

A Review on Contextualizing Health Care for Adolescents living with HIV

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ABSTRACT

Adolescents Living with HIV (ALHIV) grow up in circumstances quite different from those of their other no-infected counterparts with both psychological, economic, social and sexuality challenges and vulnerabilities. They have an urgent need for improved approaches to address their specific health care needs. Improving outcomes for adolescents and reaching global targets for an AIDS FREE generation by 2030 will require evidence-based interventions and policies. However, there is a growing area of research in HIV where a considerable amount of efforts is still needed to inform the understanding of what works for this population. Evidence indicates higher rates of loss to follow up, and poor adherence, as well as increased needs for psychosocial support among ALHIV. This population group continues to be underserved by current HIV services and have significantly worse access to and coverage of ART. A number of care models have been designed over the years to improve health outcomes among this group of population. Effective establishment of HIV treatment demands that HIV diagnosis is followed by timely linkage to outpatient care, prompt initiation of anti-retroviral therapy and prophylactic medications when indicated, and subsequent adherence to prescribed medications as revealed in individual studies. Certainty of uptake and successful outcomes demands that, patients must progress through a sequence of steps taking into account environmental, patients predisposition, perceived and enabling factors as well as health behaviour models

Keyword: Adolescents, models, context, poor adherence, HIV services, anti-retroviral therapy.

INTRODUCTION

This review focuses on Adolescent Living with HIV (ALHIV). Adolescent has been defined as a translational stage that bridges the gap between childhood and adulthood [1]. According to literature, adolescent has been described as the period where most people develop biological, psychological, sexuality and psycho-social sensitivity [2]. Adolescence is typically a period of experimentation, new experiences, and vulnerability. As a result of sexuality exploitation associated with adolescents, access to sexual and reproductive health information and services has been prioritized and has become increasingly important [3]. Despite the recognized need for protection from HIV infections and other reproductive health risks, their age, social and economic status limit adolescent access to information and services in that context [4]. Sexually active life as part of adolescence continues with a high burden of HIV, therefore adolescence offers a window of opportunity to intervene early. Comprehensive data are vital to modelling accurate HIV-related messages and services before risky behaviours are formed and become entrenched [4].

Numerous global declarations and commitments, with specific goals and targets, have been made and set by world leaders and governments to respond to the HIV and AIDS epidemic since 2000 [5]. Most of the management policies and goals regarding adolescents are general in content, however; the United Nations General Assembly Special Session on HIV and AIDS (UNGASS) reports in 2001 explicitly included a target to reduce the prevalence of HIV in young people aged 15–24 years globally by 25% targeted in 2010 and to increase young people's access to crucial HIV prevention information, skills, and services in order to reach 95% of those in need [5]. In 2015, a report by the UN Secretary General's High-Level Advisory Panel on the Post Millennium Development Goals Agenda emphasized equity, empowerment, and engagement of adolescents and youth in strengthening of data as central drivers of revolution in their next development agenda [6].

Despite the goals, targets and global commitments for adolescents, the implications and accountabilities are rarely adolescents-targeted. Also, adolescent-specific data are limited which incurs a serious barrier to measuring and monitoring progress. Although the international reporting process recommends reporting on disaggregated data on adolescents and youth, little of these data are published in global or national progress reports [7a]. Consequently, compared with infants and adults, less is known about the burden of HIV and AIDS among adolescents and the situation progress to date in addressing their needs for HIV prevention, care, and treatment services.

