“We are experiencing pain on our own”: Mental healthcare to prevail over impacts of cultural silence on HIV

Journal:	*International Journal of Human Rights in Healthcare*
Manuscript ID	IJHRH-08-2022-0089.R2
Manuscript Type:	Research Paper
Keywords:	mental health care, mental health problems, perinatally acquired HIV, psychosocial experiences, young women

"We are experiencing pain on our own": Mental healthcare to prevail over impacts of cultural silence on HIV

Introduction

A growing number of perinatally acquired HIV children are surviving into adolescence. According to Hlophe *et al.* (2022) ~~UNAIDS~~ ~~UNAIDS (2013),~~ more than ~~90%~~85% of these adolescents live in Sub-Saharan Africa (Enane *et al.*, 2018; Hlophe *et al.*, 2022). ~~I (Joint United Nations Programme on HIV/AIDS) (UNAIDS, 2013). I~~n Malawi, it is estimated that ~~10~~8.8% of the one million people living with HIV ~~(Malawi Government, 2012)~~ are children and young people and that more than 90% of these acquired HIV perinatally (Frigati *et al.*, 2020; Nutor *et al.*, 2020)~~)~~ ~~(National AIDS Commission, 2009)~~. Prior research in Africa found that adolescents living with HIV face a variety of mental health issues, such as high rates of anxiety, depression, and traumatic experiences, which may make the transition to adulthood more difficult than for their non-HIV positive peers (~~Betancourt *et al.*, 2014;~~ Dow *et al.*, 2016; Vreeman *et al.*, 2017). Suicide is the third leading cause of death during adolescence globally, and depression is the leading cause of illness and disability, with 10-20% of adolescents suffering from a disabling mental illness (Lwidiko *et al.*, 2018). Positive HIV status has psychosocial consequences, particularly for young women, including stigma, a lack of social support, low socioeconomic status, and physical manifestation (Ciciurkaite and Perry, 2018). Prior research on the unique challenges for medical and psychosocial aspects of care for perinatally HIV-infected youths revealed that a supportive environment, close friends, supportive family, or relations produced significant social capital that buffered the stress associated with living with HIV (Kodyalamoole *et al.*, 2021; Toth *et al.*, 2018)~~ (Hazra *et al.*, 2010; Toth *et al.*, 2018; Kodyalamoole et al. 2021)~~. Despite the high prevalence of mental health issues in this population, mental health research and services in resource-constrained countries such as Malawi are limited (Jervase *et al.*, 2022; Kokota *et al.*, 2020).

Objectives

The main aim of this study was to explore and understand the experiences of perinatally acquired HIV and develop strategies to improve mental health among HIV-positive young women aged 15-19 in Malawi. The specific objectives of the study were to:

1. explore the experiences of growing up with perinatally acquired HIV, specifically for young women aged 15-19 in Malawi,
2. develop strategies to improve mental health among HIV-positive young people.

Methodology

In Malawi, 14 young women with perinatally acquired HIV (aged 15-19 years), their nominated caregivers (14), and service providers (14) participated in a qualitative case study. This method was deemed appropriate because it allowed for a contextual understanding of the 'psychosocial experiences and mental health needs of people living with HIV' through the use of a variety of data sources (~~Mavhu *et al.*, 2013;~~ Remien *et al.*, 2019).

Access, recruitment, and sampling

Purposive sampling was used to recruit participants from multidisciplinary centres that provide specialised paediatric HIV care. The service providers invited all young women who met the selection criteria to participate in the study (see Box 1 for the inclusion and exclusion criteria). The young women nominated the caregivers, and the service providers were chosen by the young women and their caregivers.

The ~~I~~inclusion criteria

Young women were:

- Aged between 15-19 years.
- Perinatally exposed to HIV
- Aware of their HIV positive status.
- Willing to participate in the study
- Cognitively able to complete 'my story' book.
- Attending one of the centres for a minimum of six months
- Attending the centres during a 6-12 month data collection period.

The e~~E~~xclusion criteria:

Young women were:

- Unaware of their exposure to HIV
- Were either clinically unwell or too sick to complete 'my story' book

Those who expressed interest were invited to meet with the researcher to learn more about the study. This personalized approach ensured that everyone was fully informed. Young women under the age of 18 consented to participate in the study.

