Review

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Experiences and Perceptions of Children and Adolescents Living with HIV in Accessing Healthcare in Sub-Saharan Africa: A Scoping Review Protocol

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Abstract: Background: The increasing number of children and adolescents living with HIV (LWHIV) in Sub-Saharan Africa (SSA) remains a significant global health concern. Despite numerous studies on HIV, there has been limited focus on the lived experiences of HIV infected children and adolescents, and how these experiences affect their access to healthcare services. **Objective:** The proposed scoping review aims to synthesize the available evidence on the experiences and perceptions of children and adolescents LWHIV in accessing healthcare services in SSA. **Methods:** The review will follow the methodological framework proposed by Arksey and O'Malley (2005). Relevant studies will be identified through a comprehensive search of electronic databases (PubMed, CINAHL, and Scopus) using a combination of keywords and phrases related to the research question. Studies will be selected based on predefined eligibility criteria, including the involvement of HIV-positive children and adolescents (aged 0-19 years) in SSA and a focus on their experiences and perceptions of accessing healthcare services. Data extraction will be conducted using a standardized form, and thematic analysis will be employed to identify common experiences and perceptions. The Socio-Ecological Model will serve as a conceptual framework for analyzing the extracted data. **Discussion:** The scoping review will systematically report the existing evidence on the experiences and perceptions of HIV-positive children and adolescents in accessing healthcare services in SSA. The findings will contribute to a deeper understanding of the barriers and facilitators encountered by this vulnerable population, informing the development of comprehensive interventions and policies to improve healthcare access and promote inclusivity and support for their health and well-being. **Systematic review registration:** Not registered

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Introduction

The increasing number of individuals living with HIV (LWHIV) continues to remain a serious and threatening global health concern (Alp et al., 2011; Golrokhi et al., 2018). According to the 2022 Global HIV Statistics fact sheet, there were approximately 39 million individuals infected with HIV that year, and of these 37.5 million were adults and 1.5 million being children (UNAIDS, 2023). According to Adejumo et al., (2015), in Sub-Saharan Africa alone, there are more than 2 million adolescents living with HIV and despite numerous studies detailing how HIV-related stigma impacts

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the HIV management cascade for youth, there has been limited focus on the actual and said experiences, from the perspectives of HIV-positive children and adolescents, and how this stigma affects their daily lives (Kimera et al., 2020).

Children and adolescents remain a key and vulnerable population with respect to most public health issues, the subject of HIV not an exception, and to combat HIV more effectively, a targeted strategy for this population is thus essential. Children and adolescents face greater limitations in accessing healthcare services compared to other groups, including the need for parental consent for treatments and tests, and treatments that are usually not customized for their specific requirements (WHO, n.d). Adolescents living with HIV also need to receive beneficial support and guidance to navigate this period of growth (Hodgson et al., 2012). During adolescence, the subject of sex and safer sex practices, family planning, and HIV disclosure all increase in popularity and impact. However, HIV-positive teens are also noted to be concerned about rejection, stigma, and being exposed if they share their status (Toska et al., 2015). These numerous modifications do not only increase the vulnerability of teenagers to acquiring HIV, but also impact on prevention and treatment seeking behaviors leading to a need for innovative preventive and treatment approaches (Patton et al., 2016). Increasing evidence suggests that adolescents living with HIV are becoming increasingly challenging to retain in care and have poorer rates of adherence (Adejumo et al., 2015; Boerma et al., 2016). These rates are focused in Sub-Saharan Africa, an area with overwhelmed and under-resourced healthcare centers, especially in places where children and teenagers account for a significant portion of the population (Mayosi and Benatar, 2014; Woollett et al., 2021). The ART adherence rate is lowest among adolescents, leading to increased morbidity, virus resistance, subsequent infections, and mortality (Lowenthal et al., 2014). More so, the COVID-19 pandemic caused increased challenges for individuals to remain engaged in HIV treatment (Cluver et al., 2021). As there is an imbalance between the number of patients and healthcare providers in the system, various paraprofessionals are being swiftly hired to address the gaps in providing services (Sprague et al., 2020; Sharp et al., 2015). Sub-Saharan Africa healthcare systems will need to provide long-term care for children and adolescents with HIV, highlighting the importance of investment in preventing viral resistance and transmission while also improving maintenance and care for this vulnerable group (Maskew et al., 2019; Pettifor et al., 2019). Currently, there are not numerous effective strategies to address these problems (Woollett et al., 2021).