Background and Significance

Globally, an estimated 35.3 million people were living with HIV as at 2012, 2.1 million, of these estimated number were adolescents aged 10–19 years, of which the majority were girls accounting for 56% of the total 2.1 million estimated [5]. The gender disparity has persisted over time, with this number plateauing over the past years. According to literature, majority of this adolescent HIV burden, entirely 85.0% are resident in Sub-Saharan Africa. Trend analysis regarding HIV survival rates indicate that age-related HIV/AIDS mortality is reducing for all age groups except that of adolescents [7a]. [5], which reported that about 300,000 new infections occurred among adolescents aged 15–19 years, which accounted for about 13% of the 2.3 million new infections globally. Along with the HIV/AIDS epidemic, a number of interventions and global goals have been agreed upon, notably to reduce the HIV prevalence in young people; to provide adequate information, life skills, health, and social services; and to implement policies to reduce young people's vulnerability [8]. Despite efforts, policy formulation and implementations, levels of knowledge of HIV among adolescents and young adults are appallingly low, especially in the worst affected countries; inconsistent compliance and poor practices of policies. Recent survey in countries with generalized epidemics [5], show that, in most of the countries, less than half of adolescent, aged 15–19 years, have a basic understanding of HIV. This falls far short of the 95% target agreed in 2001 at the UNGASS. Reasonably, the vision 'ZERO New Infections; ZERO Deaths; ZERO Discrimination' formed by UNICEF for their 2020 target face the same fate. These differences persist in nearly all countries with available data [5]. Global and regional averages can mask individual country progress. A number of countries show data of enhanced knowledge about HIV prevention. For example, Belarus, Guyana, Jamaica, Namibia, Rwanda, Serbia, Swaziland, Trinidad and Tobago, Vietnam, and Zimbabwe witnessed significant increases in knowledge about HIV prevention to levels above 50% among adolescent girls, and similar increases among adolescent boys in Rwanda and Namibia in the periods of 2010 and 2012 [7].

The life of ALHIV

ALHIV grow up in circumstances quite different from those of their other no-infected counterparts with both psychological, economic, social and sexuality challenge vulnerabilities

[4]. They have an urgent need for improved approaches to address their specific health care needs [1]. While several studies have explored in details the needs and challenges of adolescents [3],[4],[2], few studies have reported on the challenges ALHIV face in reality [9], [5]. Limited or no studies have explored the overall quality of life of ALHIV in terms of the five-fold needs in life (according to Abraham Maslow's theory of needs). Entirely all studies reporting on the life of ALHIV either talks about their social disadvantages, psychological vulnerabilities, environmental unfriendliness or compromised health status. Improving outcomes for adolescents and reaching global targets for an AIDS FREE generation by 2030 [10] will require evidence-based interventions and policies. However, there is a growing area of research in HIV and a considerable amount of efforts is still needed to inform the understanding of what works for this population.

Evidence indicates higher rates of loss to follow up [11], [12], and poor adherence [13], as well as increased needs for psychosocial support among ALHIV [14]. This population group continues to be underserved by current HIV services and have significantly worse access to and coverage of ART [6]. A number of care models have been designed over the years to improve health outcomes among this group of population.

HIV testing and Disclosure models

HIV testing is the key entry point for many HIV prevention interventions and is crucial for access to care and treatment [15]. Irrespective of route of HIV acquisition, underutilization of testing and counselling services (HTC) results in late diagnosis; increasing uptake of HTC consequently leads to early diagnosis and more effective care. Although reporting data on adolescents receiving treatment is limited, adolescents' access to and uptake of treatment is often reported to be lower compared to other age groups [16], [13]. It is urgent that ALHIV are recognized and signed-up in treatment interventions with clear and consistent linkages to care and support. Due to the increasing availability of antiretroviral therapy (ART) and prevention interventions, early diagnosis and linkage to care is able to reduce transmission and improve health outcomes [13], thereby decreasing adolescent morbidity and mortality. Although adolescents represent one of the wildest rising segments of the population to acquire HIV with diverse needs from those of children and adults, there is paucity of data focusing on this group [15]. Despite the fact that there are guidance on provider initiated testing and counselling (PITC), Voluntary Counselling Test (VCT) and prevention of mother-to-child transmission (PMTCT), these guidelines do not focus specifically on adolescents' issues [5], [17]. The development of WHO guidelines on adolescent HIV testing and counselling serves to fill an important gap which plays a critical role in prevention and treatment efforts [7a]. However guidelines recommended to assist policy makers to adapt to strategies for HTC among adolescents, cognitive, personal and a regulatory framework on informed consent based on adolescents' right; health-care decision-making requiring individuals to exercise their right to independent decision-making, may limit HTC service diversity and generalization.