Data collection

Individual in-depth interviews were conducted with each of the three participant categories and were recorded with an audio digital recorder for authentication. The lead researcher conducted all interviews in Chichewa (local dialect) and translated and transcribed them into English. The interviews with young women were conducted using an innovative visual method known as "my storybook," which encouraged open discussion about sensitive topics even among those who might feel challenged to talk with the researcher (Teachman and Gibson, 2018). A different facility offering HIV services to young people pretested 'my story–book' to determine its practicability in the Malawian context. The 'story books' contained sentence completion exercises as well as images created by the researchers. Young women were asked to place stickers on images that best represented their diverse life experiences, primary needs, and issues affecting their lives as they grow up HIV-positive. The sentence completion exercise facilitated explanations and discussions with young women about the images they chose, as well as rich interview discussions with the researcher.

A semi-structured interview guide with open-ended questions allowed caregivers and service providers to recount details from any aspect of the young women's lives, as well as discuss cultural aspects of their social world and social relations that they thought were relevant. As the interviews progressed, prompts and probes were developed to encourage all participants to think more deeply and to facilitate openness to the complexity and uniqueness of individual experiences, challenges, and perceived needs of young women.

Data analysis

The data was analyzed, and findings were reported using thematic analysis within and across cases. Thematic analysis of the interviews was performed using a constant comparison approach of various data sets (Silverman, 2022). Structures, mechanisms, and issues in the data were linked to relevant concepts about experiences, values, and perceptions through a process of constant comparison to maintaining a close link between the concepts and the data (~~Prosser, 2013;~~ Tracy, 2019). This method incorporated the retroductive process, which provided an alternative method of answering 'how,' 'why,' and 'why not' questions (Jagosh, 2020). According to Saxena (2019) ~~Easton (2010), "~~retroductive analysis" is a process in which events are explained by determining the underlying mechanisms and structures responsible for the events"~~a process in which events are explained by identifying underlying structures and mechanisms capable of producing the events~~." In this context, the analysis went beyond simply identifying which events coexisted and delved into a deeper level of social reality by uncovering the true mechanisms or structures that led to the young women's experiences and practices. QSR NVivo 10 was used to systematically identify, sort, code, and categorize data for detailed case analysis and comparison (Castleberry, 2014; Hall and Steiner, 2020).

To produce more contextually grounded, transferable study results, both within-case and cross-case analyses were performed. Individual accounts within each 'case' were scrutinized to view each case individually within its context while adhering to the case study approach (Cousins and Bourgeois, 2014; Halkias *et al.*, 2022). The cross-case analysis focused on how sub-themes (issues) and themes were systematically cut across all fourteen cases to identify relationships, similarities, contradictions, and differences, and then cross-case conclusions were drawn. To increase the potential for transferability of the findings, a multiple case study approach was used, and a diverse sample of young women was chosen based on a variety of demographic, socioeconomic, and HIV-related variables to gain in-depth knowledge of a larger group.

Results

The findings came from fourteen 'cases' involving young women, designated caregivers, and service providers (42 participants). The study revealed a multifaceted picture of coping with daily life in a context marked by a lack of resources and a "cultural silence," as well as high levels of expressed emotional distress. Table 1 depicts three emerging themes and associated subthemes that will be discussed further herein.

Table 1: Summary of themes and sub-themes

Key themes	**Sub-themes**
Living with sadness and loss: Giving voice to emotional distress	• Enduring sadness • Loss of family and security worries about basic needs
Coping in a context of 'cultural silence'	• Experiencing supportive relationships and resilience • Managing status disclosure: silence and keeping status a secret
Seeking emotional support or receiving mental health care	• Receiving counselling • Benefiting from teen club meetings

Living with sadness and loss: giving voice to emotional distress

All young women reported emotional distress, and many expressed a sense of enduring sadness related to living with HIV and experiencing multiple forms of associated loss.

Enduring sadness

When young women found that they were HIV positive, they experienced sadness, anger, rejection, and longing for something better/different from others. They stated that they did not share these feelings with anyone until they were allowed to speak about their lives with the researcher. Young women living in foster care reported significant suffering, which they blamed on stigma and discrimination. Tawina described living with her stepmother as an emotionally charged experience.

> *I have suffered so long with my stepmother, treating me as an outcast, yet no one to talk to, what a hell in my own dad's home? (Tawina, 18).*

Loss of family and security worries about basic needs

> All the participants had several setbacks. These losses, which included parents/family members, reputation, and/or self-esteem, were described by the young women as significantly contributing to their emotional distress. Parents were regarded as the primary source of love and support. They believed that these losses had an impact on their functioning and socioeconomic status, jeopardizing their development of "self-identity" and a sense of belonging to their family, peers, and society. Multiple losses were regarded as crucial to their poor mental health outcomes. *...I hate life without a future; ....Without parents, friends, living in tears, no one loves, protects, and cares ....Is it worth living? (Ziliwe, 18)*

Some young women expressed strong nostalgia for their former lives, which they saw as more 'normal' and acceptable. Although they wished to return to their former lives, they acknowledged the current lack of adult support networks and social exclusion:

> *Mum was a shield, meeting all our needs; happy days were gone; it was like a dream living on an empty stomach for days* (Gonjetso, 16).

