linked to inadequate space in the clinics which further compromised their privacy. The adolescents suggested group discussions during the clinic hours so that waiting time for consultation could decrease. Like other studies, the participants suggested if adults could be separated from the adolescents during some topics for discussions (Mburu et al., 2013; Fleischman, J. & Peck, K., 2015).

For older adolescents, they expressed a need for more discussions on livelihood activities and skills training such as tailoring and cooking since they needed to earn a living for their families too. The gaps or needs reported in this study agree with the positive aspects of care which ALHIV shared in a study which included sensitive and caring treatment by providers, opportunities to share experiences and empathize with each other. Specifically, peer groups, teen clubs, and peer mentors were reliable sources of support (Mburu et al., 2014).

In a prospective qualitative study conducted in Uganda and Zimbabwe which examined children's experiences of living with HIV on treatment, 104 baseline interviews have been carried out for the 11-13-year-old adolescents while 60 had follow-up interviews, and 40 adult caregivers were also involved. The language of sickness and boundaries of HIV talk were the two main categories of the results.

Language of sickness

The results showed that experiences are mainly related to HIV sickness. Adolescents and caregivers focus more on the physical appearance of an individual like the quality of hair, skin appearance, for instance, the scars from a skin condition. However, most adolescents perceive themselves to be normal as evidenced by no reported illness despite taking ART which might conflict to how caregivers perceive them as always wanting to be extra careful and protective. The talk is always related to the period before starting taking ART where most adolescents had frequent illnesses.

Boundaries of HIV talk

The study further showed that once disclosure of HIV diagnosis occurred, there was usually silence from the caregivers. Nobody wanted to talk more about issues of HIV within the company of the affected adolescents, and if he or she asked questions he or she was not answered, or caregivers would medicalize the talk.

The caregivers always talked about adherence reminders and precautions to stay healthy and did not want to discuss any further questions that the adolescents might have. The only time the family would discuss the issues related to HIV after disclosure was when they discussed past illnesses experienced by the adolescents before starting ART. This discussion was always attached to the importance of adherence which bothered the adolescents as they had so many questions or issues which they wanted to discuss with their caregivers (Bernays et al., 2015).

Lack of sympathy by some caregivers when they failed to take drugs in a correct way was shared as a concern by the adolescents. Because of this experience, the adolescents usually edited what to tell the caregivers if they had problems taking their drugs. In general, the adolescents expressed that sense of fear of illness resurfacing made them adhere to their treatment. In some instances, caregivers who were biological parents of the adolescents were not comfortable to discuss HIV related issues to help with concealment of own status (Bernays et al.,2015; Mandalazi et al., 2015).

In a study conducted by Siu et al.,2011 which examined HIV serostatus and treatment disclosure practices and concerns of young people in Uganda, the results showed that adolescents do not favor third party disclosure where a caregiver, health worker talks about their HIV serostatus on their behalf. This practice may be common to most African context given adolescents are dependent on adults for their most decisions for care.

Adolescents called for being in control of their lives where confidentiality is maintained and respected. Other themes identified included the meaning of HIV serostatus, disclosure strategies, how much to disclose, and positive and negative aspects of the disclosure.

In addition to the study definition of disclosure which talked about the willingness to pass on private and confidential information regarding HIV status. The participants felt disclosure was more that it encompassed communication and the environment in which people live. It was more of what relationship exist with other individuals who do not have the virus where people even continue to share lived experiences (Siu et al., 2011).

On the disclosure strategies, use of jokes was one key way of introducing the HIV topic with the aim of not instilling fear, especially to the fellow adolescent. Several open acts such as taking medications in the open, displaying medical records and openly visiting the clinic followed the jokes about being HIV positive (Siu et al.,2011).

There were differences on how much to disclose, but most participants agreed that information about HIV serostatus needed to be private and confidential except for the very few who felt their HIV serostatus could be made public. Above all, participants acknowledged disclosure was not a one-off thing it was a process (Siu et al., 2011).