To further worsen this situation, as outlined earlier, adolescence in itself is commonly recognized as a challenging period of growth marked by rapid transformations in the physical and mental aspects, as well as within the family and broader community (Sawyer et al., 2012). Children and teenagers living with HIV further, experience challenges as they often encounter a “pile-up of obstacles” in meeting their psychological, social, and medical needs (Woollett et al., 2021). With limited information on what causes improved results, particularly from the perspectives of these population groups based on their own experiences especially with the “treat all” approach which majorly lumps all categories of individuals, there is the need for more thorough treatment approach and commitment from all caregivers tailored specially towards this population (Woollett et al.,).

Moreover, though multiple research studies on HIV/AIDS have been conducted (e.g., Reda and Biadgilign, 2012; Pontiki et al., 2022), most of these studies primarily concentrated on adults (e.g., Tesfay Gebreagziabher and Woldemariam, 2020), which restricted the available data and evidence on children and adolescents to create effective strategies and interventions for equal healthcare access (WHO, 2013). An example is the WHO policy brief which stated that there is insufficient evidence on effective methods to enhance the quality, utilization, and effectiveness of HIV services for adolescents (WHO, 2013). This lack of evidence hinders the development of adolescent-specific programs and services, as well as the routine monitoring and evaluation of such programs (WHO, 2013). Differentiated models of care have been proposed for managing adolescent HIV within public health systems, but the effective implementation of these models remains uncertain (MacPherson et al., 2015; Grimsrud et al., 2016). Most of these models have not been structured around the feedback and perspectives of the individuals in these groups, based on their own lived-experiences accessing

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treatment and management of this chronic disease and specifically put, there is limited feedback from adolescents on what works best for their HIV treatment and management (Woollett et al., 2021). This study aims to therefore fill a research gap by reporting available evidence on the experiences and perceptions that children and adolescents living with HIV have in accessing healthcare services in Sub-Saharan Africa.

Methodology

Eligibility Criteria

Eligibility criteria involved a structured process aimed at ensuring the inclusion of relevant studies while maintaining methodological integrity. To determine the eligibility of the research question as well as to draw up the inclusion and exclusion criteria for this review, the 'PCC' elements of review highlighted by JBI was employed (JBI, 2021) recommended as a less limiting option compared to the PICO. The PCC stands for the Participants or Population, Concept and Context.

Participants

In the study, the population will focus on HIV-positive children and adolescents in Sub-Saharan Africa. The study will involve individuals between the ages of 0-19 who have been diagnosed with HIV. This criterion ensures that the review captures factors specific to this demographic group's healthcare access, accounting for their healthcare needs and vulnerabilities. This review will exclude studies only involving the viewpoints and experiences of caregivers or healthcare providers without input from children and adolescents.

Concept

The research will focus on how HIV-positive children and adolescents experience and perceive accessing healthcare services. The study will examine factors such as barriers, facilitators, satisfaction, choices, and challenges related to the accessibility of healthcare services. Studies focusing solely on clinical outcomes or treatment efficacy will not be included.

Context

The review will consider studies carried out in Sub-Saharan African countries. Research conducted in different areas will not be included.

Types of Sources

The scoping review will involve a range of study designs, such as qualitative, quantitative, and mixed-methods studies published in a scientific journal or a verifiable source such as a website or institutional database. All other publications, including, comments from editors, study notes conference proceedings, book reviews, unpublished data, and readers' comments will be excluded from the study because they may not present the lived experience of children and adolescents. In addition, Studies that are not in English will not be included.

Designs

The review will be guided by the methodology framework developed by Arksey and O'Malley (2005) (Arksey & O'Malley, 2005), which comprises: (1) identifying the research question, (2) identifying relevant studies, (3) selecting studies, (4) charting the data, and (5) collating, summarizing, and reporting the results.

1. Identifying the Research Question

It is imperative to emphasize the importance of gaining a comprehensive understanding of children's and adolescents' experiences and their perceptions when it comes to accessing healthcare.

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This understanding is necessary to improve the quality of the health services delivery to them, particularly within the context of SSA where HIV remains a significant global burden (Ammon et al., 2018). Therefore, we seek to review currently available evidence which will be guided by the research question, *"What is known about the experiences and perceptions that children and adolescents living with HIV in accessing healthcare services in Sub-Saharan Africa?"*

2. Identifying Relevant Studies

A comprehensive search for articles for this review will be conducted through the following electronic databases; PubMed, CINAHL, and Scopus, to identify relevant studies.
The search strategy will start by employing a systematic approach to identify relevant articles, using a combination of keywords and phrases related to the research question by Boolean operators such as 'AND', and 'OR'. Also, to capture variations in terminology, truncation will be used where appropriate.

