

HIV and adolescents: guidance for HIV testing and counselling and care for adolescents living with HIV

ANNEX 11 (b): Values and preferences: ALHIV care, treatment, and attitudes – literature review

**Care and treatment values, preferences, and attitudes of adolescents living with HIV:
a review of qualitative literature**

Introduction

Globally, over two million adolescents aged 10–19, and five million young people aged 15–24 are living with HIV. Many factors contribute to this high prevalence: from low levels testing and linkage to care and prevention, to poor retention in care and adherence to antiretroviral treatment (ART) in this population. By increasing adolescent-focused treatment and care services, adolescents and young people (10–24 years) will be more likely to be better engaged in care and treatment, thus reducing morbidity and mortality in this greatly underserved population.

Adolescents living with HIV (ALHIV) have been infected with HIV through one of two pathways: through vertical transmission (from mother to child via pregnancy or breastfeeding) or through horizontal transmission (from either sexual or non-sexual methods, e.g. injecting drug use, exposure to infected blood, medical procedures).

For these guidelines, two other reviews were conducted to examine the availability of HIV testing and counselling services for adolescents and services providing HIV care and treatment for ALHIV. These reviews have indicated significant barriers and facilitators to improving the provision of and access to health care and HIV services for ALHIV; however, few of the included studies included the perceptions, values, and preferences of the adolescents themselves.

This systematic review was conducted to look specifically at published literature on research conducted directly with ALHIV aimed at gaining their experiences with, perceptions of, and/or desires to access various types of HIV services. The review was limited to literature published in the last five years, and was conducted using PubMed (including MEDLINE), Google Scholar, and Google. The search method employed combinations of terms for adolescents, HIV, care, service, and values and preferences. Of the 42 qualified studies, 74% were descriptive (31), while only 19% (8) were quasi-experimental and 7% (3) were RCTs. Forty per cent (17) of the studies were conducted in middle or low-income countries, while 60% (25) of the studies were conducted in high-income countries (although a majority of these were in rural or low-income areas or examined significantly underserved populations).

The results from this review will inform the development of World Health Organization (WHO) guidelines on the provision of health and HIV care to adolescents living with HIV.

Within this literature review, the following questions were explored:

- What are adolescent perceptions of and attitudes toward health-care and HIV service delivery?
- What do adolescents perceive and value in adolescent-focused models or interventions recently developed and/or studied?

- What do adolescents perceive and value as facilitators to disclosure, adopting preventative behaviours (secondary prevention), accessing care, adhering to ART, being retained in care, and successfully transitioning from paediatric and/or adolescent HIV care services to adult HIV care services?
- What do adolescents perceive as barriers to disclosure, adopting preventative behaviours (secondary prevention), accessing care, adhering to ART, being retained in care, and successfully transitioning from paediatric and/or adolescent HIV care services to adult HIV care services?

Methods

A systematic review of literature published in the last five years was conducted using PubMed (including MEDLINE), Google Scholar, and Google. The search method employed combinations of terms for adolescents, HIV, care, service, and values and preferences (Table 1).

Table 1. PubMed search filters and results

Search terms and filters	Results
(((("hiv"[MeSH Terms] OR "hiv"[All Fields]) OR ("hiv"[MeSH Terms] OR "hiv"[All Fields] OR ("human"[All Fields] AND "immunodeficiency"[All Fields] AND "virus"[All Fields]) OR "human immunodeficiency virus"[All Fields])) AND (((("adolescent"[MeSH Terms] OR "adolescent"[All Fields]) OR ("adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "adolescents"[All Fields])) OR ("adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "youth"[All Fields])) OR (young[All Fields] AND ("persons"[MeSH Terms] OR "persons"[All Fields] OR "people"[All Fields])))) AND ((care[All Fields] OR services[All Fields]) OR service[All Fields]) AND (((values[All Fields] OR preferences[All Fields]) OR ("perception"[MeSH Terms] OR "perception"[All Fields] OR "perceptions"[All Fields])) OR opinions[All Fields]) OR ("attitude"[MeSH Terms] OR "attitude"[All Fields] OR "attitudes"[All Fields])) AND ("2008/03/02"[PDat] : "2013/02/28"[PDat])	1090

Inclusion criteria

Studies were considered eligible for inclusion based on the following criteria:

1. Studies may include randomized controlled trials, observational studies, case reports, expert opinion pieces
2. Unpublished studies and studies published in non-English language journals
3. Studies must include discussion or reports of youth between the ages of 10-24 years
4. Studies considered eligible for inclusion must pertain to one of the following topics:
 - Description, comparison, or evaluation of a study aimed at gaining the health-care values, preferences, attitudes, or perceptions of adolescents living with HIV
 - Perceived and actual barriers to adopting preventative behaviours
 - Perceived and actual barriers to accessing HIV and health care and retention in care
 - Perceived and actual barriers to adherence to ART
 - Perceived and actual barriers to successful transition from paediatric and/or adolescent services to adult services
 - Perceived and actual facilitators to adopting preventative behaviours
 - Perceived and actual facilitators to accessing HIV and health care and retention in care
 - Perceived and actual facilitators to adherence to ART
 - Perceived and actual facilitators to successful transition from paediatric and/or adolescent services to adult services

5. Published and unpublished articles or reports entered into the databases between February 2008 and February 2013 were included in the review. No other limitations were used.