Successes and challenges documented on implementing psychosocial support programs for adolescents and young women living with HIV and AIDS in Sub-Saharan Africa

Successful transition to adult services

Since adolescence is a period of transitioning from childhood to adulthood, it is important to have established pathways to adult care (Fatusi, A. O., & Hindin, M. J. 2010). WHO suggests that there should be a systematic process that avoids abrupt changes and that the processes should be in a joint manner involving the adolescent, parents or guardians, and the health care providers. While the guidelines are available, little documentation is available to ascertain adequacy both domestically and globally (Lee, S., & Hazra, R. 2015). One of the greatest challenges to proper transitioning is a poor evaluation of adolescents' abilities to receive and make meaning of the information which usually results from improper communication with care providers.

On a different note, family-centered and peer support interventions, self-esteem and coping skills building activities facilitate the ease transition process (WHO, 2013). Some literature criticizes the focus on the transition process being on medical guidelines for medical providers and patients themselves as opposed to the need to shift implementation science research efforts given the dynamic variations in the context of HIV and associated factors such as geographical settings and policies (Lee, S., & Hazra, R. 2015). Focusing the transition on the HIV field has potential to address broader issues of chronic illness during adolescence especially in resource constraints regions like Sub-Saharan Africa (Lee, S., & Hazra, R. 2015).

Identified psychosocial needs

Hodgson et al., 2011 conducted a study which explored and documented the informational, psychosocial sexual and reproductive health needs of adolescents where fear and depression associated with initial HIV diagnosis were paramount. Immediate and subsequent support such as support groups especially those that promoted social and vocational skills were rated positively towards reducing the challenges associated with knowing one's serostatus. Some adolescents identified the environment at the clinic as frightening, considering the very sick people that come on a wheelchair and who compounded with memories of parents who might have died and were attending services from the same clinic **(**Hodgeson et al., 2011**).** While adults accompanying adolescents was a supportive action, it prevented freedom to discuss issues related to sexual and reproductive health.

Popular Interventions for adolescents

Youth centers, peer education, and high profile meetings are commonly used in many countries but may not contribute effectively to changing adolescent sexual and reproductive health knowledge, attitudes, beliefs and behaviors. On the other hand, youth centers are considered good avenues for social interactions an aspect which prevent adolescents and young women from engaging in risky behaviors such as drug and alcohol abuses (Amzel et, al., 2013).

Peer education, on the other hand, has been documented to benefit the educators more with the skills and knowledge rather than transferring expertise and knowledge to their peers. However, there is the strong positive effect on information sharing. Given the evidence of peer education programs being a good way of providing information. Some literature suggests the peer educators provide teaching and referral to experts and services. In this line of thinking, task shifting could be an opportunity (Amzel et al.,2013).

Interventions such as youth friendly services and comprehensive sexuality education have been found to be effective but are not usually fully implemented due to implementation challenges (Tanner et al.,2014; Amzel et al.,2013).

Chandra-Mouli et al., 2015 identified four core things when implementing youth friendly health services.These are the training of care providers to be friendly, the conducive environment of the health facilities, well-established referral and linkage system which has an element of creating awareness of the program and having communities which are supportive and appreciate the importance of providing these YFHS to adolescents.

In 2007, Government of Malawi initiated Youth Friendly Health Services(YFHS) to make all health services more acceptable, accessible and affordable to young people .Later in 2013, an evaluation of the services was done . The results showed that despite the national attention paid to YFHS, awareness of the YFHS was low with only one –third of the surveyed youth having heard about it and only 13% ever used of the YFHS (Chandra-Mouli et al., 2015).

Young people, parents and community leaders lacked information and expressed doubts about the quality of services available. Despite government issuing of YFHS standards less than one –third reported implementing key aspects of the standards which included signage, trained providers, outreach to adolescents, and adolescent-specific educational materials. Nevertheless, the young people who reported having visited a YFHS facility in the past 12 months expressed satisfaction with the care provided (Chandra-Mouli et al., 2015).