Coping in a 'cultural silence'

Some young women stated that the stigma of HIV infection prevented them from receiving the necessary support and care. Stigma and discrimination manifested themselves in a variety of ways, from neglect and isolation to verbal and physical abuse. Despite visible evidence of HIV, such as physical marks, most caregivers did not want to share the young women's status with others for fear of social isolation. Young women's thoughts and feelings about being HIV positive were not discussed in most families or health-care settings. As Mr. Zaneni (Nane's 43-year-old caregiver) lamented: :

> *It is not easy talking about HIV with your child, and careless sexual behaviours, how could I explain? The taboo of not discussing sexual issues with children, I could not….*

Nonetheless, young women's accounts provide insight into key factors that aid them in coping with difficult situations. These strategies included having supportive relationships and being resilient and dealing with disclosure issues by remaining silent and keeping secrets. These strategies are expanded upon herein: ~~:~~

Experiencing supportive relationships and resilience

When young women were able to engage in affectionate and supportive relationships with their parents/caregivers, peers, and significant others, they had a positive self-image. They required social capital and could obtain it through supportive relationships. :

> *…. With my father's encouragement, I look at life positively. Now 'am pursuing an HIV Management course.* (Nane, 19)

Gonjetso and Tanyada, who benefited from significant advantages, such as strong family support and other supportive relationships, accumulated the social capital required to achieve their self-determined goals. According to Gonjetso, these goals were important in defining their identity, guiding their behaviour, buffering against life stress/challenges, and thus building their self-confidence.:

> *…mum was good, she emphasized ~~on~~ school, am now a community midwife….* (Gonjetso, 16)

Managing status disclosure: silence and keeping status a secret

The stigma associated with HIV made most young women and caregivers keep their status secret at the family and community levels.

> *.How could I disclose my status? It is a pin code (secret) if they (friends) know my status, will they not isolate me?* (Chitsanzo, 19)

The disclosure was discussed not only in terms of others' knowledge of young women's HIV status but also in terms of the women themselves being told they had HIV. Most caregivers stated that they were hesitant to reveal their status to the young women.

> *We did not tell her because she was very sick. How do we communicate? Would she keep this secret?* Mr. Mpando (Tanyada's caregiver, 48)

For Nane and Alindine, late disclosure meant that the disease was associated with shame, unacceptable behaviour, or sexual immorality, all of which they perceived as unwilling to discuss with their caregivers.

> *...is it because HIV is sexually related, and thus, why are they ashamed? It pains me that dad took a long time to have tested.* (Nane, 19)

Nonetheless, once informed of their situation, all young women followed their caregivers' lead by remaining hidden from their peers and significant others. Tanyada was concerned that informing others about the diagnosis would result in a double disclosure, revealing the parent's positive status or previously hidden lifestyle(s).

> *I could not disclose my status and will not disclose my parents' status. What do they think about them?* (Tanyada, 16)

Seeking emotional support or receiving mental health care

Some young women stated that receiving counselling while learning they were HIV positive and attending teen club meetings were extremely valuable because they relieved their emotional tension and contributed to them living positively. According to Penina (19), they reported feeling more optimistic and accepting their future and self:

> *I was distressed after testing positive, but with counselling, I look to the future to live long.*

The majority of young women's accounts revealed that access to counselling was limited, their traumatic experiences were ignored, and no one supported them.

> *...counselling is limited. My friends posted my status on Facebook after discovering my ARVs; I wished that I were dead. for several months, and none of them assisted until I met the researcher. (Penina, 19)*

Similarly, some service providers believed that the stigma associated with mental health problems, combined with the stigma already associated with HIV-positive status, created barriers to thorough risk assessment and deprived young women of appropriate mental healthcare.

> *The stigma attached to mental problems labelling it 'madness' ...creates a barrier to needing care. a lot is missed ...... We lack expertise. (Ms Rwinu, Penina's service provider, 33)*

These findings indicate that endured emotional pain resulted from thoughts about the negative effects of a chronic illness, traumatic experiences of neglect, and being in an emotional desert for years after being diagnosed as HIV-positive, or the loss of their parents. These issues affecting young women in real-life contexts at the individual, familial, and community levels, as well as within healthcare settings, have rarely been openly addressed. Such profound life challenges, taken together, seriously threatened the young women's perceptions of self and sense of belonging.