Generally, studies of adolescents have found that disclosure has a significant association with improved clinical outcomes as measured by increased CD4 cell counts [18], decreased number of partners [19], and better linkage to care and adherence [20]. Disclosure decisions are often made to tell everyone (making HIV status a central attribute of one's identity), no one (requiring strategies for securing social support while remaining anonymous) or some people (requiring strategic decisions based on context) [21]. Knowing that disclosure decisions are central to personal identity, disclosure policies and strategies and as well as future researches should focus on communication strategies to present a coherent identity. Several studies have suggested disclosure strategies at different sites across different level including group counselling [22], structured support groups [23], one-on-one counselling, peer-led counselling

[24], community-based interventions with disclosure component [25], individual counselling based intervention [26], and online computer or mobile phone base intervention [27].

ART initiation and Linkage to care models

Following HIV diagnosis, several studies [13], [28] revealed that linkage to outpatient treatment, antiretroviral initiation, and longitudinal retention in care characterize the basis for successful management. Effective establishment of HIV treatment demands that HIV diagnosis is followed by timely linkage to outpatient care, prompt initiation of ART and prophylactic medications when indicated, and subsequent adherence to prescribed medications as revealed in individual studies [29], [30], [31]. Certainty of uptake and successful outcomes demands that, patients must progress through a sequence of steps taking into account environmental, patients predisposing factors, perceived and enabling factors as well as health behaviour models as proposed in a study by Ulett et al. [28].

Unfortunately for ALHIV, studies reporting on ART initiation following diagnosis and linkage to care have its bases and concept not specific to adolescents. On the demands of ART initiation programs and subsequent long-term retention and successful outcome as reported by Ulett et al.[28], the contributing environmental, personal and health models is not well documented among ALHIV. However, the emphasis rely more on adults and children [32], [12]. A study conducted in the USA by [33] highlighted areas that could be explored for targeted interventions resulting in earlier diagnosis, ART initiation, improved adherence and retention in care among HIV-infected adolescents and young adults. They conclude that although there have been significant developments in HIV prevention with pre-exposure prophylaxis (PrEP) and treatment as prevention for adults, these interventions have not been sufficiently investigated, tailored, or scaled for youth. Their cascade highlighted that current efforts for treating already-infected adolescents and young adults remain a challenge. Most interventions to address the cascade have been developed for adults. These are not particularly generalizable to youth struggling with identity formation, economic hardships, and unstable housing. Youth-focused interventions are necessary to improve the HIV cascade for adolescents and young adults.

Management and treatment models for ALHIV

A combination of factors interdependent on themselves comes to play when conceptualizing and contextualizing management models for ALHIV (Figure 1).

