

Adolescents Living with HIV and Shame: A Systematic Review of Experiences and Coping Mechanisms

INPLASY202480063

doi: 10.37766/inplasy2024.8.0063

Received: 13 August 2024

Published: 13 August 2024

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ADMINISTRATIVE INFORMATION

Support - RCSI Research Summer School Skills Programme 2024.**Review Stage at time of this submission** - Data extraction.**Conflicts of interest** - None declared.**INPLASY registration number:** INPLASY202480063**Amendments** - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 13 August 2024 and was last updated on 13 August 2024.

INTRODUCTION

Review question / Objective The review question is 'How do adolescents living with HIV experience and cope with shame?' The primary objective of this systematic review is to explore how adolescents with HIV experience shame and what coping mechanisms do they engage with.

Rationale Human Immunodeficiency Virus (HIV) represents a major global health challenge (1). As of 2021, it is estimated that 38.4 million people were living with HIV (PLHIV), with about 67% residing in Sub-Saharan Africa (SSA)(2). Despite a declining trend in HIV incidence over the past decade, young people aged 15-24 remain disproportionately affected. In 2019, nearly 30% of new global HIV infections were among people aged 15-24 (3). Within this age group, 1.7 million adolescents and 3.4 million young people are living with HIV. Notably, young women and adolescent girls accounted for 77% of all new HIV infections in 2022 (1).

PLWH face immense stigmatisation and discrimination because of their status(4). The extensive stigma associated with HIV is a known barrier to effective prevention, care, and treatment as it can delay testing and hinder appropriate medical care, increase the risk of discontinuing care, and contribute to poor adherence to antiretroviral therapy (ART)(5). Additionally, stigma can result in a reluctance to disclose one's HIV status. Stigma adversely affects both physical and psychosocial well-being, leading to poor mental health states and an overall decline in quality of life(4)(5). This is especially critical in adolescence—a stage marked by the onset of physical and emotional maturity, increased vulnerability, and heightened social scrutiny (6). The stigma associated with HIV during this period can exacerbate feelings of shame, a distressing emotion often linked to perceptions of personal failure and self-deficiency (6).

Adolescents and young people living with HIV (AYPLHIV) experience higher rates of treatment

failure, morbidity, and mortality compared to other age groups(7). The concept of shame, often considered a key component of internalised stigma, varies in its definition and assessment. Some measures of internalised stigma include shame-related items alongside assessments of HIV-related stereotypes, social relationship stigma, and disclosure concerns(6). Others focus on both shame and guilt, while some use more specific measures to evaluate embarrassment and difficulty in disclosing HIV status(6). Although shame and guilt are often confused, they are distinct in their characteristics and impacts. Shame tends to arise from global and stable attributions for negative events, leading individuals to perceive themselves as inherently flawed or defective, whereas guilt is linked to specific and unstable attributions, focusing on particular actions or behaviours rather than one's overall self-concept and can motivate reparative actions, such as seeking medical care (6).

1. World Health Organization. (2023, July). HIV/AIDS [Fact sheet]. <https://www.who.int/news-room/fact-sheets/detail/hiv-aids>
2. Moyo, E., Moyo, P., Murewanhema, G., Mhango, M., Chitungo, I., & Dzinamarira, T. (2023). Key populations and Sub-Saharan Africa's HIV response. *Frontiers in Public Health*, 11, 1079990.
3. UNAIDS. (2021). Young people and HIV
4. Tran, B. X., Phan, H. T., Latkin, C. A., Nguyen, H. L. T., Hoang, C. L., Ho, C. S. H., & Ho, R. C. M. (2019). Understanding global HIV stigma and discrimination: Are contextual factors sufficiently studied? (GAPRESEARCH). *International Journal of Environmental Research and Public Health*, 16(11), 1899.
6. Boerma, R. S., Boender, T. S., Bussink, A. P., Calis, J. C., Bertagnolio, S., Rinke de Wit, T. F., & et al. (2016) Suboptimal viral suppression rates among HIV-infected children in low- and middle-income countries: A meta-analysis. *Clinical Infectious Diseases*, 63(12), 1645–1654.
7. Bennett, D. S., Traub, K., Mace, L., Juarascio, A., & O'Hayer, C. V. (2015). Shame among people living with HIV: A literature review. *AIDS Care*, 28(1), 87–91.
8. M8. Mavhu, W., Willis, N., Mufuka, J., Bernays, S., Tshuma, M., Mangenah, C., . . . Cowan, F. M. (2020). Effect of a differentiated service delivery.