Discussion

The accounts of young Malawian women living with HIV shed light on the complex emotional challenges they face, particularly the enduring sadness. Their psychosocial experiences were characterised by culturally sanctioned silence and access to mental health services. Most caregivers were significantly compelled by HIV-related stigma to prioritize maintaining HIV secrecy over meeting young women's caring needs. This 'hidden' imperative collectively deprived young women of the future, support, and education they required. Nonetheless, education has a positive impact on HIV-infected adolescents and is a significant protective factor against poor mental outcomes (Mburu *et al.*, 2014; Toth *et al.*, 2018). For young women, strong support networks and counselling have emerged as effective coping strategies and resources. The young women who received various forms of social support stated that it increased their social capital, allowing them to potentially achieve their academic and vocational goals. This is significant because socioeconomic status and social health protection status are important predictors of optimal mental health outcomes. The following are the major issues that influenced their psychosocial experiences: enduring sadness: the unanticipated consequences of cultural silence; and the anticipation and reality of mental health care.

Enduring sadness: unforeseen impact of cultural silence

Positive HIV status harmed young women's sense of belonging and self-worth, with many of them experiencing a sense of sadness that was rarely openly addressed, according to this study. A life of secrecy and silence surrounding HIV status was distressing, encouraging social exclusion and feelings of moral judgment in young women. A study conducted in ~~Ethiopia~~ Tanzania yielded similar results~~-~~ (Ismail *et al.*, 2021) ~~(Biadgilign *et al.*, 2011).~~ The study also revealed that caregivers were hesitant to disclose their status for fear of being stigmatized or losing social support. Other studies conducted in Southern Africa have linked a lack of social support to poor quality of life, a higher perception of stigma, and poor mental health among young people (Lall *et al.*, 2015; Toth *et al.*, 2018). Our research discovered that most families and health services do not address young women's thoughts and feelings about their positive HIV status, living with a stigmatized disease, disruptions in family structures, and sexual relationships, leaving them to suffer alone. As a result, our findings suggest that youth-appropriate and targeted interventions at multiple levels of the cultural, and sociological context (Mburu *et al.*, 2014) could effectively help break the deep-seated culturally sanctioned silence. This will allow all young people living with HIV, particularly females, to gain access to relevant information and available mental health services to improve their psychosocial well-being.

In the current study, young women are characterized as a population "enduring long-suffering on their own" due to cultural silence, which in this study refers to cultural taboos against discussing sexual-related issues, death, and mental illness with young people (Bikila *et al.*, 2021; Mekie *et al.*, 2019; Page, 2019)~~)~~.~~ (Munthali *et al.*, 2006).~~ When people ~~are ~~feel abandoned, degraded, or perceived to be unworthy of others' love, they withdraw from others ~~(Zavaleta Reyles, 2007) ~~to avoid further ~~embarrassment~~disgrace (Nöstlinger *et al.*, 2015). The difficulties the~~se~~ young women in the current study faced created ~~psychosocial issues~~more negative health outcomes~~—~~ that were beyond their ability to resolve, resulting in ~~profound emotional distress~~enduring suffering on their own. However, as in many ~~African ~~societies~~cultures~~ (Kodyalamoole *et al.*, 2021; Nabunya *et al.*, 2021), Malawians believe that ~~death and sexual issues ~~HIV positive status, death and sexual issues are too sensitive for young people to ~~deal with~~handle them on their own (Kodyalamoole *et al.*, 2021). Such beliefs and fears limited young women's opportunities to discuss ~~social ~~their positive status and sexual issues openly, as well as their ability to deal with their intense feelings and challenges, resulting in poor mental health indicators. The findings show that the inability to express intense feelings, hidden pains, and experiences causes young women to go unheard or to be misinterpreted. Due to a lack of understanding about the plight of young people, many caregivers, including service providers, have struggled to deal with the practical psychosocial, economic, and sexual issues affecting young women, resulting in poor mental health outcomes. Nonetheless, the majority of the young women worked hard to establish a positive social identity for themselves by cultivating affectionate and supportive relationships and establishing small-scale businesses. Recent research confirms that supportive relationships function as emotional buffers (Brener *et al.*, 2020; Casale *et al.*, 2019; Fang *et al.*, 2019). Strong adult support networks and peer relationships were important in the broader aspects of young women's lives, reducing mental health problems and leading to academic and vocational success.