Additionally, a concept map comprising synonymous and alternative terms will be utilized in place of the primary search terms, example are: Adolescent*/ teenage* / youth / "young adult" /children / child / preschooler, "HIV Infections" / "Human Immunodeficiency Virus" / HIV / "HIV-positive" / AIDS / "Acquired Immunodeficiency Syndrome", / "Health care services" / "HIV services" / "HIV care" / "Health care" / "Health services", / Nigeria / "South Africa" / Ghana / Tanzania / Kenya / Rwanda / Botswana / Cameroun / Senegal / Angola / Uganda / Mali / "Sierra Leone" / "Ivory Coast" / Ethiopia / Lesotho / Zambia / Zimbabwe / Namibia / Guinea / Mauritius / Mozambique / Niger / Seychelles / "Burkina Faso" / Burundi / "Cape Verde" / Cameroon / "Central African Republic" / chad / Comoros / "Democratic Republic of Congo" / "DR Congo" / Djibouti / "Cote D'ivoire" / Congo / "equatorial guinea" / Eritrea / Gabon / Guinea-bissau / Madagascar / "Congo Republic" / "Sao Tome and Principe" / Swaziland / Togo / Benin / Liberia / Namibia / Gambia / "Ce t Afr Republ" / "Equat Guine" / "Papua N Guinea" / "Sao Tome E Prin" / principe / "Sao Tome E Principe" / "Sub Saharan Africa". The search strategy will be tailored to the requirements and syntax of each database (*see Additional file 1*).

3. Selecting Studies

This phase of the review process will focus on refining search options based on inclusion and exclusion criteria. Whereas the inclusion criteria broadened the search, encompassing more articles, the exclusion criteria served as a filter, narrowing down the search results to articles directly relevant to the objective.

To ensure uniformity of the selected articles, after the search, the reference lists of all retrieved records will be exported and organized in a Mendeley reference management system. Which will later be exported to Microsoft Excel through Bibtex. In Microsoft Excel, the records will be deduplicated and screened by two independent reviewers (WKA and JC) against all inclusion and exclusion criteria. To ensure the expeditious completion of this study, only full-text articles available online will be sourced and used. Articles that did not include the search terms will not be included in the selection.

The selection process will consist of two main stages of screening; (1) a title and abstract screening and (2) a full-text screening;

Stage 1: The titles and abstracts of all the identified articles will be screened to determine their relevance to the topic. In any instances where their relevance is ascertained, their full-text papers or reports will be retrieved. When it is difficult to establish whether literature is potentially relevant or in a case where there are no abstracts, the full report will be retrieved and a decision will be made on it.

Stage 2*:* All the retrieved potentially relevant full-text articles will be appraised for eligibility to determine if they meet the inclusion criteria. Any discordant full-text articles will be scrutinized a second time at the full-text review stage. When there is uncertainty about the inclusion of any articles, the article will be referred to a third reviewer (MSS) to resolve any discrepancies through discussion until full agreement is obtained

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4. Charting the Data

Data extraction will be conducted using a standardized form to capture relevant information from selected studies

Data from the included studies will be extracted using a standardized data extraction form. Key information extracted will include study characteristics (e.g., author, publication year), country, participant characteristics (e.g., age, HIV status), methodology, and key findings related to the experiences and perceptions of children and adolescents in accessing healthcare services including barriers, facilitators, identified in the studies.

5. Collating, Summarizing, and Reporting the Results

Data will be collated and summarized using thematic analysis to identify common experiences and perceptions of children and adolescents living with HIV in accessing healthcare services in SSA. Results will be reported narratively, and organized around key themes identified during data analysis. Additionally, descriptive statistics will be used to summarize the characteristics of included studies. The findings will be presented in a scoping review report following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (Tricco et al., 2018).

Conceptual Framework

We will employ the Socio-Ecological Model (SEM) as a conceptual framework for analyzing the extracted data in this review as based on this framework, we can systematically investigate the interaction between multi-level factors and identify key determinants of health behaviors and outcomes for these vulnerable individuals. It suggests that interactions between individuals and their social and physical environments across multiple levels of influence affect human behavior (Caperon, Saville and Ahern 2022). The SEM comprises the following components; intrapersonal, interpersonal, institutional and community or societal level (Scarneo et al., 2019).

At the intrapersonal level, personal characteristics like knowledge, attitudes, and beliefs have a significant impact on influencing behaviors and outcomes.

At the interpersonal level, connections with family, peers, and social networks can either facilitate or impede behavior change and adaptation.