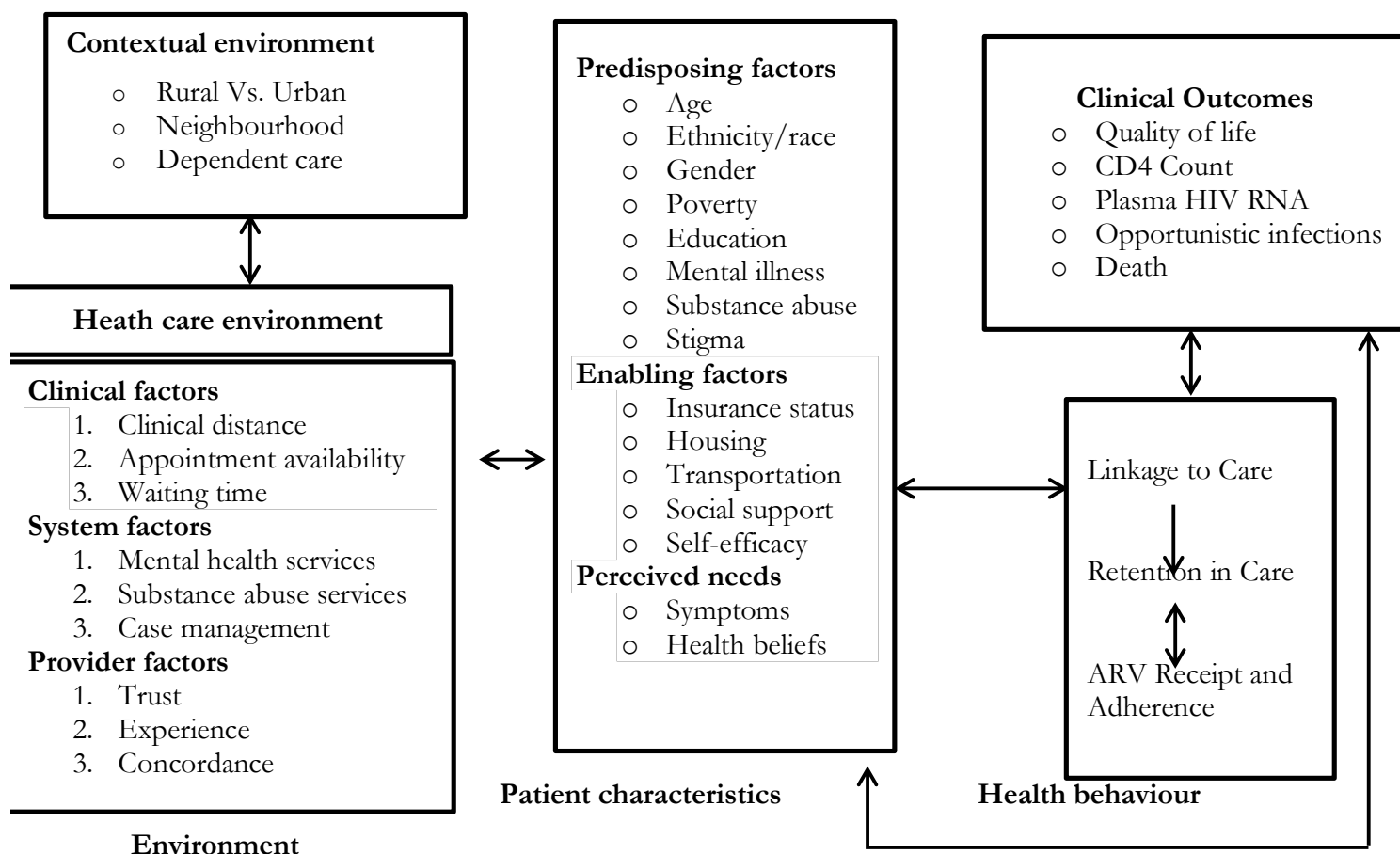


Fig 1.2 Adaptation of the behavioural model of health services operation to provide a theoretical framework to evaluate the relationships between patient characteristics, their background and health care environmental factors in contributing to health behaviours outlined in the “HIV management success” that ultimately influence clinical outcomes.

Source: Adapted from Ulett et al. (2009)

From literature search and WHO recommendations, two major intervention programs to support adherence to ART and retention in care included training of health workers and a range of community-based approaches. Adolescent management and care models for ALHIV happen to be one of the major areas mostly explored by researchers. Suggestions for improvements in services for ALHIV included age-appropriate support, material support (clothing, food, support for orphans), more protection from the damaging effects of stigma and discrimination, more comprehensive information about all the ways that HIV is transmitted, dedicated spaces and activities for ALHIV where they can be with peers who understand what it is like to live with HIV, and with educational opportunities for those who do not attend school [7a], [7b]. However despite effort made in the area of ALHIV care and management, age-disaggregated data on coverage of antiretroviral treatment (ART) among adolescents are lacking. Retaining adolescents in care is particularly challenging. Dealing with the prospect of lifelong treatment is daunting at any time in life, but for adolescent this comes on top of piloting the usual challenges of their developing maturity; emotionally, psychologically, physically, and sexually [5].

