UNIVERSITY OF CAPE TOWN

Stressors and Coping Behaviours of Caregivers and Children Across the Pediatric HIV-Disclosure Stages in Resource-limited Settings

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PLAGIARISM DECLARATION

I, Amy Bustamam, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work or any part thereof has been, is currently being, or is to be submitted for another degree at this or any other university.

I further declare that this work was not published prior to my registration for the degree of Master of Public Health. I empower the university to reproduce for the purpose of research either the whole or any portion of the contents of this dissertation in any manner whatsoever.

Signature: Signed by candidate

Date: 24 January 2024

DEDICATION

To my Father God, my Mom, and my Love.

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Thank you to Prof. Chris Colvin, my supervisor, for his continued support during the development and writing of this research, for always being so calm and wise, and for his guidance and encouragement throughout this process.

ABSTRACT

The stressful nature of pediatric HIV disclosure has contributed to the less than optimal disclosure rates in many resource-limited settings. This study examined the presence of disclosure stressors and coping behaviours used by South African caregivers and children during the disclosure phases to promote a healthy disclosure process.

Disclosure experiences of 54 caregivers and 27 children (not-dyads) attending HIV-groups in Khyletisha were assessed using the directed approach to content analysis method to identify stressors and coping use. Data from six FGDs and eight IDIs were coded using predetermined coping batteries.

10 disclosure stressors and 12 coping behaviours were identified. Transcripts revealed that the common barriers reported in the literature, like HIV-stigma and caregiver unpreparedness, functioned as stressors influencing the use of coping mechanisms. Identified Adaptive coping strategies included: Social Support, Restraint Coping, Selective Disclosure, Active Coping/Problem Solving, Positive Thinking/Cognitive Restructuring, Religious Coping, Acceptance, and Information-seeking, which often encouraged full disclosure, brought resolution to stressful situations, maintained positive self-esteem, or encouraged adherence to ART. Maladaptive coping behaviours included: Behavioural Disengagement, Confrontive Coping, Escape-Avoidance/Tension Reduction, and Suicidal. Throughout the disclosure stages, coping behaviours dynamically changed to perceived consequences/stressors (i.e potential stigmatization) and changing situational dynamics. Coping use and recommendations for disclosure interventions were discussed.

Coaching of healthy coping strategies to caregivers and children is essential in combating the stressful nature of disclosure and critical in promoting adequate disclosure processes, outcomes, and timely disclosure.

Key words: child disclosure, coping, stressors, HIV, disclosure barriers

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CDP	Caregiver-led Disclosure Programme
CRC	UN Convention of the Rights of the Child
FGD	Focus group discussion
HIV	Human immunodeficiency virus infection
HREC	Health Sciences Faculty Human Research and Ethics Committee
IDI	In-depth interview
MSF	Médecins Sans Frontières
NGO	Non-governmental organization
UCT	University of Cape Town
WHO	The World Health Organization

Table of Contents

PART A: RESEARCH PROTOCOL

INTRODUCTION

1. Background

There are an estimated 7.6 million people living with HIV South Africa in 2022; up to 520,000 of which are children (<14 years old) [1]. There has been tremendous pediatric ART coverage since 2010, with 54% of children currently receiving ART among those living with HIV in South Africa [1]. With increase in ART use, 23-84% of HIV-positive children in South Africa are showing sustained viral load (VL) suppression and high rates of immune reconstitution[1]; thereby, living for longer periods. HIV-infection is shifting from a life-threatening to a chronic disease.

With prolonged mortality, comes complex issues affecting children's survival post-ART initiation, such as, retention in care, medication adherence, psychosocial implications, and life-skills training for HIV-positive children; thus, posing a continuous challenge for caregivers and health workers in the management of pediatric-HIV[2-5].

2. Pediatric-HIV Disclosure and Prevalence

An important undertaking that can support the long-term management of children/adolescents with perinatally-acquired HIV is pediatric HIV disclosure. The literature defines pediatric HIV disclosure as an act and process of informing a child the status of his or her HIV diagnosis [5, 6].