The anticipation and reality of mental health care

Coming to terms with their HIV-positive identity and multiple losses was difficult for the young women participants' self-image and self-esteem (Bernays *et al.*, 2018). Yu *et al.* (2017) ~~Mellins and Malee (2013) co~~nfirm that young people struggle to disassociate themselves from adults who acquire HIV through socially or sexually unacceptable behaviours. This resulted in internalized stigma, which hurt their feelings about themselves and their associations with peers, affecting their mental well-being (Dow *et al.*, 2016). Even though most studies focused on biomedical outcomes, there is growing recognition that young people living with HIV are at high risk for mental health problems due to genetic, biomedical, familial, and environmental factors (~~(Mellins and Malee, 2013).~~(Govindasamy *et al.*, 2020; Okonji *et al.*, 2020) ~~-~~Individuals living with HIV have long been associated with sexual promiscuity and immorality (Niu *et al.*, 2019; Yu *et al.*, 2020), implying that they are perceived to have engaged in deviant and unacceptable behaviour (Soffer, 2020). ~~(Nepal and Ross, 2010).~~ Individual counselling, on the other hand, aided young women in this study in coping with their emotional difficulties. Although the young women believed that counselling helped them cope with their emotional situations, they believed that they could have benefited from routine and comprehensive emotional assessments and care, as well as initiative-taking, and planned, and ongoing individual counselling sessions. Counselling was provided in response to situations such as disclosure of status and/or any deviant behaviour (as reported by the caregivers). According to ~~Chiwaru et al. (2010)~~(Zgambo *et al.*, 2018), counselling for young people should focus on reducing risky behaviours and promoting positive living. As a result, addressing complex mental health issues among young women living with HIV is critical to achieving optimal mental health outcomes.

Study limitations

The study only included females; therefore, it would be interesting to learn about males' psychosocial experiences and health-seeking behaviours. Growing up with perinatal HIV was likely to present different mental health challenges for these children.

Conclusion and recommendations

Given the poor mental health outcomes among young women, it is necessary to create new programs and interventions or modify the existing ones so that they provide them with thorough knowledge, the opportunity to socialize with others and develop entrepreneurial skills to promote optimal mental health outcomes. Since~~,~~ ~~Positive~~ positive mental health improves a young woman's ability to direct her life,~~;~~ ~~thus,~~ our study recommends that HIV care services incorporate mental health assessment from routine screening to thorough assessment and care provision. Our findings further suggest that ~~staff~~ parental and health worker training on child/youth counselling strategies, as well as individualised counselling sessions, could effectively help break the deep cultural silence, thereby improving the mental health outcomes of young women. This will enhance not only mental health but also enhancing general health and lower~~ing~~ the risk of HIV transmission to others.

Acknowledgement

We are grateful to all the young women, caregivers, and service providers who took the time to participate in this study. We are also grateful to all service providers at Lighthouse and Baylor College of Medicine in Malawi for their time and assistance.

Ethical approval and consideration

The University of Nottingham Research and Ethics Committee in the United Kingdom, the Kamuzu University of Health Sciences Ethics Committee in Malawi (P.09/11/1124), and the HIV centres' review boards all granted ethical approval. Each research site provided written permission. Young women (aged 18 and up), their caregivers, and service providers who expressed an interest in participating provided both verbal and written consent. Young women under the age of 18 agreed to participate if they had parental permission. Young women and caregivers who were unable to write signed consent forms with their light thumbprints, and service providers signed as witnesses. To ensure maximum confidentiality, all participants' responses were anonymous, and pseudonyms created by the young women themselves were used for their stories and 'my story books.

Availability of data and materials

Due to ethical constraints, the data used for this analysis cannot be made public. They can be obtained by contacting the Principal Investigator ~~(Dr. Gertrude Mwalabu) at gmwalabu@kuhes.ac.mw.~~

Consent for publication

Consent for publication was obtained from the participants, as stated in the informed consent form.

Funding

The data used for this analysis were collected as part of a larger study funded by the Malawi Government through the Kamuzu University of Health Sciences, and the writing of this manuscript was supported by the University of Nottingham through the School of Health Sciences.

Authors' contributions

GM conceived of the study and wrote the first draft of the manuscript. CE and SR provided methodological and content expertise at all levels. CE and SR provided feedback on the initial manuscript. The final manuscript was drafted, reviewed, and edited by PP and PM.

Competing interests

The authors declare that they have no conflict of interest.

References

Bernays, S., Bukenya, D., Thompson, C., Ssembajja, F. and Seeley, J. (2018), "Being an 'adolescent': The consequences of gendered risks for young people in rural Uganda", *Childhood*, SAGE Publications Ltd, Vol. 25 No. 1, pp. 19–33, doi: 10.1177/0907568217732119.