Condition being studied Although stigma has been widely discussed in the literature, there is a gap in understanding how shame specifically impacts the well-being of individuals living with HIV. This review aims to investigate the experiences of shame among adolescents living with HIV. By gaining deeper insight into the role of

shame, we hope to inform more targeted interventions and support strategies that specifically address shame for adolescents living with HIV.

METHODS

Search strategy A search strategy was developed in consultation with a librarian from the Royal College of Surgeons in Ireland, University of Medicine and Health Sciences and will be carried out by two of the authors (AA and EB). Databases to be searched will include: EBSCOhost (Medline, APA PsycInfo, CINAHL), SCOPUS, Web of Science, and PubMed. The search will integrate three concepts—Concept 1 HIV ("human immunodeficiency virus" OR "acquired immunodeficiency virus" OR "HIV"), Concept 2 shame ("shame" OR "guilt"), and Concept 3 Adolescents. The concepts will be combined with "AND," or a filter will be applied to focus on the age group of adolescents if available and therefore Concept 3 would not be included in the search. Search strategy by database:

1. Web of Science:
 "HIV" OR "human immunodeficiency virus" OR "acquired immunodeficiency syndrome" OR "AIDS" OR "human immune-deficiency virus" OR "acquired immune-deficiency syndrome" OR "people living with HIV AIDS" OR "PLWHA" OR "PLHIV" OR "HIV patients" OR "HIV-infections" OR "HIV-positive" OR "people with HIV"

AND

'shame' OR 'guilt'

2. Cochrane:
 #1: MeSH descriptor: [HIV] explode all trees
 #2: MeSH descriptor: [Shame] explode all trees
 #3: MeSH descriptor: [Adolescent] explode all trees
 #4: (HIV OR "human immunodeficiency virus" OR "acquired immunodeficiency virus" OR AIDS OR "human immune-deficiency virus" OR "acquired immune-deficiency syndrome" OR "people living with HIV AIDS" OR PLWHA OR PLHIV OR "HIV patients" OR "HIV-infections" OR "HIV-positive" OR "people with HIV")
 #5: #1 OR #4
 #6: (shame OR guilt)
 #7: #2 OR #6
 #8: (Teens OR "young people" OR juvenile)
 #9: #3 OR #8
 #10: #5 AND #7 AND #9

3. Medline (EBSCO):

S1: (MM "HIV") OR (MM "HIV Infections")
 S2: (MM "Shame")
 S3: AB ((HIV OR "human immunodeficiency virus" OR "acquired immunodeficiency virus" OR AIDS OR "human immune-deficiency virus" OR "acquired immune-deficiency syndrome" OR "people living with HIV AIDS" OR PLWHA OR PLHIV OR "HIV patients" OR "HIV-infections" OR "HIV-positive" OR "people with HIV"))
 S4: AB (shame or guilt or self-blame or self-criticism)
 S5: S1 OR S3
 S6: S2 OR S4
 S7: S5 AND S6
 S8: S5 AND S6 (Narrow by SubjectAge: – adolescent: 13-18 years)

4. CINAHL :

S1: (MM "HIV") OR (MM "HIV Infections")
 S2: (MM "Shame")
 S3: AB ((HIV OR "human immunodeficiency virus" OR "acquired immunodeficiency virus" OR AIDS OR "human immune-deficiency virus" OR "acquired immune-deficiency syndrome" OR "people living with HIV AIDS" OR PLWHA OR PLHIV OR "HIV patients" OR "HIV-infections" OR "HIV-positive" OR "people with HIV"))
 S4: AB (shame or guilt or self-blame or self-criticism)
 S5: S1 OR S3
 S6: S2 OR S4
 S7: S5 AND S6
 S8: S5 AND S6 (Narrow by SubjectAge: – adolescent: 13-18 years)