Numerous evidence-led and step-by-step recommendations have proposed the *how and when* to disclose to children/adolescents with perinatally-acquired HIV of their status[7-10]. In 2011, *World Health Organisation (WHO*) [6] recommended that child disclosure should be implemented as a process of adjustment by the child, caregivers, and the community that could take place over a few years, and one that should respond to life challenges that is typical to the illness. The WHO proposed several key recommendations, such that: (a) children of school age should be fully disclosed of their and their parent's HIV positive status; (b) younger children should be partially disclosed of their status and their parents, incrementally, responding to their cognitive skills and emotionally maturity; and (c) deciding on who will conduct the disclosure (partially or fully) should be based upon the intent to minimize the risk to the child's well-being and improve the quality of the relationship between child and parent/caregiver.

The Manual on Paediatric HIV Care and Treatment for District Hospitals by WHO [11] further provided the step by step approach to disclosure and psychosocial support for children, from how to help caregivers better understand the situation to age-appropriate disclosure recommendations. The manual suggests a culture of open communication about the infection to create space for the child to express his/her fears, obtain support, understand his/her illness, and participate in their own care. More importantly, it recommended linking the caregiver to a support group. The National Department of Health South Africa [12] highlights that a successful disclosure process is one that involves a supportive and enabling environment, health promotion, well prepared caregivers, and that caregivers and children are linked to appropriate support.

When conducted well, disclosure can alleviate the challenges seen in pediatric HIV care: i.e. improve ART adherence, positive psychological outcomes, positive dyads relationship, social support, self-care promotion, and reduction in peer-to-peer transmission[13-17]. In that, after disclosure, children appear to be happier, confident, and are better able to communicate to caregivers. A retrospective cohort study with routine follow-up data, found retention in care to be higher for those disclosed than undisclosed children[18].

The literature recommends early disclosure to ensure early preparations for dealing with the challenges associated with children's HIV[10, 19]. Specifically, full disclosure is recommended prior to children reaching adolescents for adequate transitioning into management of their own health and to prevent initiation of HIV-risk behaviours[12, 19, 20].

However, despite these benefits and guidelines, disclosure prevalence of children/adolescents with perinatally-acquired HIV is still lower than expected in many resource-limited settings[15, 21-23]. A recent systematic review on disclosure of HIV status to children in Sub-Saharan Africa found that prevalence of disclosure can range between 9-72%, and varied dramatically between age (with most children knowing their status only years later after diagnosis) [13, 21, 22, 24];. The high prevalence reported in the literature may be an overestimation since caregivers are more likely to report full-disclosure, compared to self-reported status by children [25]

3. Pediatric-HIV Disclosure: a stressful transaction for caregivers

The low disclosure rates of children/adolescents with perinatally-acquired HIV in resource-limited settings have been reported to be largely contributed by the compounded stress associated with disclosure.

HIV alone is already an extremely stressful and demanding illness to those affected [23, 26]. It evokes stressors such as stigmatization, risk of death, life-long adherence to the complex medication regimens, side-effects of ART, symptoms associated with disease progression, and the creation of new identity[27-29]. Compounded by this, disclosure involves complex stressors that not only implicate the caregiver, but also the child. Many caregivers believe that disclosing to a child with perinatally-acquired HIV poses high risk of harm to the parent-child relationship, shame and suffering onto the child, inability to cope with the news (child), self-harm (child), and child's emotional distress (i.e. sadness, resentment, or depression)[30-43]. More importantly, disclosure can lead to harmful discrimination and stigmatization towards the dyads by the community or family members[25, 35, 36, 38, 40-42, 44-48].

Numerous studies have reported disclosure to be a painful transaction for caregivers, causing 'guilt-inducing' elements, anxiety, and overwhelming fear[11, 13, 39, 49, 50]. For most caregivers, it involves the possibility of exposing family secrets: i.e. disclosing the status of the caregiver and informing the child about how the infection was acquired[20, 39, 46, 51, 52]; this often places the caregivers at a disempowered position[48]. Disclosure of maternal-HIV/AIDS has been shown to have a negative effect on child/adolescent outcomes, including child/adolescent depression, anxiety/worry, aggression, and self-concept[53].

4. Disclosure and Coping

Lazarus and Folkman defined coping as a cognitive and behavioral response to manage (master, reduce, or tolerate) a stressful appraisal –taxing demands, characterized by threat, challenge, or harm-loss that has exceeded the resources of the person[54, 55]. Coping is functional for the user since it helps regulate the distressing emotions (emotion-focused coping) or it has the ability to change the problem causing the distress (problem-focused coping).