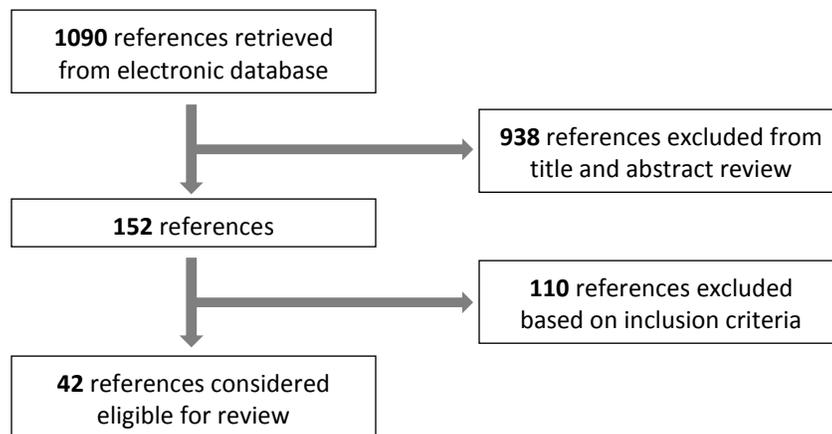
Data Extraction

Data from the articles were extracted and organized into a table by study design, methods used, sample size and population factors, the inclusion of comparison or additional groups (if relevant), location(s) of the study, topics addressed, and main conclusions or outcomes. The studies were ranked according to their study design type and quality of evidence using the same four-point scale (with four representing the highest quality) as other systematic reviews: 4 = randomized controlled trials (RCTs); 3 = quasi-experimental, involving a comparison group; 2 = descriptive, with no comparison group; 1 = reviews, case studies, or grey literature.

Results

The literature search retrieved 1090 references. Of these 1090 references, 938 were excluded following title and abstract review. Of the remaining 152, a further 110 were excluded based on retrieval of the full paper and based on the previously mentioned inclusion criteria. Forty-two references remained eligible and were included in the review (figure 1).

Figure 1. Inclusion flow diagram



Description of Included Studies

As the purpose of this review was to examine adolescent values, preferences, and perceptions, it is not surprising that the 74% of studies were descriptive (31), while only 19% (8) were quasi-experimental and 7% (3) were RCTs. Only 40% (17) of the studies were conducted in middle or low-income countries, while 60% (25) of the studies were conducted in high-income countries (although a majority of these were in rural or low-income areas or examined significantly underserved populations).

Table 2. Countries and regions represented in the studies*

Countries and regions represented	No. of studies per country or region
Africa	17
Botswana	1
Ethiopia	1
Kenya	1
Malawi	1
South Africa	5
Tanzania	3
Uganda	4
Zambia	1
Americas	19
USA (& Puerto Rico)	19
Asia	3
Australia	1
China	2
Europe	6
Romania	1
Switzerland	2
United Kingdom	3

* The total numbers do not correspond to the total number of articles; some references were multi-country studies.

Key findings

Within the literature review, five key areas were identified:

Confidentiality and disclosure. For ALHIV privacy and confidentiality are major concerns in the provision of care. Adolescents are particularly sensitive to the stigma associated with HIV, and it is important for providers to offer a safe environment that ensures the privacy of young patients or clients and confidentiality of their discussions, decisions, test results, and treatment. The literature discussed disclosure in three ways: disclosure of parent or guardian’s serostatus to the adolescent, disclosure of the adolescent’s status by the parent or guardian, or disclosure of the adolescent to others. Major facilitators to the latter included the recognition by health-care providers that disclosure is a gradual process that should be based on the adolescent’s development and readiness to reveal their HIV status to others, and that this process requires a wide range of support – from providers, caregivers, peers, and the community – and skills development to increase self-confidence, self-efficacy, and empowerment. The major barriers to disclosure were fear of unintended or unwanted disclosure by teachers, parents, or friends, or because of inadequate privacy in clinics or pharmacies; and fear of negative reactions from family, friends, and the community.

Table 3. Confidentiality and disclosure

Confidentiality and Disclosure	
PERCEIVED / ACTUAL FACILITATORS	
Structural / facility-based / programming	<ul style="list-style-type: none"> • Strategies and support for disclosure to friends, family, partners (33, 32) • Disclosure as a process, not a one-time event (33, 20) • Disclosure to some, not all (20) • 'The health-care team should systematically address the issue of disclosure with the adolescent and his family (or foster parents), the aim being to balance the right of the adolescent and that of the adolescent's family to maintain privacy against the concerns of sexual partners, as well as the adolescent's interest in divulging HIV status to relatives, school staff, and friends.' (30) • Programming areas: (27) <ul style="list-style-type: none"> ○ providing immediate post-diagnosis support (27) ○ stigma reduction (within the child's "circles of care") (27) ○ capacity building (of the caregivers and children to meet their own PSS needs) (27)