Betancourt, T., Scorza, P., Kanyanganzi, F., Fawzi, M.C.S., Sezibera, V., Cyamatare, F., Beardslee, W., *et al.* (2014), "HIV and child mental health: a case-control study in Rwanda", *Pediatrics*, Vol. 134 No. 2, pp. e464-472, doi: 10.1542/peds.2013-2734.

Bikila, T.S., Dida, N., Bulto, G.A., Debelo, B.T. and Temesgen, K. (2021), "Adolescents' Communication on Sexual and Reproductive Health Matters with Their Parents and Associated Factors among Secondary and Preparatory School Students in Ambo Town, Oromia, Ethiopia", *International Journal of Reproductive Medicine*, Vol. 2021, p. 6697837, doi: 10.1155/2021/6697837.

Brener, L., Broady, T., Cama, E., Hopwood, M., de Wit, J.B.F. and Treloar, C. (2020), “The role of social support in moderating the relationship between HIV centrality, internalised stigma and psychological distress for people living with HIV”, *AIDS Care*, Taylor & Francis, Vol. 32 No. 7, pp. 850–857, doi: 10.1080/09540121.2019.1659914.

Casale, M., Boyes, M., Pantelic, M., Toska, E. and Cluver, L. (2019), “Suicidal thoughts and behaviour among South African adolescents living with HIV: Can social support buffer the impact of stigma?”, *Journal of Affective Disorders*, Vol. 245, pp. 82–90, doi: 10.1016/j.jad.2018.10.102.

Castleberry, A. (2014), “NVivo 10 [software program]. Version 10. QSR International; 2012.”, *American Journal of Pharmaceutical Education*, American Journal of Pharmaceutical Education, Vol. 78 No. 1, doi: 10.5688/ajpe78125.

Ciciurkaite, G. and Perry, B.L. (2018), “Body weight, perceived weight stigma and mental health among women at the intersection of race/ethnicity and socioeconomic status: insights from the modified labelling approach”, *Sociology of Health & Illness*, Vol. 40 No. 1, pp. 18–37, doi: 10.1111/1467-9566.12619.

Cousins, J.B. and Bourgeois, I. (2014), “Cross-case analysis and implications for research, theory, and practice”, *New Directions for Evaluation*, Vol. 2014 No. 141, pp. 101–119, doi: 10.1002/ev.20078.

Dow, D.E., Turner, E.L., Shayo, A.M., Mmbaga, B., Cunningham, C.K. and O’Donnell, K. (2016), “Evaluating mental health difficulties and associated outcomes among HIV-positive adolescents in Tanzania”, *AIDS Care*, Vol. 28 No. 7, pp. 825–833, doi: 10.1080/09540121.2016.1139043.

Enane, L.A., Davies, M.-A., Leroy, V., Edmonds, A., Apondi, E., Adedimeji, A. and Vreeman, R.C. (2018), “Traversing the cascade: urgent research priorities for implementing the ‘treat all’ strategy for children and adolescents living with HIV in sub-Saharan Africa”, *Journal of Virus Eradication*, Elsevier, Vol. 4 No. Suppl 2, p. 40.

Fang, L., Chuang, D.-M. and Al-Raes, M. (2019), “Social support, mental health needs, and HIV risk behaviors: a gender-specific, correlation study”, *BMC Public Health*, Vol. 19 No. 1, p. 651, doi: 10.1186/s12889-019-6985-9.

Frigati, L.J., Ameyan, W., Cotton, M.F., Gregson, C.L., Hoare, J., Jao, J., Majonga, E.D., *et al.* (2020), “Chronic comorbidities in children and adolescents with perinatally acquired HIV infection in sub-Saharan Africa in the era of antiretroviral therapy”, *The Lancet. Child & Adolescent Health*, Vol. 4 No. 9, pp. 688–698, doi: 10.1016/S2352-4642(20)30037-7.

Govindasamy, D., Seeley, J., Olaru, I.D., Wiyeh, A., Mathews, C. and Ferrari, G. (2020), “Informing the measurement of wellbeing among young people living with HIV in sub-Saharan Africa for policy evaluations: a mixed-methods systematic review”, *Health and Quality of Life Outcomes*, Vol. 18, p. 120, doi: 10.1186/s12955-020-01352-w.

Halkias, D., Neubert, M., Thurman, P.W. and Harkiolakis, N. (2022), *The Multiple Case Study Design: Methodology and Application for Management Education*, 1st edition., Routledge.

Hall, D.M. and Steiner, R. (2020), “Policy content analysis: Qualitative method for analyzing sub-national insect pollinator legislation”, *MethodsX*, Vol. 7, p. 100787, doi: 10.1016/j.mex.2020.100787.