Fragmentation in the delivery of services to adolescents and the youth is one key challenge to effective interventions which then calls for a whole systems approach of which strong leadership is a core component (Amzel et al., 2013: Tanner et al., 2014). Critiques of the traditional approaches to improving adolescent health have usually focused on problem behaviors with a single intervention such as abstinence and delay on sexual initiation. Interventions are now considering taking into consideration problem behaviors and increase protective factors that mitigate against risk behaviors (Catalano et al., 2012; Chandra-Mouli et al., 2015).

Approaches to Pediatric HIV Psychosocial support

At the core of the psychosocial support interventions is the fact that living with HIV is a chronic disease often surrounded with challenges such as stigma and discrimination, difficulties surrounding disclosure, treatment access, and retention in care. Interventions may, therefore, require more coordinated efforts with the clinical care, caregivers and ensure the reach of the adolescents and young women in their respective places such as communities, clinics, and schools. Further to this is the need to target interventions at different levels such as individual, family level, health care services and school-based (Chandra-Mouli et al., 2015).

Individual and family-level interventions

Individual and family-level interventions help to reduce stigma, promote disclosure and improve drug adherence. One to one counseling and mentoring are often used to support people living with HIV.

The Regional Psychosocial Support Initiative (REPSSI) is an example of community and family psychosocial support interventions to address needs of children affected by AIDS and their households. The intervention aimed at empowering HIV-infected children to face, address and respond to stigma through enhanced and mainstreaming of key child care programming areas. Some of the key programming areas include pediatric antiretroviral (ARV) programs, and schools and children's education systems, to directly or indirectly serve children affected by HIV/AIDS, poverty and conflict in East and Southern Africa (Matikanya et al.,2006).

The key achievements of REPSSI were a capacity enhancement, knowledge generation, and advocacy. The initiative created a pool of facilitators to increase knowledge around psychosocial support and met the psychosocial demands of organizations across REPSSI's 13 countries of operation (Lesotho, Swaziland, South Africa, Tanzania, Uganda, Zambia, Zimbabwe, Kenya, Angola, Mozambique, Botswana, Malawi, and Namibia) (Matikanya et al., 2006).

REPSSI provided financial and technical assistance to key operating partners to enable them to scale up access and integrate psychosocial support into their existing programs and facilitated partnerships with universities in the region to offer undergraduate/graduate education in psychosocial support. On knowledge generation, REPSSI facilitated development and piloting of psychosocial support tools and incorporated operations research, monitoring and evaluation. In all the 13 operating countries there were advocacy coalitions which facilitated participation in relevant forums and interventions.

Health services interventions

Interventions delivered by skilled personnel such as psychologists and counselors are likely to have a positive impact on the psychosocial wellbeing of children and their caregivers. SSA has only 3% of the world health workforce but carries 25% of the global disease burden and spends less than 1% of the world's financial resources on health (Anyangwe, S. C. & Mtonga, C., 2007). Despite efforts to improve healthcare systems, delivery of specialized care remains a challenge. Task shifting services through the use of community lay counselor allows for wider awareness and information giving and help with linkage to specialized care for psychosocial support for adolescents and young women.

School-based interventions

The education system has a bearing on the psychosocial well-being of HIV-infected adolescents through addressing structural barriers to school access. Supporting disclosure in a school setting may have positive outcomes such as acceptance, reassurance, and support from school staff. However, if people are not well-informed children may face social isolation by peers and teachers.

Individual, programmatic and structural factors

Financial and logistical constraints affect adolescents' access to health services including ART. Gama et al., 2011, conducted a study in Malawi of which one of its objectives, was to identify challenges associated with rationing and access mechanisms that affect youth access to ART in Malawi. Nine HAART providers, nine Youth HAART recipients and nine youth from associations of People Living with HIV and AIDS (PLWHA). The results showed that despite the free ART being available to the young people, some associated costs such as those related to routine tests like checking CD4 count in private institutions posed a challenge to youth accessing the services.