	<ul style="list-style-type: none"> ○ addressing grief (as a process) (27) ○ promoting peer support (through forums for interaction and peer support) (27) ● Peer support groups should be immediately available the child is disclosed to (27) ● Programmes attempted to address stigma in social environments, such as communities and schools (27) ● Suggested gradual, partial disclosure based on child's readiness (27) ● Psychosocial support (PSS) for disclosure (27) ● Structured disclosure (18) ● Services that encourage empowerment (18)
Knowledge	<ul style="list-style-type: none"> ● Disclosure strategies (33) <ul style="list-style-type: none"> ○ To adolescent ○ By adolescent ● Understanding the meaning of disclosure (33) ● Knowledge of HIV (32) ● Disclosure as an adherence strategy (28)
Caregivers (parent, guardian, etc.)	<ul style="list-style-type: none"> ● Passive disclosure: 'the decision to disclose was most often taken by the parents/foster parents who would frequently make the disclosure themselves or advise their children how to do so (e.g., to school staff)' (30) ● Suggested gradual, partial disclosure based on child's readiness (27) ● Tell the truth (27)
Psycho-emotional factors	<ul style="list-style-type: none"> ● Trust (33, 19, 17) ● Autonomy / power (33) ● Construction of identity (32) ● Relationship with HIV (32) ● Motivational readiness (31) ● Self-efficacy (31) ● Group and individual counselling and support help ALHIV fend off internalized stigma (27) ● Grief support (27) ● Psychosocial support (PSS) for disclosure (27) ● Positive views of life: strong family relationships, support from family/caregivers, strong friendships, clinic as positive support, participating in activities (including school) (24) ● Positive views of the future: normal lives, having families (24) ● Self-esteem/self-worth/self-confidence (20) ● Developing disclosure skills (20, 16)
Social / Sexuality and relationships	<ul style="list-style-type: none"> ● Active disclosure: 'refers to the adolescent's decision to reveal his or her condition directly (e.g., to friends, or sexual partners). ● psychosocial support (PSS) for disclosure, stigma, and grief (27) ● Families (18, 7) ● Support groups (18) ● Peer support (16, 8, 7)
PERCEIVED / ACTUAL BARRIERS	
Therapeutic	<ul style="list-style-type: none"> ● Non-compliance often connected with fear of disclosure (36, 4)
Structural / facility-based / programming	<ul style="list-style-type: none"> ● Lack of communication and impersonal interactions with health-care providers regarding disclosure (32) ● Lack of privacy at clinics - particularly if parents are required to accompany them (18) ● Weak health systems, negative health-care providers' attitudes, poor evaluation of adolescents' abilities to receive and process information (18)
Knowledge	<ul style="list-style-type: none"> ● No understanding of the meaning of HIV serostatus disclosure (33) ● Conflicting ideas about ART and the restriction it places on their lives (32) ● Knowledge of HIV (32) ● Lack of knowledge in the general public may lead to inappropriate reactions (30) ● Myths and misconceptions (18, 13) ● Lack of tailored messages (18) ● Lack of communication directly with adolescent (18) ● Information from friends is wrong (18)
Caregivers (parent, guardian, etc.)	<ul style="list-style-type: none"> ● HIV-positive mothers 'were more insistent on not disclosing even if the adolescent wanted to' (30) ● Teachers who do not treat the disclosure as privileged information (30) ● Mother's afraid to disclose their own status to their HIV-infected children (fear that their child would hate them, not sure of the reaction) (29) ● Family disclosure to child (often not related to the child's capabilities, e.g. personal reasons, or to protect the child from stigma) (27)
Psycho-emotional factors	<ul style="list-style-type: none"> ● Trust (19) ● Fear of negative repercussions / reactions from disclosure (40, 30) ● Fear of unintended/unwanted disclosure (8) ● Indecision because of difficulty accepting their infection and do not feel like 'normal' adolescents (30) ● How much to disclose (33) ● Support versus vulnerability (33) ● Relationship with HIV (32)

	<ul style="list-style-type: none"> • Construction of identity (32) • Depression (31, 21) • Fear of rejection, discrimination (30, 19) • Seropositivity is a very personal and intimate (30) • Hiding the disease was perpetuating the stigmatization that makes their lives more difficult (30) • Age-specific disclosure issues: (30) <ul style="list-style-type: none"> ○ younger adolescents - attitudes toward disclosure mostly related to attitudes of the parents, particularly the mother. (30) ○ older adolescents - 'engaged in their search for autonomy, tended to decide independently what to say and to whom'. (30) • Suggested gradual, partial disclosure based on child's readiness (27) • Stressors (26) • Negative aspects of life: HIV physically and emotionally painful, affected social interactions, isolation from others, keeping status a secret (fears of stigma), family violence, poverty, crime and drugs, verbal and physical abuse) (24) • Stigma and emotions related to disclosure (difficulty keeping it a secret, fear of a negative reaction to disclosure of status), (23): • Trust issues related to disclosure (barrier: trusting the person they disclose to, unsure how to handle disclosure even to someone they trust) (23) • Reasons for disclosing (desiring a closer relationship with someone, warn others of the risk) (23) • Lack of self-esteem/self-worth/self-confidence (20) • Emotional abuse as a result of disclosure (20)
Social / sexuality and relationships	<ul style="list-style-type: none"> • Fear of stigma and discrimination (33, 30, 18, 3) • Hiding the disease was perpetuating the stigmatization that makes their lives more difficult (30) • Protecting loved one from distressing information (33) • Telling partners (33) • Rejection and lack of support (family, friends, significant others) (20) • Lack of age-appropriate disclosure (18) • Non-disclosure from parents (18) • Poor or no social networks (18)

Accessing care. Access to care—broadly defined to include not only physical access to treatment and care, but also financial and social support—is important for AHLIV. Those adolescents studied wanted not only universal access to care, but also care designed specifically for their needs and provided in a youth-friendly atmosphere. Positive trusting relationships with and between parents or guardians and health-care providers, and the availability of counselling and support were the primary facilitators of adolescents accessing care. Provider and community stigma, as well as inadequate or misinformation about HIV were found to be major barriers to utilization of available services.

Table 4. Accessing care

Accessing Care	
PERCEIVED / ACTUAL FACILITATORS	
Protective behaviours	<ul style="list-style-type: none"> • Rejecting difference, portraying positivity and health, HIV is a small part of life (19) • Protective behaviours used to deal with <u>stigma</u>: (35) <ul style="list-style-type: none"> ○ seek treatment earlier for common conditions (I visit the clinic every time I am sick (seek treatment earlier for minor conditions) (35) ○ I don't allow myself to get sick (even get flu injections) (35)
Therapeutic	<ul style="list-style-type: none"> • ART extends lives and provides opportunities for PLHIV to actively engage in a range of activities (family and community) (13)
Structural / facility-based / programming	<ul style="list-style-type: none"> • Measures implemented by clinics to help with transportation (40) • Support from family and day-care centres/orphanages (40) • Improved training and simple measures employed at clinics (40) • Communication with clients/patients (39) • Programmes attempted to address stigma in social environments, such as communities and schools (27) • Confidentiality/privacy (26) • the importance of conducting treatment readiness (26) • HIV services (18) • Supportive health-care professionals (7)
Knowledge	<ul style="list-style-type: none"> • Inclusion of normalizing statements before asking for sensitive information (content includes: dose timing, disclosure, stigma, and food insecurity) (37)