Problem-focused coping is used more frequently in situations "that were appraised by the person as changeable than in those appraised as unchangeable" (pg. 152)[54]. Whereas, emotion-focused coping is "used more frequently in encounters that were appraised as unchangeable." Therefore, the types of coping used are dependent upon whether the person sees the situation/encounter/stressors as *changeable* or *unchangeable*.

Although no study to date has formally investigated the coping mechanisms used by caregivers during pediatric HIV-disclosure processes in limited-resource settings, disclosure studies have tinged on caregivers' coping behaviours in their findings, such as: restraining disclosure (i.e. minimal explanation about the illness and use of non-stigmatizing chronic illness to address children's symptoms (i.e. asthma, tuberculosis, sickle cell or skin disease) or avoiding disclosure (i.e. deflection of information; children's questions for hospital visits often met with either no explanation or said to be for associated illness or routine health check-up)[13, 30]. The literature also reported other coping tendencies from caregivers during the pre-disclosure stages, such as, selective disclosure and seeking social support in forms of advice from an HIV counsellor[56].

The literature has also touched on behaviours related to both effective and ineffective coping styles in children. When faced with confusion and frustration from unanswered questions of medication use and hospital visits, children tend to commonly behave in ways that depict confrontive coping (i.e. persistent questioning of medication and threats of stopping medications) [20, 50, 57-59]. Studies with adolescents in low- and middle-income countries found that positive coping mechanisms (such as adhering to medications and familial/peer social support) were identified as important for the general well-being of adolescents[60, 61]. A cross-sectional study in Southern Nigeria found that the majority of children used prayer as a coping strategy post-disclosure [62].

PROBLEM STATEMENT AND RATIONALE FOR STUDY

The stressful nature of pediatric HIV-disclosure has contributed to the less than optimal disclosure rates in many resource-limited settings. Reported barriers of disclosure to children/adolescents with perinatally-acquired HIV (i.e. as stigma, children's distress, and revelation of family secrets) have caused caregivers to avoid and delay disclosure. In the context of extreme stressors, use of coping must be managed carefully.

Healthy coping strategies are essential in combating the stressful nature of pediatric HIV-disclosure. Knowledge of ineffective and effective ways of coping with disclosure stressors is critical in promoting the best possible disclosure processes, outcomes, and promote timely disclosure. Moreover, having effective ways to cope help both caregivers and children/adolescents with perinatally-acquired HIV maintain good psychological and physical well-being in the long-term.

No study to date has empirically investigate the stressors and associated coping behaviours used by caregivers and children/adolescents with perinatally-acquired HIV during the pediatric HIV-disclosure stages. The extent to which these coping behaviours are employed during the disclosure processes and stages is poorly understood. Understanding disclosure stressors and coping use during the disclosure stages is pertinent for the development of relevant interventions that can improve rates of pediatric HIV-disclosure. This study is important for intervention development for caregivers and children/adolescents with perinatally-acquired HIV facing disclosure stressors, and for the health-care providers who work with them.

OBJECTIVES AND RESEARCH QUESTIONS

Using Lazarus and Folkman's (1984) transactional theory of stress and coping, this study sought to understand the presence of disclosure stressors and associated coping behaviours within the different pediatric-HIV disclosure stages, utilized by caregivers and children/adolescents with perinatally-acquired HIV in South Africa.

1. Research Question

What are the disclosure stressors and coping behaviours used by caregivers and children/adolescents with perinatally-acquired HIV during the pre- and post-HIV-disclosure stages?

METHODOLOGY

1. Study Design

This study will make use of data previously collected for a formative evaluation study. The data was collected to inform the development of the Caregiver-led Disclosure Programme (CDP). It was conducted by the University of Cape Town with the collaboration of MSF Khayelitsha between 2014-2015, and received ethics approval from the University of Cape Town ethics committee (HREC/REF: 125/2014, Appendix 1). Permission for use of data for the current study was obtained from the University of Cape Town Research Ethics Committee (REF: 399/2021, Appendix 2).