Revised theoretical model from reviewing literature

Despite significant HIV burden among adolescent and increased attention to integration of management services, there is uncertain evidence on the implementation of adolescent HIV management programs for adolescents living with HIV, nonetheless integrating such programs will improve outcome among ALHIV. Several studies have accounted for the successes of HIV clinics following the integration of secondary interventions such as peer support groups, mobile phone sections, community interventions [8], Adolescent Coordinated Transition (ACT) models [34] and family centred models [35].

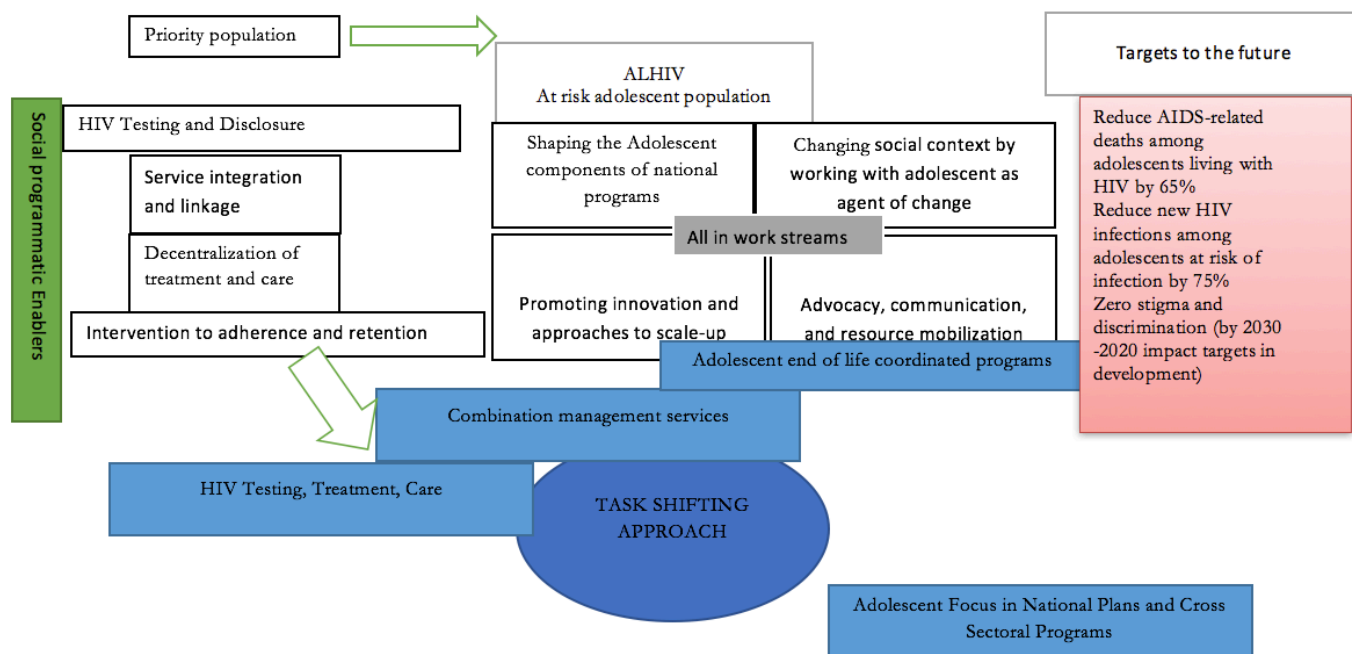


Figure 1.1: All in one strategic management model for ALHIV

RECOMMENDATIONS AND FUTURE DIRECTIONS

The physiognomies and requirements of adolescents cannot be addressed by applying guidelines based on evidence and recommendations relating to paediatric or adult populations. Moreover, adolescents themselves are not a homogeneous group. Physical and psychological (cognitive and emotional) development varies among adolescents, and differing social and cultural factors as well as their evolving capacities can affect both their ability to make important personal decisions and their access to services. For these reasons guidelines should take into consideration the range of adolescents' needs and issues surrounding their health. Again Stakeholders involved in clinical and operational research and policy formulation in adolescent HIV care can support the successful implementation of this task by actively engaging the adolescent and the established priorities and integrating them into their activities for adolescents.

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