	<ul style="list-style-type: none"> Defining and understanding terms: 'missing a dose', 'having a side effect'; understanding the difference between 'occasionally' and 'almost never' (37) Knowledge of HIV (32)
Caregivers (parent, guardian, etc.)	<ul style="list-style-type: none"> Seeing children's health improve on treatment (40) Well-educated caregiver (3) Good relationship between caregiver and health-care provider (3)
Psycho-emotional factors	<ul style="list-style-type: none"> Trust in physicians (17) Trust in health-care system (17) Attitudes about HIV medication (17) better public knowledge about HIV would facilitate uptake (40) Construction of identity (32) Relationship with HIV (32) Motivational readiness (31) Self-efficacy (31, 21, 17, 16, 11, 9) Self-esteem (27, 23, 20) Peer support (27) Group and individual counselling and support help ALHIV fend off internalized stigma (27) Grief support (27) Reordering priorities (focusing on the positive), infusing ordinary events with positive meaning, relying on their spirituality to help them adjust to their HIV diagnosis (26) Positive views of life: strong family relationships, support from family/caregivers, strong friendships, clinic as positive support, participating in activities (including school) (24) Positive views of the future: normal lives, having families (24) Self-esteem/self-worth/self-confidence (20) Empowerment (learning to support, accept, and value themselves; decision-making skills; role models) (20)
Social / Sexuality and relationships	<ul style="list-style-type: none"> Psychosocial support (PSS) for disclosure, stigma, and grief (27) Self-efficacy (21, 11, 9) Peer support (16, 8, 7)
Technology	<ul style="list-style-type: none"> Communication with clients/patients: (39) <ul style="list-style-type: none"> cell phones (39) text messaging (39) +CLICK (web-based intervention) animated educational tool to be used to increase knowledge (25)
PERCEIVED / ACTUAL BARRIERS	
Protective behaviours	<ul style="list-style-type: none"> Protective behaviours used to deal with <u>stigma</u>: (35) <ul style="list-style-type: none"> keep silent about HIV status (pretend I haven't been tested, only my family and support group know, people never say when they are ...divorced or beaten) (35)
Therapeutic	<ul style="list-style-type: none"> Fear of re-infection or 'superinfection' (15) Condom negotiation (some reported 60-70% of sexual acts were unprotected) with multiple barriers to safe sex (lack of communication, lack of access to condoms, lack of education about STIs, 'getting caught up in the moment', partners not caring - e.g. there's medication for it, so why use a condom?) (20)
Structural / facility-based / programming	<ul style="list-style-type: none"> Long queues (40) Negative staff attitudes (inapproachability, rudeness, patient-blaming) (40) Missed testing opportunities at health-care facilities (providers do not routinely suggest testing despite symptoms presented) (40) provider difficulties with paediatric counselling (40) Venesection (more training needed for providers) (40) Weekly visits too challenging, monthly better (39) Providers had to offer flexible scheduling (39) Lack of communication and impersonal interactions with health-care providers (32) Lack of privacy at clinics - particularly if parents are required to accompany them (18) Lack of adolescent care or youth-friendly services (15) Public clinic nurses generate much of the stigma (nurses tell the adolescents they are not supposed to have children because they have HIV and are dying) (15) Pregnant women are primary beneficiaries, pregnant adolescents more likely to go to ANC where they will get better treatment (12, 11) Distance to clinic (11)
Knowledge	<ul style="list-style-type: none"> Misperceptions about HIV and ART (ART will make you sicker, diagnosis will make the illness proceed faster) (40) Difficulty describing specific drug information (37) Conflicting ideas about ART and the restriction it places on their lives (32) Myths and misconceptions (18, 13) Lack of tailored messages (18) Lack of communication directly with adolescent (18) Information from friends is wrong (18) Conspiracy beliefs (17)

Caregivers (parent, guardian, etc.)	<ul style="list-style-type: none"> • Lack of money for: (40) <ul style="list-style-type: none"> ○ transportation ○ food ○ treatments for opportunistic infections; • Poor access to welfare grants (40) • Lack of coordination amongst multiple caregivers (40) • Maternal guilt (40)
Psycho-emotional factors	<ul style="list-style-type: none"> • Construction of identity (32) • Hiding the disease was perpetuating the stigmatization that makes their lives more difficult (30) • Stressors (26) • Negative aspects of life: HIV physically and emotionally painful, affected social interactions, isolation from others, keeping status a secret (fears of stigma), family violence, poverty, crime and drugs, verbal and physical abuse) (24) • Lack of self-esteem/self-worth/self-confidence (20)
Social / sexuality and relationships	<ul style="list-style-type: none"> • Stigma (41, 34, 33, 30, 3) <ul style="list-style-type: none"> ○ perceived public stigma against PLWHA (41) ○ perceived public stigma against children affected by HIV (41) ○ person stigma (41) ○ enacted stigma (41) ○ hiding the disease was perpetuating the stigmatization that makes their lives more difficult (30) • Disorganized social environments (36) • Adolescent sexuality (36) • Rejection and lack of support (family, friends, significant others) (20) • Poor or no social networks (18) • Lack of adolescent care or youth-friendly services (15) • Poverty (11)

Adherence to ART. High adherence to ART by ALHIV was linked to adequate psychological adjustment, effective coping mechanisms, and discussion about and adoption of explicit medication routines. ALHIV identified both positive and negative factors as facilitators to adherence to ART: positive – e.g. free or low-cost medications, an electronic reminder, family and peer support, self-esteem and empowerment skills building and support; and negative – e.g. taking medication regularly so ‘people won’t know I’m sick’, fear of consequences, and fear of re-infection or superinfection. Depression, regimen fatigue, weak health-care systems, lack of youth-friendly services or privacy, and incorrect or misinformation were articulated as the primary barriers to adherence to ART for ALHIV.