The mandatory guardian presence when accessing treatment was yet another stumbling block for adolescents accessing treatment in some facilities. This practice further complicated for school going adolescents in boarding schools who were expected to ask for permission from the school authorities if they were to go for their scheduled appointment dates.

Beyond the access to treatment, were the challenges in finding places to safely store the drugs without being asked by peers or being laughed at (Gama et al., 2011).On a positive note, social structures available to the adolescents such as family members instilled a feeling of hope and facilitated initiation and maintenance of taking ART through their convincing opinions (Gama et al., 2011).

Programmatic factors affected the adherence to treatment either positively or negatively. The group discussions before starting ART were associated with positive results as they strengthened information on the importance of adhering to treatment. Power dynamics between genders was one of the identified barriers especially for young women who needed to start treatment; they could only do so with prior permission from their partners (Gama et al., 2011).

Several studies have reported that older adolescent age and non-adherence to treatment are associated. Premature responsibility may contribute to them not being ready to take on the responsibility of their care and the situation gets more complicated when there are no continued discussions when disclosure happens, which leaves adolescents with many unanswered questions (Mellins et al., 2004; Bernays et al., 2015). The role of disclosure on adherence is not clear given other confounding factors such as age. Coincidentally, reports show that disclosure starts at the age of 10 or older when adherence problems seem to be more prominent (Mellins et al., 2004). Community-based settings have been documented to support adherence to treatment and retention in care for people living with HIV and AIDS. However, challenges such as familiarity with the interventions can impact on confidentiality which could lead to increased stigma, which calls for more research on what works for adolescents.

Common Implementation challenges

Most literature cites lack of confidentiality and privacy as barriers to accessing health services by the adolescents. The need for own space for adolescents and young women's sexual and reproductive services is one recommendation to address confidentiality and privacy. However, there is also need for dedicated and trained staff to work in these designated spaces. While the lack of space limits privacy, the reality of creating youth space may not be justified in all settings. In cases where there is constant low patient volume throughout, having a designated space for adolescents and young women may not be cost effective, feasible and justifiable. Training of all health workers could be an approach to address the barrier of lack of confidentiality and privacy as is one key component of the Youth Friendly Health services training.Youth friendly services have shown great impact places like Tanzania and South Africa(Alli etal,2013;Geary et.al,2014)

To address the feasibility of training all staff,the content should be incorporated in the preservice curriculum and orientation of new staff should be ongoing.

Unfriendly and judgmental attitudes by the providers contribute to even more adolescents shunning the reproductive health services (Alli et al., 2013; Kennedy et al.,2013). In some studies, adolescents and young women describe the interactions they have with health workers as instructional, rushed and often judgmental. Adolescents and young women in some cases perceive the providers as their mother and father as they attend to adolescents. This is capitalized with huge age differences between providers and the adolescents. (Ali et al., 2013; Kennedy et al.,2013

Funding opportunities supporting adolescents and young women programs/interventions

There is increasingly wide recognition of adolescents and youth needs globally and nationally. All In! to end Adolescent AIDS is one platform that enhances collaboration among stakeholders.These stakeholders include; the United Nations Children's Fund(UNICEF);the Joint United Nations Program on HIV and AIDS(UNAIDS)the United Nations Population Fund(UNFPA),the World Health Organization, President's Emergency Plan for AIDS Relief(PEPFAR),the Global Fund to Fight AIDS, Tuberculosis and Malaria(Global Fund),the MTV Staying Alive Foundation ,and the adolescent and youth movement representing the HIV Young Leaders Fund (UNAIDS,2015)

The platform unites actors accelerate the reduction in AIDS-related deaths and new HIV infection among adolescents by 2020 with the quest to end AIDS epidemic by 2030. The collaboration has led to young people be included as a priority in the major documents and recommendations for the post- 2015 development framework (UNAIDS, 2015)

Despite the increased recognition of adolescents and youth needs globally and nationally, failure to reach set targets has been one of the documented challenges which calls for more action (Fleischman, J., & Peck, K. 2015). Lack or inadequate data for adolescents and youth has led to the magnitude of the HIV to be invisible resulting into difficulties planning programs and interventions. Promising practices are starting to take place in some countries where data for the ages 10-14 and 15-19 years are available in health facilities (UNAIDS, 2015).