Hlophe, L.D., Tamuzi, J.L., Shumba, C. and Nyasulu, P.S. (2022), "Barriers to anti-retroviral therapy adherence among adolescents aged 10 to 19 years living with HIV in sub-Saharan Africa: A mixed-methods systematic review protocol", *Plos One*, Public Library of Science, Vol. 17 No. 9, p. e0273435, doi: 10.1371/journal.pone.0273435.

Ismail, N., Matillya, N., Ratansi, R. and Mbekenga, C. (2021), "Barriers to timely disclosure of HIV serostatus: A qualitative study at care and treatment centers in Dar es Salaam, Tanzania", *PLoS ONE*, Vol. 16 No. 8, p. e0256537, doi: 10.1371/journal.pone.0256537.

Jagosh, J. (2020), "Retroductive theorizing in Pawson and Tilley's applied scientific realism", *Journal of Critical Realism*, Routledge, Vol. 19 No. 2, pp. 121–130, doi: 10.1080/14767430.2020.1723301.

Jervase, R., Adams, B., Myaba, J. and Vallières, F. (2022), "An evaluation of mental health capacity building among Community Rehabilitation Officers in Malawi: A mixed-methods case study", *SSM - Mental Health*, Vol. 2, p. 100108, doi: 10.1016/j.ssmmh.2022.100108.

Kodyalamoole, N.K., Badiger, S.B., Dodderi, S.K. and Shetty, A.K. (2021), "Determinants of HIV status disclosure to children living with HIV in coastal Karnataka, India", *AIDS Care*, Vol. 33 No. 8, pp. 1052–1058, doi: 10.1080/09540121.2020.1851018.

Kokota, D., Lund, C., Ahrens, J., Breuer, E. and Gilfillan, S. (2020), "Evaluation of mhGAP training for primary healthcare workers in Mulanje, Malawi: a quasi-experimental and time series study", *International Journal of Mental Health Systems*, Vol. 14 No. 1, p. 3, doi: 10.1186/s13033-020-0337-0.

Lall, P., Lim, S., Khairuddin, N. and Kamarulzaman, A. (2015), “Review: An urgent need for research on factors impacting adherence to and retention in care among HIV-positive youth and adolescents from key populations”, *Journal of the International AIDS Society*, Vol. 18, p. 19393, doi: 10.7448/IAS.18.2.19393.

Lwidiko, A., Kibusi, S.M., Nyundo, A. and Mpondo, B.C.T. (2018), “Association between HIV status and depressive symptoms among children and adolescents in the Southern Highlands Zone, Tanzania: A case-control study”, *PloS One*, Vol. 13 No. 2, p. e0193145, doi: 10.1371/journal.pone.0193145.

Mavhu, W., Berwick, J., Chirawu, P., Makamba, M., Copas, A., Dirawo, J., Willis, N., *et al.* (2013), “Enhancing psychosocial support for HIV positive adolescents in Harare, Zimbabwe”, *PLoS ONE*, Vol. 8 No. 7, p. e70254, doi: 10.1371/journal.pone.0070254.

Mburu, G., Ram, M., Oxenham, D., Haamujompa, C., Iorpenda, K. and Ferguson, L. (2014), “Responding to adolescents living with HIV in Zambia: A social–ecological approach”, *Children and Youth Services Review*, Vol. 45, pp. 9–17, doi: 10.1016/j.childyouth.2014.03.033.

Mekie, M., Taklual, W., Melkie, A. and Addisu, D. (2019), “Parental communication on sexual and reproductive health issues and its associated factors among preparatory school students in Debre Tabor, Northcentral Ethiopia: institution based cross-sectional study”, *BMC Research Notes*, Vol. 12 No. 1, p. 598, doi: 10.1186/s13104-019-4644-y.

Nabunya, P., Byansi, W., Muwanga, J., Damulira, C., Brathwaite, R., Namuwonge, F., Bahar, O.S., *et al.* (2021), “Gender, HIV knowledge and prevention attitudes among adolescents living with HIV participating in an economic empowerment intervention in Uganda”, *AIDS Care*, Vol. 33 No. 7, pp. 888–896, doi: 10.1080/09540121.2020.1844860.

Niu, L., Wang, Z., Fang, Y., Ip, M. and Lau, J.T.F. (2019), “Behavior intention to use routine opt-out HIV testing in primary care settings among men who have sex with men in China”, *AIDS Care*, Vol. 31 No. 12, pp. 1565–1573, doi: 10.1080/09540121.2019.1612003.