Table 5. Adherence to ART

Adherence to ART	
PERCEIVED / ACTUAL FACILITATORS	
Protective behaviours	<ul style="list-style-type: none"> • Protective behaviours used to deal with stigma: (35) <ul style="list-style-type: none"> ○ adherence to ARTs (take medication (regularly) so people won't know I'm sick) (35) • Rejecting difference, portraying positivity and health, HIV is a small part of life (19) • Fear of consequences (2)
Therapeutic	<ul style="list-style-type: none"> • Attitudes toward the disease: cost kept one adherent (29) • Availability of ART (18) • Fear of re-infection or ‘superinfection’ (15) • ART extends lives (13, 12) • ART provides opportunities for PLHIV to actively engage in a range of activities (family and community) (13, 12) • Presence of a wall/mobile alarm (3)
Structural / facility-based / programming	<ul style="list-style-type: none"> • Adherence support (32) • The setting and organisation of health-care teams should allow for ongoing discussions with HIV-positive adolescents that focus on their perceptions of their disease, how they cope with it and their treatment, and how they could improve their adherence (29) • Evolving strategies for adherence, adherence partnerships, reliance on professionals for adherence support (28) • Contextual factors (28) • Programmes attempted to address stigma in social environments, such as communities and schools (27) • Disclosure as an adherence strategy (28) • confidentiality/privacy (26) • The importance of conducting treatment readiness (26)

	<ul style="list-style-type: none"> • Peer educators and support (18, 11) • Parental support (18) • Services that encourage empowerment (18) • Supportive health-care professionals (7) • ART clinic set-ups (3)
Knowledge	<ul style="list-style-type: none"> • Knowledge of HIV (32) • Beliefs and expectations about HIV (28) • Expert patients (18) • Tailored information (18)
Caregivers (parent, guardian, etc.)	<ul style="list-style-type: none"> • Experience with and attitudes toward paediatric health-care providers and the health-care system (28) • Families (18) • Well-educated caregiver (3) • Good relationship between caregiver and health-care provider (3)
Psycho-emotional factors	<ul style="list-style-type: none"> • Trust in physicians (17) • Attitudes about HIV medication (17) • Relationship with HIV (32) • Motivational readiness (31) • Self-efficacy (31,21, 17, 16 11, 9) • Self-esteem (27, 23, 20) • Peer support (27) • High adherence linked to adequate psychological adjustment and effective coping mechanisms, as well as with discussion and adoption of explicit medication-taking strategies (29) • Effective coping strategies or mechanisms (29, 26) • Group and individual counselling and support help ALHIV fend off internalized stigma (27) • Grief support (27) • Adaptive goal processes (26) • Reordering priorities (focusing on the positive), infusing ordinary events with positive meaning, relying on their spirituality to help them adjust to their HIV diagnosis (26) • Positive views of life: strong family relationships, support from family/caregivers, strong friendships, clinic as positive support, participating in activities (including school) (24) • Positive views of the future: normal lives, having families (24) • Self-esteem/self-worth/self-confidence (20) • Empowerment (learning to support, accept, and value themselves; decision-making skills; role models) (20) • Skills building (16) • Conflict/anger management, skill learning and education (16)
Social / Sexuality and relationships	<ul style="list-style-type: none"> • Adherence as a way to avoid stigma (35) • Episodic influence of informal social support (28) • Psychosocial support (PSS) for disclosure, stigma, and grief (27) • Self-efficacy (21, 11, 9) • Family support (21, 18, 7) • Expert patients (18) • Community support and collective efficacy (18, 9) • Social networks (18) • Peer support (16, 8, 7) • Sustained motivation (11)
Technology	<ul style="list-style-type: none"> • Younger patients depended on their parents to remind them, older patients had different strategies to remind them (a little box I keep with me, first thing I do when I wake up, alarm clocks or cell phones, post-it notes on mirrors.) (29) • Media (18) • Cellphone reminders • Web-based training programme
PERCEIVED / ACTUAL BARRIERS	
Protective behaviours	<ul style="list-style-type: none"> • Alcohol use (2)
Therapeutic	<ul style="list-style-type: none"> • Attitudes toward the disease: many did not perceive medicine taking as part of their routine (29) • Poor adherence to medication regimens (36) • Fear of re-infection or 'superinfection' (15) • ARVs rationed, adolescents low in priority (11) • Inadequate food supply (to take with medication) (11, 10) • Existence of mandatory guardian presence in the process of youth accessing HAART (11) • Fears of adverse side effects / drug toxicity (10, 4, 1) • Regimen fatigue (10, 4) • Severity of illness (10) • Difficult med routine / too many pills (10, 4, 3) • Drug / alcohol use (10)