The institutional level involves the organizational factors that shape the context within which individuals lives. This includes rules, regulations, policies and systems of power that influence access and availability of resources along with disparities and social determinants of health.

Finally, the community level synthesizes the wider social environment, such as resource availability, social norms, and community support systems. Community factors such as access healthcare availability, socio-economic status, and cultural beliefs, can greatly influence the way people behave and their health outcomes.

Discussion

The scoping review would be aimed at systematically reporting existing evidence regarding the experiences as well as the perceptions of children and adolescents who are living with HIV in accessing healthcare services and based on preliminary search of studies done to guide this protocol, the review would emphasize the urgent need for such research in this vulnerable population which would inform interventions to address the substantial impact of such challenges on the health of HIV-positive children and adolescents.

We have described our protocol, which offers a feasible means to investigate, characterize, and describe knowledge gaps regarding what is known about children's and adolescents' lived experiences with accessing healthcare services.

In mapping out these experiences, the qualitative analysis paradigm would be employed as we aim to draw out the lived experiences ad perceptions and not quantify them.

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Methodologically, our review would adopt a detailed and systematic approach to address existing gaps in the literature. For instance, research on HIV has been widely investigated but limited among children and adolescents (WHO, 2013). Notably, previous reviews often lacked in-depth classification and descriptions of data on this age group, prompting us to provide a thorough framework to minimize inconsistencies, allows an in-depth evaluation of data while providing a transparent, effective, and structural ways of addressing these issues.

In our study, we propose employing thematic analysis techniques. Thematic analysis consists of systematically recognizing, examining, and reporting patterns found in the data (Dawadi, 2020). In the context of our study, thematic analysis would aid in identifying, organizing, summarizing, and comprehending the barriers and facilitators outlined in the selected literature, whether quoted or thus just listed, to offer insights into common themes and variations across different studies.

Additionally, we will use the "socio-ecological model" to effectively and appropriately represent the retrieved information. This information could be related to access, implementation, attitudes, policy, resource constraints, or any other relevant aspect. In analyzing information using the socio-ecological model, we will systematically examine data within the framework of multiple levels of influence on human behavior and health outcomes. This model acknowledges that individual behavior is shaped by interactions between personal characteristics and various environmental factors across different levels: intrapersonal, interpersonal, institutional, community, or societal (Scarneo et al., 2019).

We will make sure our review process is reliable by having two reviewers check each other's work, making our decisions more consistent and accurate.

Despite this proposed protocol and the rigor in its detail to meet publishing and public health standards for implementation in policies that inform workable interventions, and the plan to follow this protocol in the conduct of the review, we understand that various limitations and setbacks could account for a damper in the standardization as opposed to the protocol plan, therefore as and when the review itself is ongoing, there would be a continuous appraisal of the methodology by the research team and consultants to meet the purpose and aim of the study before approval.

Our review of the experiences of children and adolescents living with HIV will show how important it is to understand how they interact with healthcare system and services. We are using a qualitative approach to deeply understand their experiences, which can help improve how healthcare is provided, shape policies, and guide future research.

By investigating these experiences, we aim not to only strengthen the voices of these individuals who are affected but also hope to raise awareness of the need for comprehensive interventions that promote inclusivity, empathy, and support to their health and wellbeing.

Supplementary Materials: The following supporting information can be downloaded at the website of this paper posted on Preprints.org.

SUPPLEMETARY ITEMS

Abbreviations

COVID-19: Coronavirus Disease 2019
DPU: D. Y. Patil University
HIV: Human Immunodeficiency Virus
LJMU: Liverpool John Moores University
LWHIV: Living with HIV
PCC: Population or Participants, Concept, and Context
PICO: Population, Intervention, Comparison, and Outcome
SEM: Socio-Ecological Model
SSA: Sub-Saharan Africa
UHAS: University of Health and Allied Sciences
UHS: University Hospital Sharjah
WHO: World Health Organisation

Definition of Terms

Children and/or adolescents: - are defined as persons up to 19 years of age.

Experiences: - a state of being affected by a personal event.

Perceptions: - a conceived belief or opinion held by a person about a subject.

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Consent for Publication: Not applicable

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Authors' Information: *WKA* is a Registered Nurse at UHS and an MBA student at DPU. He has obtained a BSc in Nursing from UHAS, and an MSc in International Public Health from LJMU. *JC* is a General Practitioner at True Faith Health Services, Juaben, Ghana, He obtained an MSc in International Public Health from LJMU. *MSS* is a Registered Nurse at UHAS

Conflicts of Interest: The authors declare that they have no competing interests

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