DREAMS is delivering a core package of evidence-based interventions in interventions in 10 countries which are Kenya, Lesotho, Malawi, Mozambique, South Africa, Swaziland, Tanzania, Uganda, Zambia, and Zimbabwe.This initiative receives support from PEPFAR, the Bill & Melinda Gates Foundation, Girl Effect, Johnson& Johnson, Gilead Sciences, and ViiV Healthcare (Fleischman, J., & Peck, K. 2015).

The interventions are expected to go beyond health sectors and address fundamental drivers with a focus on 15 to 24 year- old females. However, there are challenges on the efficiency of the interventions given the hot spot approach which DREAMS will use which does not cover the whole region, and not many studies have been done to evaluate this type of approach (Fleischman, J., & Peck, K. 2015). The other challenge related to DREAMS implementation how to sustaining efforts given the first funds are only for two years. However, the assumption is that the initial gains will spark interest for more donors to support the programs or interventions (Fleischman, J., & Peck, K. 2015).

Chapter 4: Discussion, recommendations, and conclusions

Discussion

Adolescents and young women psychosocial interventions are increasingly receiving attention. In this review, ten studies conducted between 2010 and 2015 met the inclusion criteria. The studies concentration in the span of 5 years shows that psychosocial issues are becoming more important and highly recognized. While no single intervention has existed, the review indicates that three critical players for psychosocial support interventions include adolescents or young women, family, and healthcare workers.The triads have been singled out in most interventions to support psychosocial needs in both clinical and community settings.

Improved communication is one key outcome of the psychosocial interventions which has an impact on drug adherence, trust and improved self-confidence in both the caregivers and adolescents.Worse communication and higher caregiver stress were singled out as some possible contributors to nonadherence to treatment (Simon et al.,2007)

Well-established communication can consequently facilitate a spillover effect occurring in the household which may result in acquiring the new meaning of life, reduced stigma, and individual empowerment.The family involvement could be a better way of reaching out to other members to know their HIV serostatus and remain healthy. Improved communication leads to a transition from negative to positive messaging which creates safe space for both caregivers and adolescents/young women.The findings are in agreement with Simoni et al.,2007 who identified that isolated family disruptions and characteristics of caregiver towards child affect drug adherence (Amzel et.al.,2013)

Medication fatigue is one challenge in particular among the adolescents and young women that require repeated knowledge especially when roles change to adulthood

(UNICEF,2016).Repeated and constant exposure to HIV and AIDS information may support increased adherence to treatment. Interventions such as teen clubs and support groups contribute lowly to behavior change but are good avenues for information especially when professionals are part of the discussions.

The absence of dedicated facilities and personnel to provide care for adolescents contributes to the setback in managing this group. Pediatricians develop a trusting long lasting relationship with adolescents which may be challenging to properly transition the care to adult-oriented physicians who may not be comfortable dealing with the adolescent's issues (Coovadia, H., & Mantell, J. E. 2010; Tanner et.al.,2014).

This review also contributes to understanding the psychosocial interventions for adolescents and young women in SSA through describing what interventions are available, outlining the perspectives from the adolescents which may not be the case with the general public. While WHO defines psychosocial support as ongoing addressing psychological and social problems of HIV-infected individuals, their partners, families, and caregivers. By searching for psychosocial interventions /strategies, it is hard to come up with articles specifically talking about HIV and AIDS psychosocial interventions, but there were other related topics such as mental health or management of mental disorders other than routine care for adolescents living with HIV and AIDS.