	<ul style="list-style-type: none"> • Ran out of pills (10) • Too busy, schedule interfered (10, 4) • Forgot (10, 4) • Concerns about fake drugs on the market (1) • Fear of withdrawal of donor support (1) • Child refused, felt sick, felt good (4)
Structural / facility-based / programming	<ul style="list-style-type: none"> • Lack of communication and impersonal interactions with health-care providers (32) • Lack of privacy at clinics - particularly if parents are required to accompany them (18) • Weak health systems, negative health-care providers' attitudes, poor evaluation of adolescents' abilities to receive and process information (18) • Lack of adolescent care or youth-friendly services (15 public clinic nurses generate much of the stigma (nurses tell the adolescents they are not supposed to have children because they have HIV and are dying) (15) • Pregnant women are primary beneficiaries, pregnant adolescents more likely to go to ANC where they will get better treatment (12, 11) • Staff misassessing the youth's stage (11) • Distance to clinic (11) • Existence of mandatory guardian presence in the process of youth accessing HAART (11)
Knowledge	<ul style="list-style-type: none"> • Conflicting ideas about ART and the restriction it places on their lives (32) • Attitudes toward the disease: while understood to be part of their disease, many did not perceive medicine taking as part of their routine (29) • Adherence is fluid (both definition and practice) (28) • Myths and misconceptions (18, 13) • Lack of tailored messages (18) • Lack of communication directly with adolescent (18) • Information from friends is wrong (18) • Conspiracy beliefs (17) • Access to ART limited to wealthy, famous, or socially or politically connected (12) • Having sex on ART makes you weak (12) • Beliefs that exchange blood transfusion can replace 'dirty' blood (HIV infected) with 'clean' blood (uninfected) (12) • Inaccurate beliefs about treatment (3)
Caregivers (parent, guardian, etc.)	<ul style="list-style-type: none"> • Multiple caregivers (4) • Frequent and situational challenges to adherence (caregivers being away, running out of medication, child sleeping, difficulty keeping to dosage schedules during the summer months) (28) • Roles of caregiver / lack of autonomy for adolescent (4) • Absence of a private place to take medication when neighbours/relatives visit (3)
Psycho-emotional factors	<ul style="list-style-type: none"> • Emotional struggles / depression (34, 31, 21, 4) • Attitudes toward the disease: while understood to be part of their disease, many did not perceive medicine taking as part of their routine (29) • Opposition to the medication-taking as children grow older (28) • Stressors (26) • Negative aspects of life: HIV physically and emotionally painful, affected social interactions, isolation from others, keeping status a secret (fears of stigma), family violence, poverty, crime and drugs, verbal and physical abuse) (24) • Lack of self-esteem/self-worth/self-confidence (20) • Child's age (4)
Social / sexuality and relationships	<ul style="list-style-type: none"> • Stigma (41, 34, 33, 30, 3) <ul style="list-style-type: none"> ◦ perceived public stigma against PLWHA (41) ◦ perceived public stigma against children affected by HIV (41) ◦ person stigma (41) ◦ enacted stigma (41) ◦ hiding the disease was perpetuating the stigmatization that makes their lives more difficult (30) ◦ rejection and lack of support (family, friends, significant others) (20) • Poor or no social networks (18) • Lack of adolescent care or youth-friendly services (15) • Poverty (11)
Technology	<ul style="list-style-type: none"> • Less adherent adolescents were less explicit about their strategies: 'it comes naturally [no need for electronic reminders], I just tell myself that I shouldn't miss it' (29)

Retention in care. All health-care facilities or delivery sites should be safe spaces where adolescents can freely express their emotions and concerns, and where providers demonstrate patience, understanding, acceptance and knowledge about the choices and services available to the adolescent. For ALHIV, health-care providers' attitudes were either significant facilitators or barriers to retention in care. Also

important was the strength of the relationship between the health-care provider and adolescent (and parent or guardian depending on the age and readiness of the adolescent). Like the other key findings, an ALHIV's level of self-esteem and feeling of empowerment to make decisions improved retention, as did supportive family or family-like environments and peer support. Similarly, barriers to retention in care included the lack of youth-focused services and privacy, poor communication with health-care providers, misinformation, and anxiety or depression.

Table 6. Retention in care

Retention in Care	
PERCEIVED / ACTUAL FACILITATORS	
Protective behaviours	<ul style="list-style-type: none"> • Protective behaviours used to deal with <u>stigma</u>: (35) <ul style="list-style-type: none"> ◦ seek treatment earlier for common conditions (I visit the clinic every time I am sick (seek treatment earlier for minor conditions) (35) • Rejecting difference, portraying positivity and health, HIV is a small part of life (19) • Fear of consequences (2)
Therapeutic	<ul style="list-style-type: none"> • Fear of re-infection or 'superinfection' (15) • Simpler med routine
Structural / facility-based / programming	<ul style="list-style-type: none"> • Programmes attempted to address stigma in social environments, such as communities and schools (27) • Confidentiality/privacy (26) • The importance of conducting treatment readiness (26) • Peer educators and support (18, 11) • Supportive health-care professionals (7)
Knowledge	<ul style="list-style-type: none"> • Knowledge of HIV (32)
Caregivers (parent, guardian, etc.)	<ul style="list-style-type: none"> • Well-educated caregiver (3) • Good relationship between caregiver and health-care provider (3)
Psycho-emotional factors	<ul style="list-style-type: none"> • Trust in physicians (17) • Trust in health-care system (17) • Relationship with HIV (32) • Motivational readiness (31) • Self-efficacy (31, 21, 17, 16, 11, 9) • Self-esteem (27, 23, 20) • Peer support (27) • Coping strategies (29, 26, 20) • Group and individual counselling and support help ALHIV fend off internalized stigma (27) • Grief support (27) • Adaptive goal processes (26) • Reordering priorities (focusing on the positive), infusing ordinary events with positive meaning, relying on their spirituality to help them adjust to their HIV diagnosis (26) • Positive views of life: strong family relationships, support from family/caregivers, strong friendships, clinic as positive support, participating in activities (including school) (24) • Positive views of the future: normal lives, having families (24) • Self-esteem/self-worth/self-confidence (20) • Empowerment (learning to support, accept, and value themselves; decision-making skills; role models) (20)
Social / Sexuality and relationships	<ul style="list-style-type: none"> • Family-centred support (21, 7) • Group homes (rather than orphanages) fostered better mental health and 'family' atmosphere, reducing issues of isolation and community-based discrimination/stigmatization (42) • Psychosocial support (PSS) for disclosure, stigma, and grief (27) • Peer support (16, 8, 7) • Sustained motivation (11)
PERCEIVED / ACTUAL BARRIERS	
Therapeutic	<ul style="list-style-type: none"> • Complex medical routine (10, 4, 3) • Drug / alcohol use (10) • Regimen fatigue (10) • Severity of illness (10)
Structural / facility-based / programming	<ul style="list-style-type: none"> • Lack of communication and impersonal interactions with health-care providers (32) • Lack of privacy at clinics - particularly if parents are required to accompany them (18) • Lack of adolescent care or youth-friendly services (15) • Distance to clinic (11) • Transportation (3)
Knowledge	<ul style="list-style-type: none"> • Conflicting ideas about ART and the restriction it places on their lives (32) • Myths and misconceptions (18, 13)