5. APA PsycInfo:

S1: (MM "HIV") OR (MM "HIV Infections")
 S2: (MM "Shame")
 S3: AB ((HIV OR "human immunodeficiency virus" OR "acquired immunodeficiency virus" OR AIDS OR "human immune-deficiency virus" OR "acquired immune-deficiency syndrome" OR "people living with HIV AIDS" OR PLWHA OR PLHIV OR "HIV patients" OR "HIV-infections" OR "HIV-positive" OR "people with HIV"))
 S4: AB (shame or guilt or self-blame or self-criticism)
 S5: S1 OR S3
 S6: S2 OR S4
 S7: S5 AND S6
 S8: S5 AND S6 (Narrow by SubjectAge: – adolescent: 13-18 years)

6. Embase:

#1: 'human immunodeficiency virus'/exp
 #2: 'shame'/exp
 #3: hiv OR 'human immunodeficiency virus' OR 'acquired immunodeficiency syndrome' OR aids

OR 'human immune-deficiency virus' OR 'acquired immune-deficiency syndrome' OR 'people living with hiv aids' OR plwha OR plhiv OR 'hiv patients' OR 'hiv-infections' OR 'hiv-positive' OR 'people with hiv'

#4: shame OR guilt

#5: #3 AND #4

#6: #5 AND [adolescent]/lim

7. PubMed:

((HIV[Title/Abstract] OR "human immunodeficiency virus"[Title/Abstract] OR "acquired immunodeficiency syndrome"[Title/Abstract] OR AIDS[Title/Abstract] OR "human immune-deficiency virus"[Title/Abstract] OR "acquired immune-deficiency syndrome"[Title/Abstract] OR "people living with HIV AIDS"[Title/Abstract] OR PLWHA[Title/Abstract] OR PLHIV[Title/Abstract] OR "HIV patients"[Title/Abstract] OR "HIV-infections"[Title/Abstract] OR "HIV-positive"[Title/Abstract] OR "people with HIV"[Title/Abstract]) OR ("HIV"[Mesh]) AND ((shame[Title/Abstract] OR guilt[Title/Abstract]) OR "Shame"[Mesh] AND (adolescent[Filter]))

7. Scopus:

Search within: Article title, Abstract, Keywords; HIV OR "human immunodeficiency virus" OR "acquired immunodeficiency virus" OR AIDS OR "human immune-deficiency virus" OR "acquired immune-deficiency syndrome"

AND Search within: Article title, Abstract, Keywords; shame* OR guilt*

Limited to:Adolescents

Participant or population Adolescents living with HIV.

Intervention No intervention.

Comparator None.

Study designs to be included All study designs will be included.

Eligibility criteria To be eligible for inclusion in this systematic review, studies must be available in full English text. The review will encompass all study designs, including peer-reviewed articles, conference abstracts, and poster presentations. The studies need to involve adolescents living with HIV, aged 13-18. The review will include studies that assess outcomes related to shame, guilt, self/internal/personal stigma, and self-image/perception. Studies do not need to include an intervention or programme provided the article discusses adolescents living with HIV and shame.

Studies will not be eligible if they involve adults and children only living with HIV. Documents with a specific focus on key populations, diseases or conditions or experiencing particular traumatic events will be excluded even if adolescents living with HIV are within this group.

Information sources Databases to be searched will include: EBSCOhost (Medline, APA PsycInfo, CINAHL), SCOPUS, Web of Science, and PubMed. Additionally, all literature reviews retrieved on the topic will be examined to ensure all relevant publications are included in our review. Main authors of included articles may be contacted for any further information or documentation they may have that has not been retrieved.

Main outcome(s) The outcomes will be:

1. Description of how shame is discussed in published literature in relation to adolescents living with HIV.
2. Reported experiences and coping mechanisms of adolescents living with HIV and shame.
3. Quality assessment of the reported studies.

Additional outcome(s) No additional outcomes are expected.

Data management As all data is publicly available no research ethics will be obtained. Covidence software will be used to manage the data and the data will be extracted into excel. The excel file will be kept in a file on the RCSI password protected shared drive to facilitate sharing of data and version control.

Quality assessment / Risk of bias analysis

Quality will be evaluated differently depending on the study types using the most commonly used checklists for each research design (1). For qualitative studies the Critical Appraisal Skills Programme (CASP) (2) will be used. For Randomised Controlled Trials (RCTs), the risk of bias (RoB-2) revised tool will be used (3). Quasi-experimental studies will be assessed using the Joanna Briggs Institute (JBI) Checklist for Quasi-Experimental Studies (non-randomized experimental studies) (4). Mixed-methods studies will be assessed using the mixed-methods questions from the CASP Mixed Methods Appraisal Tool (5).