Evidence-based interventions have focused more on adults.Deliberate efforts should be made to have studies that focus on adolescents and young women that are implemented on a wider scale to assess feasibility, acceptability and with well-documented processes for easy replication. The process should be consultative in nature to isolate different needs presented by key players such as caregivers, adolescents and young women and health workers. Learning should involve some element of fun and active involvement. The study calls for a well-established/laid up structure to guide every step of implementation.

The review suggests that there is need to refocus where to invest. Traditionally programs/interventions have focused on where there are more risks associated, but this review proposes going beyond the risks and focusing on the assets that are available and capitalize on them. Interventions for adolescents and young women should carry names that give hope to attract the users.

Like many studies, this review highlights the importance of disclosure in HIV and AIDS management which should follow an incremental model aligned with life course activities. The studies have strongly supported the use of simple strategies which may be deemed necessary by the adolescents or caregivers (Butler et.al.,2009).

Clear guidelines to proper transitioning should be well documented and followed in taking care of the adolescents and young women care.

Strengths and limitations

We used an extensive search strategy including multiple databases. This review includes data from a range of countries and settings, which lends support to the generalizability of findings, at least within SSA, but also means that interventions/programs offered are varied.

However, the majority of studies identified by this review were cross-sectional in clinical settings, limiting the ability to infer causal relationships between adherence and interventions. These results, therefore, emphasize the need for rigorous prospective studies that measure the effect of interventions on adherence to treatment by adolescents and young women.

Recommendations

- No single intervention will suffice the psychological requirements of the adolescents and young women as such the future of public health planning and actions should be flexible and adapted to suit the context in which the intervention applies.
- Given the different roles parties like family members and adolescents themselves may take, the involvement of these two sides is a prerequisite to successful interventions. However, the programs should always create safe space for the various parties as needed.
- Evidence-based interventions should be adapted and modified to suit different cultural settings while maintaining the core issues in order not to lose the proven evidence.
- Adolescents and young women should be supported to create secure networks that will give a voice at the table when debating for decisions.
- Disclosure of HIV test results should be a gradual, incremental process which matches with life course. For this to be successful, deliberate programs should target caregivers' empowerment such as being knowledgeable of the HIV and AIDS issues while upholding truth to avoid creating unnecessary expectations from the adolescents and young women. Help Caregivers to cope with stress related to managing adolescents and young women living with HIV and AIDS.
- Psychosocial programs should incorporate well laid out steps for transitioning from pediatric to adult care.
- There is need to strengthen links between health facilities and communities to facilitate continuum of care from childhood, adolescence and into adult care
- Use positive interventions that capitalize on the strengths of the adolescents and young women other than just focusing on the risks associated with the adolescents and young women living with HIV and AIDS.

- Intensify monitoring and evaluation systems to improve data collection that will eventually help to set realistic targets, allocate adequate resources and report on the successes.
- The gaps in literature is an opportunity for donors to institute rigorous evaluations of the interventions to isolate best practices and identify cost-effective interventions with maximum impact on adolescents and young women affected by HIV and AIDS.

Conclusions

This systematic review identified several interventions associated with psychosocial support for adolescents and young women through adapting existing adult interventions. However, very few reports are available documenting interventions taking place across the SSA region.

Interventions targeting adolescents and young women living with HIV and AIDS are slowly receiving attention in SSA with increased political will and support from the major donors.

The research findings further suggest that symbiotic relationships among the adolescents, young women, caregivers and health workers have a greater influence on implementing effective programs targeting disclosure and adherence to treatment. Early commencement of disclosure alongside the developmental process is key to safer transitioning from pediatric to adult care. However, incomplete reporting of the interventions from the other countries limit the application of previous experiences. Universal guidelines would enable future psychosocial programs to benefit from past endeavors. Studies in this review focused on the group of adolescents and young women getting services from the clinics; future research can focus on psychosocial interventions for adolescents and young women from other avenues who have different dynamics from clinical settings. As part of continuous monitoring and evaluation assessing readiness and ability to adhere to antiretroviral treatment should routinely include psychosocial needs of the adolescents and young women.

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