	<ul style="list-style-type: none"> • Lack of tailored messages (18) • Lack of communication directly with adolescent (18) • Information from friends is wrong (18) • Inaccurate beliefs about treatment (3)
Caregivers (parent, guardian, etc.)	<ul style="list-style-type: none"> • Low household income (3)
Psycho-emotional factors	<ul style="list-style-type: none"> • Mental health issues / anxiety / depression (34, 31, 21, 4) • Stressors (26) • Negative aspects of life: HIV physically and emotionally painful, affected social interactions, isolation from others, keeping status a secret (fears of stigma), family violence, poverty, crime and drugs, verbal and physical abuse) (24) • Lack of self-esteem/self-worth/self-confidence (20)
Social / sexuality and relationships	<ul style="list-style-type: none"> • Stigma (41, 34, 33, 30, 3) <ul style="list-style-type: none"> ◦ perceived public stigma against PLWHA (41) ◦ perceived public stigma against children affected by HIV (41) ◦ person stigma (41) ◦ enacted stigma (41) ◦ Hiding the disease was perpetuating the stigmatization that makes their lives more difficult (30) ◦ Rejection and lack of support (family, friends, significant others) (20) • Lack of adolescent care or youth-friendly services (15) • Poverty (11)
Technology	<ul style="list-style-type: none"> • Less adherent adolescents were less explicit about their strategies: 'it comes naturally [no need for electronic reminders], I just tell myself that I shouldn't miss it' (29)

Successful transition to adult services. It is vital that adolescents have a clearly defined pathway into adult care and that the transition is carefully managed. Abrupt changes can be destabilizing and confusing; continuity of care and the transition to adult services should be a joint effort involving the adolescent, their parent or guardian, and the health-care provider, the balance of which should be determined by rights, readiness, and willingness of the adolescent to assume responsibility for various activities—e.g. taking medication, making appointments, asking questions of health-care providers, and helping to choose their own treatment plans. Facilitators to ALHIV taking responsibility for these types of activities included family-centred and peer support and counselling; self-esteem, empowerment, and coping skills-building activities and support; and a gradual developmental approach that takes into consideration the individual's particular needs. The greatest barriers to successful transition for ALHIV included the poor evaluation of adolescents' abilities to receive and process information, and the lack of or poor communication with health-care providers. The loss of a good relationship with a paediatric provider was also a major barrier to ALHIV successfully moving to adult services when developmentally appropriate.

Table 7. Successful transition to adult services

Successful Transition to Adult Services	
PERCEIVED / ACTUAL FACILITATORS	
Protective behaviours	<ul style="list-style-type: none"> • Rejecting difference, portraying positivity and health, HIV is a small part of life (19)
Therapeutic	<ul style="list-style-type: none"> • Improved health care (14) • Transition readiness was determined by: demonstrating a basic health-care awareness, an awareness of their status, and understanding of their disease, and the initial development of their health-care management skills (5)
Structural / facility-based / programming	<ul style="list-style-type: none"> • Comfort discussing issues with staff (5) • Having the choice to move, when ready / time (5) • Transition support (14, 5) • Open communication between paediatric and adult clinical staff (14) • Provide ongoing support to HIV-infected adolescents to assist them in accepting the consequences of HIV infection (32) • Programming areas: (27) <ul style="list-style-type: none"> ◦ providing immediate post-diagnosis support (27) ◦ stigma reduction (within the child's "circles of care") (27) ◦ capacity building (of the caregivers and children to meet their own PSS needs) (27)

	<ul style="list-style-type: none"> ○ addressing grief (as a process) (27) ● Promoting peer support (through forums for interaction and peer support) (27) ● Programmes attempted to address stigma in social environments, such as communities and schools (27) ● Suggested gradual, partial disclosure based on child's readiness (27) ● Confidentiality/privacy (26) ● The importance of conducting treatment readiness (26) ● Making process that changes over time and is influenced by developmental factors and societal attitudes towards HIV (19) ● Peer educators and support (18, 11, 5) ● Services that encourage empowerment (18) ● Youth friendly services (5) ● Games in waiting room (5) ● Morning or evening appointments (5) ● Staff trained to /know how to talk with and listen to young people (5) ● Condoms available (5)
Knowledge	<ul style="list-style-type: none"> ● Open communication between paediatric and adult clinical staff about transition (14) ● Access to information (14, 5) ● Knowledge of HIV (32) ● Tailored information (18) ● Sexual health information (5) ● Reproductive health information (5)
Caregivers (parent, guardian, etc.)	<ul style="list-style-type: none"> ● Suggested gradual, partial disclosure based on child's readiness (27) ● Tell the truth (27) ● Gradual developmental approach, that best suits the individual (14)
Psycho-emotional factors	<ul style="list-style-type: none"> ● Preparation for adulthood (14) ● Control and responsibility (14) ● Gain independence and formulate self-identity (38, 5) ● Age-appropriate interests (38) ● Strengthening peer and romantic relationships (38) ● Defining future role in life and feeling understood (38) ● Dealing with immorality (38) ● Establish a sense of control over diagnosis/treatment - including relinquishing control when ready (regarding end of life decisions) (38) ● Construction of identity (32) ● Motivational readiness (31) ● Self-efficacy (31, 21, 17, 16, 11, 9, 5) ● Self-esteem (27, 23, 20) ● Peer support (27) ● Coping strategies (29, 26, 20) <ul style="list-style-type: none"> ○ focusing on the positivity (many mentioned that faith/religion helped keep them positive) (26) ● Reordering priorities (focusing on the positive), infusing ordinary events with positive meaning, relying on their spirituality to help them adjust to their HIV diagnosis (26) ● Group and individual counselling and support help ALHIV fend off internalized stigma (27) ● Grief support (27) ● Seeking and being provided with support (especially peer support) (26) ● Adaptive goal processes (26) ● Positive views of life: strong family relationships, support from family/caregivers, strong friendships, clinic as positive support, participating in activities (including school) (24) ● Positive views of the future: normal lives, having families (24) ● Self-esteem/self-worth/self-confidence (20) ● Empowerment (learning to support, accept, and value themselves; decision-making skills; role models) (20, 5) ● Making process that changes over time and is influenced by developmental factors and societal attitudes towards HIV (19) ● Conflict/anger management, skill learning and education (16) ● Acknowledging both independence and the need for support (readiness to play a bigger part in their own health care; support included practical help such as getting transportation to the events) (8)
Social / Sexuality and relationships	<ul style="list-style-type: none"> ● Psychosocial support (PSS) for disclosure, stigma, and grief (27) ● Family-centred support (21) ● Self-efficacy for sexual discussion (21) ● Making process that changes over time and is influenced by developmental factors and societal attitudes towards HIV. (19) ● Peer support (16, 8, 7)
PERCEIVED / ACTUAL BARRIERS	
Therapeutic	<ul style="list-style-type: none"> ● Condom negotiation (some reported 60-70% of sexual acts were unprotected) with multiple barriers to safe sex (lack of communication, lack of access to condoms, lack of education about STIs, 'getting caught up in the moment', partners not caring - e.g. there's medication for it, so why use a condom?) (20)