References:

(1) Ma, L.-L., Wang, Y.-Y., Yang, Z.-H., Huang, D., Weng, H., & Zeng, X.-T. (2020). Methodological quality (risk of bias) assessment tools for primary and secondary medical studies: what are they and which is better? *Military Medical Research*, 7(1), 7.

<https://doi.org/10.1186/s40779-020-00238-8>

(2) CASP, CASP qualitative checklist 2022 [Available from: https://casp-uk.net/images/checklist/documents/CASP-Qualitative-Studies-Checklist-2018_fillable_form.pdf

(3) Higgins JP, Altman DG, Gøtzsche PC, Jüni P, Moher D, Oxman AD, et al. 2011, The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. *BMJ*. 2011;343:d5928

(4) Tufanaru, C., Munn, Z., Aromataris, E., Campbell, J., & Hopp, L. (2017). *Systematic reviews of effectiveness*. Joanna Briggs Institute reviewer's manual, 3.

(5) Hong QN, Pluye P, Fàbregues S, Bartlett G, Boardman F, Cargo M, et al. 2019 Improving the content validity of the mixed methods appraisal tool: a modified e-Delphi study. *J Clin Epidemiol*. 111:49-59.e1.

Strategy of data synthesis Covidence software will be used to manage the search process. Search results from the databases will be uploaded to Covidence and duplicates will be automatically removed. Two authors (AA and EB) will independently screen the titles and abstracts to exclude irrelevant studies, resolving any disagreements/conflicts through discussion. For potentially relevant papers, full-text documents will be obtained and examined in detail by the same two authors independently to ensure they meet the eligibility criteria. Any conflicts at this stage will also be resolved through discussion. Where conflicts cannot be resolved between the two authors, the third author (VM) will be brought in to resolve the situation. One of the authors (AA) will cross-reference articles included in our review with those found in related systematic or scoping reviews. One author (AA) will also contact authors, mainly via ResearchGate, when the full text for an article cannot be retrieved or to inquire whether there is any additional information available elsewhere from the author.

The synthesis of data will be conducted following a comprehensive review of the existing evidence which will be contained in our data extraction form. To synthesis the data we will potentially use theoretical frameworks from the main shame and psychoanalytic theories to understand the types of shame, such as internalised and bypassed and to organise our findings around the main debates and discussions on living with shame and HIV in general such as the language of shame, processes of healing, the concept of shared shame and collectivism, and the impact of family and cultural contexts where discussed. Specifically the experience and coping mechanisms of adolescents

living with HIV will be extracted. The study data extraction form will therefore include a detailed description of the discussion of shame, experiences and coping mechanisms and will be organised based on emerging themes. Following data extraction, we will export the information to Excel for detailed analysis.

To ensure comprehensive coverage of all systematic review components, we will use the Cochrane Handbook Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist (1).

Reference

(1) Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E.

Subgroup analysis It is unlikely that sufficient data will be obtained to conduct a subgroup analysis. However, if possible subgroup analysis by gender and country will be conducted.

Sensitivity analysis No sensitivity analysis will be conducted.

Language restriction English language.

Country(ies) involved International study with authors from Saudi Arabia, Zimbabwe and Ireland.

Other relevant information None

Keywords adolescents; shame; HIV.

Dissemination plans The preliminary findings will be shared at the Irish Forum for Global Health to be held in RCSI, October 2024. A graphically illustrated poster will be developed to be presented in different forums, such as RCSI research day, the public engagement building in RCSI, and in Zimbabwe at events where mental health of adolescents and young people is being debated. The results will be published in a peer reviewed academic journal and the results will inform further design and development of mental health applications for adolescents and young people in Zimbabwe and hopefully globally.

Contributions of each author

Author 1 - Aram Al Furaydi - AA will be involved in all stages of the review, from searching databases, screening, data extraction, quality assessment, data synthesis, contacting authors for additional information, drafting and finalising the manuscript.

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Author 2 - Vongai Munatsi - VM will be involved in finalising the manuscript, dissemination and use of the findings in refining and designing positive health interventions for adolescents living with HIV.

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Author 3 - Elaine Byrne - EB will be involved in all stages of the review, from searching databases, screening, data extraction, quality assessment, data synthesis, drafting and finalising the manuscript.

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