The CDP study took on a qualitative approach with an iterative design that involved focus group discussions (FGD's) and in-depth interviews (IDIs) with caregivers, children, healthcare workers, and group counselors. The principal objective of the CDP study was to capture the reality around disclosure processes so as to inform the barriers and promotion of pediatric HIV disclosure and to assess programme materials to better develop the disclosure programme. The CDP data reached saturation.

The current study will capture coping use and associated stressors experienced by caregivers and children during the disclosure processes from the data collected for the CDP study.

2. Study Population and Setting

To fulfil the objectives of the current study, data from all consenting caregivers (n=54) and children (n=27) will be included in the study. The current study will not include data from healthcare workers/counsellors.

All the caregivers and children that participated in the CDP study were living in Khayelitsha, Cape Town, South Africa.

Eligibility criteria for caregivers to participate in CDP study were as follows:

- Caregivers who were caring for an HIV positive child
- Were involved in the disclosure process (partial or full disclosure) of the child

Eligibility criteria for children were:

- Between the ages of 5-18 years
- HIV positive
- Have been fully disclosed of their status.

During the time of data collection, Khayelitsha was known to be the largest township in the Western Cape Province and has one of the highest burdens of HIV infection in South Africa, with prevalence of HIV antenatal at a high of 26% in 2010[63].

Poverty is rife and access to basic needs is low in Khayelitsha; a high 38% of the labour force was unemployed in 2011 and more than half of the residents live in informal dwellings or shacks (55%). Almost 40% of its residents do not have access to piped water in their premises and the majority attains less than Grade 12 education (47.3%, aged 20+)[64].

It was in 2004 that pediatric ART was decentralized to primary clinics. ART programmes for children in Khayelitsha resulted in significant improved mortality at 5 years on ART. Mortality rates has steadily decreased between 2003 to 2009 for infants on ART [63]. Thus, pediatric ART care made it possible for children to reach the threshold for the recommended age or cognitive maturity for HIV disclosure in Khayelitsha [19].

3. Sampling and Recruitment

Purposive sampling strategy was utilized during the CDP study due to the iterative design and the preselected criteria of the population of interest described above. Since disclosure programmes have mainly been clinic/facility-based, participants were chosen from clinics and local NGOs involved in disclosure practices in Khayelitsha. The Ubuntu Clinic was pre-selected as the main site to commence the CDP study.

Initial recruitment of caregivers and children at clinics and NGOs was conducted by clinic staff (i.e. counselors) and institutional staff who have worked closely with the caregivers and children on disclosure.

4. Data Collection

Data format for the current study will be textual, obtained from field notes and transcribed and translated transcripts captured from eight IDIs with caregivers and six FGDs (three with caregivers, two with children, and one combined). IDIs and FGDs were already transcribed and translated into English during the main study. Data such as, HIV status of the caregivers, age, disclosure age, reported stressors, and coping responses will be captured from the transcriptions.

IDIs discussed and explored sensitive topics surrounding HIV and personal perspectives of individuals. FGDs aimed to understand the cultural norms and the interactions of caregivers with HIV-positive children. These discussions explored disclosure experiences and the subjective meaning of the disclosure processes that the caregivers and children had. Further details of the interviews and focus groups are mentioned in the main CDP study protocol (HREC/REF: 125/2014).

5. Data Safety and Management

All transcribed and translated data generated for this study will be stored locally on a password protected secure server that is only accessible to the local study team. All data will be kept for up to 5 years or after all possible reports have been published. Data storage will be kept under strict confidentiality.

6. Data Analysis

To promote a more structured process than the conventional method of qualitative synthesis, the author will use a *directed* approach to *content analysis [65]*:

- Codes will be defined before and during data analysis.
- Transcripts will be first highlighted for all texts that on initial impression appears to represent a disclosure stressful appraisal, reported emotions, or instances/experiences of coping. This will also provide initial familiarization of the data and contextual understanding.
- Then, all highlighted passages will be coded using the predetermined codes. Any text that could not be categorized with the initial coding scheme will be given a new code, 'thereby increasing the trustworthiness and internal validity of the findings'[65].