Structural / facility-based / programming	<ul style="list-style-type: none"> • Lack of communication and impersonal interactions with health-care providers (32, 14) • Lack of privacy at clinics - particularly if parents are required to accompany them (18) • Weak health systems, negative health-care providers' attitudes, poor evaluation of adolescents' abilities to receive and process information (18) • Public clinic nurses generate much of the stigma (nurses tell the adolescents they are not supposed to have children because they have HIV and are dying) (15) • Lack of adolescent care or youth-friendly services (15) • Staff misassessing the youth's stage (11)
Knowledge	<ul style="list-style-type: none"> • Perceptions of the disease from different developmental perspectives: under 16 years - had a 'concrete vision' of their disease, but were unable to explain what it mean and why (e.g., CD4 count, parents call them little soldiers, HIV is a virus, not sure how long I will live) (29) • Myths and misconceptions (18, 13) • Lack of tailored messages (18) • Lack of communication directly with adolescent (18) • Information from friends is wrong (18)
Caregivers (parent, guardian, etc.)	<ul style="list-style-type: none"> • Family disclosure to child (often not related to the child's capabilities, e.g. personal reasons, or to protect the child from stigma) (27) • Guardians mentioned the loss of the relationship with the paediatric provider (14)
Psycho-emotional factors	<ul style="list-style-type: none"> • Loss of the relationship with the paediatric provider (14) • Mental health issues / anxiety / depression (34, 31, 21) • Families' negative perceptions of and experiences with stigma of HIV disease (which undermined the desire to meet new providers) (36) • Perceived and actual lack of autonomy (paediatric providers feared that staff in adult clinics would demand a level of independence that adolescents did not have) (36) • Difficulty letting go of relationships (adolescents, guardians, and providers described a familial relationship and expressed anxiety about terminating their relationships.) (36) • Non-compliance often connected with fear of disclosure (36) • Construction of identity (32) • Children are unable to process their grief and get closure (27) • Suggested gradual, partial disclosure based on child's readiness (27) • Stressors (26) • Negative aspects of life: HIV physically and emotionally painful, affected social interactions, isolation from others, keeping status a secret (fears of stigma), family violence, poverty, crime and drugs, verbal and physical abuse) (24) • Lack of self-esteem/self-worth/self-confidence (20) • Transition through adolescence (4)
Social / sexuality and relationships	<ul style="list-style-type: none"> • Stigma (41, 34, 33, 30, 3) <ul style="list-style-type: none"> ◦ perceived public stigma against PLWHA (41) ◦ perceived public stigma against children affected by HIV (41) ◦ person stigma (41) ◦ enacted stigma (41) • Hiding the disease was perpetuating the stigmatization that makes their lives more difficult (30) • Culture prohibits the discussion of death and grief with children (27) • Rejection and lack of support (family, friends, significant others) (20) • Lack of age-appropriate disclosure (18) • Non-disclosure from parents (18) • Poor or no social networks (18) • Lack of adolescent care or youth-friendly services (15)

Limitations

At present, there are few studies, especially clinical trials, focused on adolescent populations. This is in no small part due to the legal and ethical issues related to the minimum age of consent to HTC and medical care and treatment as defined by each country.

This literature review was limited to articles published in the last five years available through PubMed, Google Scholar, and Google. While the search did not exclude articles published in other languages, the search engines did not return relevant non-English-language options. By including other search engines or databases, additional publications may have been found.

Conclusions

Primary concerns of adolescents are: universal access to care and medication; transition to and continuity of care; opportunities to participate in and be responsible for their own health-care decisions; access to provider, family, and peer support; access to informational materials about HIV, sex, and reproductive health; support for disclosure; and safe, youth-friendly, adolescent specific facilities and services.

The systematic literature review of research on the care and treatment values, preferences, and attitudes of adolescents living with HIV highlights that adolescents need to be engaged in their HIV care and treatment and have access to adolescent-specific or youth-friendly facilities and services.

Governments and organizations need to provide adolescent-friendly and adolescent-focused services that emphasize the development of responsibilities aimed at self-care. At the same time, governments must identify and address barriers to acceptable and effective provision of services to adolescents, including the training of service providers to better communicate with this unique and underserved population.

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