

# Perceptions and experiences of young people adhering and not adhering to Antiretroviral Therapy in sub-Saharan Africa: a scoping review.

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## 1. Background

- In sub-Saharan Africa (SSA), the number of young people living with HIV (YPLHIV) has increased over time.
- Compared to adults, adherence to Antiretroviral Therapy (ART) in young people has been low.
- Although treatment guidelines from the World Health Organization (WHO) have increased timely ART initiations, adherence to ART remains a challenge for YPLHIV.
- Evidence on the perspectives and experiences of YPLHIV in SSA in HIV treatment and care, that have the burden of taking life-long treatment, appear to be limited.
- Factors that influence adherence to ART for YPLHIV are important because they have a bearing on their HIV-related and treatment support needs.
- Study aim: to conduct a scoping review to map the research on the perceptions and experiences of YPLHIV on ART in SSA to inform future research to improve HIV care for this population.

## 2. Methods

- Guided by the release of the 2010 WHO recommendations for ART, we conducted a search for research from 1 January 2010 to 30 September 2022.

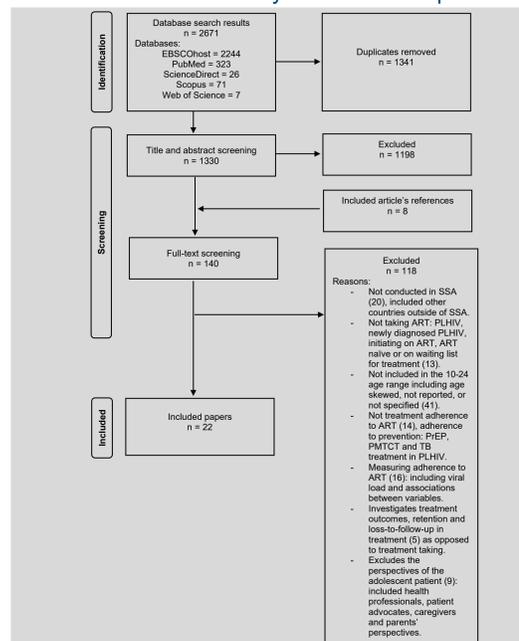


Fig 1. PRISMA flow diagram of selection process.

## 3. Results

- Quantitative and qualitative data analyses were conducted.
- Sixteen studies were qualitative, three mixed methods, and three quantitative. Data for fourteen qualitative studies were cross-sectional and two longitudinal.

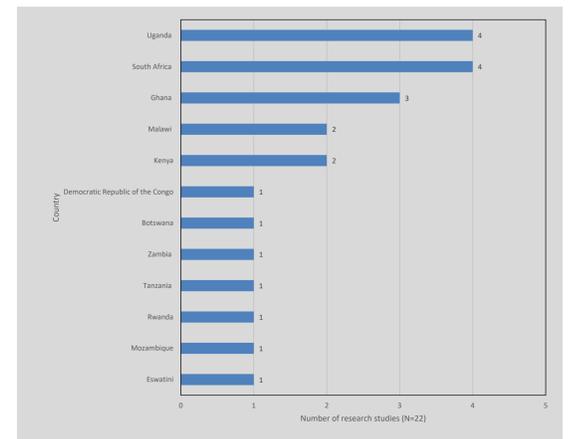


Fig 2. Country of research studies.

- All studies reported findings from YPLHIV on ART. Some studies included caregiver, community member and healthcare provider perspectives.

## 3.1. Experiences, perceptions, and needs

Table 1. Experiences and perceptions by number of research studies.

Experiences and perceptions	Range of studies
Stigma (perceived and experienced)	≥ 10
Need for family support	
Need for medication adherence support	
Difficulty in tolerating ART regimen (pill taste, size, number, frequency, dispensed formulation and side effects)	
Disclosure difficulties	
Food stability, transport costs and material needs	5-9
Secrecy during ART	
Inadequate community and social support	
Desire for a normal and healthy life or future	
Non-adolescent friendly services	
Difficulty in identifying and developing better coping strategies against HIV and ART	1-4
Mental health needs to overcome HIV-induced depression and stress	
Motivation (self, religion, faith, God, spirituality)	
Misinformation, misconception and misperceptions about HIV and related events	
Violence, abuse and neglect	
Need for healthcare provider support	
School system not considerate of ALHIV needs	
Desire for more knowledge about HIV	
Negative health provider attitudes towards ALHIV when they miss ARVs	
Lack of adolescent autonomy during treatment	
Communication challenges around HIV	
Desire to socialise with peers	
Difficulty in accepting HIV diagnosis	
Self-care and responsibilities for others	
Desire to love and be loved in return	
Facility turnaround time during ARV refills	

- The studies reported on the negative perceptions and challenges of YPLHIV taking ART.
- Multiple interconnected factors operating in the social context – individual, health systems, psychological, social, and economic - affected the circumstances of YPLHIV on ART.
- Stigma, secrecy during ART and disclosure difficulties; and dependency during HIV and ART in the form of family, medication, and financial -support were among the most prevalent factors found to challenge ART adherence.
- YPLHIV adherence to ART were negatively influenced by inadequate or challenging social, community and health and mental healthcare –support and patient-level coping strategies; personal goals; and motivations.
- School schedules; health provider attitudes and ART provision at facilities and adolescent developmental, social and informational -needs, although less prevalent, were also found to compromise ART adherence.
- Themes on needs ranged from most to least prevalent, that address psychosocial factors for YPLHIV on treatment (64) to requirements for adequate patient information (8).

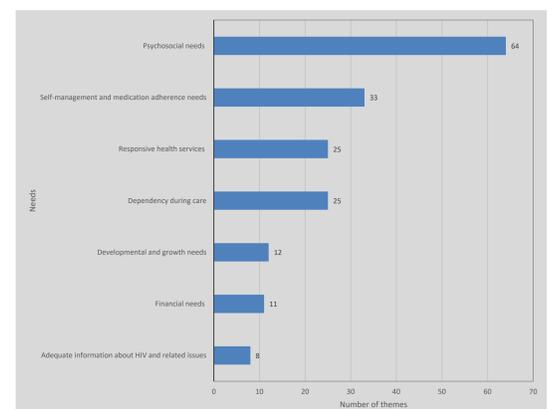


Fig 3. Themes on needs.

- Needs were directly and indirectly related to ART adherence in YPLHIV.
- Self-management and medication support directly influenced ART adherence.
- Responsive adolescent and youth friendly health services; the dependency of YPLHIV during care; developmental and growth needs during adolescence; and financial needs were factors in the social context of YPLHIV on ART that had an indirect bearing on ART adherence.

## 4. Conclusion

- Study limitation: a quality of assessment of selected studies was not conducted.
- The experiences, perceptions and needs of YPLHIV on ART were influenced by social context.
- Multiple interconnected factors influenced ART adherence in YPLHIV.
- YPLHIV on ART have HIV-related and treatment support needs that indirectly and directly influence their adherence.
- Several cross-sectional qualitative studies have been conducted, however research focusing on the perspectives of YPLHIV on treatment, over time, is limited.
- Research privileging the perspectives of YPLHIV on ART in SSA, is needed to inform decision-making for treatment services and interventions for this population.

## 5. Acknowledgements

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