Nöstlinger, C., Loos, J. and Verhoest, X. (2015), “Coping with HIV in a culture of silence: results of a body-mapping workshop”, *AIDS Research and Human Retroviruses*, Vol. 31 No. 1, pp. 47–48, doi: 10.1089/aid.2014.0316.

Nutor, J.J., Duah, H.O., Agbadi, P., Duodu, P.A. and Gondwe, K.W. (2020), “Spatial analysis of factors associated with HIV infection in Malawi: indicators for effective prevention”, *BMC Public Health*, Vol. 20 No. 1, p. 1167, doi: 10.1186/s12889-020-09278-0.

Okonji, E.F., Mukumbang, F.C., Orth, Z., Vickerman-Delport, S.A. and Van Wyk, B. (2020), “Psychosocial support interventions for improved adherence and retention in ART care for young people living with HIV (10–24 years): a scoping review”, *BMC Public Health*, Vol. 20 No. 1, p. 1841, doi: 10.1186/s12889-020-09717-y.

Page, S. (2019), “‘Harmful Cultural Practices’ and AIDS”, in Page, S. (Ed.), *Development, Sexual Cultural Practices and HIV/AIDS in Africa*, Springer International Publishing, Cham, pp. 61–106, doi: 10.1007/978-3-030-04119-9_4.

Prosser, J.D. (2013), “Visual methodology”, in Denzin, N.K. and Lincoln, Y.S. (Eds.), *Collecting and Interpreting Qualitative Materials*, 4th ed., Sage, Thousand Oaks, CA, pp. 223–260.

Remien, R.H., Stirratt, M.J., Nguyen, N., Robbins, R.N., Pala, A.N. and Mellins, C.A. (2019), “Mental health and HIV/AIDS: the need for an integrated response”, *AIDS (London, England)*, Vol. 33 No. 9, pp. 1411–1420, doi: 10.1097/QAD.0000000000002227.

Saxena, D. (2019), “The Search for Mechanisms in Business Research: Reflections on Retroductive Analysis in a Multilevel Critical Realist Case Study”, *Electronic Journal of Business Research Methods*, Vol. 17 No. 1, p. 17-27.

Silverman, D. (2022), *Interpreting Qualitative Data*, 7th ed., Sage, Los Angeles.

Soffer, M. (2020), “HIV/AIDS-related beliefs among Israeli Arab-Palestinian women”, *Health & Social Care in the Community*, Vol. 28 No. 1, pp. 216–224, doi: 10.1111/hsc.12855.

Teachman, G. and Gibson, B.E. (2018), “Integrating visual methods with dialogical interviews in research with youth who use augmentative and alternative communication”, *International Journal of Qualitative Methods*, SAGE Publications Inc, Vol. 17 No. 1, p. 1609406917750945, doi: 10.1177/1609406917750945.

Toth, G., Mburu, G., Tuot, S., Khol, V., Ngin, C., Chhoun, P. and Yi, S. (2018), “Social-support needs among adolescents living with HIV in transition from pediatric to adult care in Cambodia: findings from a cross-sectional study”, *AIDS Research and Therapy*, Vol. 15, p. 8, doi: 10.1186/s12981-018-0195-x.

Tracy, S.J. (2019), *Qualitative Research Methods: Collecting Evidence, Crafting Analysis, Communicating Impact*, 2nd ed., Wiley, New York.

Vreeman, R.C., McCoy, B.M. and Lee, S. (2017), “Mental health challenges among adolescents living with HIV”, *Journal of the International AIDS Society*, Vol. 20 No. Suppl 3, p. 21497, doi: 10.7448/IAS.20.4.21497.

Yu, C., Zuo, X., Blum, R.W., Tolman, D.L., Kågesten, A., Mmari, K., De Meyer, S., *et al.* (2017), “Marching to a Different Drummer: A Cross-Cultural Comparison of Young Adolescents Who Challenge Gender Norms”, *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, Vol. 61 No. 4S, pp. S48–S54, doi: 10.1016/j.jadohealth.2017.07.005.

Yu, J., Nehl, E.J., Dinh, V.P., Liang, B., Son, N.V., Meng, D., Zhang, Y., *et al.* (2020), "Vietnamese female sex workers in rural cross-border areas of Guangxi, China: migration and HIV/STI risk behaviors", *AIDS Care*, Vol. 32 No. 12, pp. 1515–1523, doi: 10.1080/09540121.2020.1719968.

Zgambo, M., Kalembo, F.W. and Mbakaya, B.C. (2018), "Risky behaviours and their correlates among adolescents living with HIV in sub-Saharan Africa: a systematic review", *Reproductive Health*, Vol. 15 No. 1, p. 180, doi: 10.1186/s12978-018-0614-4.