Further step-by-step analysis are described below:

- Establishing Stressors in our Data:
    - Firstly, it is important to establish that disclosure stressors exist within the disclosure stages. Disclosure stressors are circumstances/events that causes stress. Oken and colleagues [66] explained that, "the state of stress results from a perturbation arising from the internal or external environment (stressor)." Hence, without stressors, stress does not exist and there is not much need for coping. Similarly, Folkman and Lazarus, 1985, defined stress as 'a relationship between the person and the environment that is appraised by the person as relevant to his or her well-being and in which the person's resource are taxed of exceeded', pg. 152. Coping methods are efforts to manage this negative person-environment-relationship.
    - Within this framework, we will study the data to define and understand the stressors (causes of stress) during disclosure that initiated caregivers and children's coping.
    - Examination of stressors will involve two aspects: stressful appraisals (i.e. threat, challenge or harm-loss) and/or reported emotions [67]. Only data that holds either of these two variables will be considered as stressors.
- Identifying Coping Behaviours:

- With these stressors in mind, the data will then be assessed for a broad range of coping responses based upon a predetermined set of coping strategies from commonly use batteries in the HIV literature [28]: the COPE Inventory [68], Ways of Coping Battery [54], The Brief RCOPE [69], and Responses to Stress Questionnaire [70]. However, the author will also consider other scales that was developed specifically for coping with HIV:
    - Murphy et al. (2003) [71]: Positive Action, Passive Problem Solving, Self-Destructive Escape, Social Support, Spiritual Hope, Depression/Withdrawal, and Nondisclosure/Problem Avoidance.
    - Moneyham et al.'s (1998) [72]: Seeking Peer Support, Living Positively, Managing HIV Disease, Seeking Support of Family/Friends, Isolation/Withdrawal, Spiritual Activities, Denial/ Avoidance, and Seeking Information.
- The data will also be analyzed with the goal to identify new types of coping strategies among HIV-affected dyads that is specific to pediatric-HIV disclosure.

For the purpose of this study, only situational coping (how one cope with the recent event, i.e. disclosure stressors) will be assessed. Dispositional coping (how one usually copes with stress) is not within the interest of this study. Although there is certainly overlap between dispositional and situational coping, they are not identical.

7. Methodological Considerations

Reflexivity

The author recognizes that her own perceptions, assumptions, personal experiences, and ideological positions can influence the interpretation of the data or the coding process. Hence, to remove potential biases, the approach to data analysis will be conducted with a more structured approach by using the directed content analysis methodologies to increase trustworthiness and transparency. As well, the author will continuously reflect upon her own subjectivity and influence during the data analysis processes through literature re-review/checking and diary keeping.

Rigour

The strength of claims is dependent upon the data analysis techniques. Hench, to ensure thoroughness, exhaustiveness, and accuracy of the findings, the study will use a variety of scales to identify and determine coping use, not only those that were developed for coping-with-HIV studies, but also general coping scales that have been used in coping studies for the African population. Additionally, to confirm the existence of one specific coping strategy, associated stressor(s) would need to be evident in the transcripts, thereby promoting accuracy and removing bias. Moreover, determination of stressors need to involve one of two aspects: there has to be apparent stressful appraisals in the transcript (i.e. threat, challenge or harm-loss) and reported emotions, which increase trustworthiness of our findings. The identification of stressors and coping use requires the need for multiple read-through of the transcripts.

To ensure further validity and reliability of interpretation of data, the author will embark upon various strategies to achieve analytical roundedness and trustworthiness:

- Triangulation of Sources: The author will compare consistency of findings with the existing coping literature.
- Negative of Deviant Case Analysis: Elements of data that contradict patterns or explanations will be taken into consideration to add, refine, or revise the interpretation of the findings. This aspect will go hand in hand with the triangulation of resources.

8. Ethical Considerations & Potential Harm and Benefits

The present study will analyze data gathered from the main CDP study (HREC/REF: 125/2014). Permission for use of data will be obtained from the University of Cape Town Research Ethics Committee.

Voluntary written and verbal informed consent were obtained during the main CDP study: invitation sessions and the consent process were conducted in the preferred language of the participants; written consent and assent were obtained prior to the interviews and FGDs; children with legal guardians who were not readily accessible were consented by their main caregiver after efforts of contacting the guardian was taken without success. See Appendix 3 and 4 for examples of consent forms and information sheets provided to caregivers and children during the main CDP study.

Inclusion of children's views and coping use' in this study is essential and in line with the UN Convention of the Rights of the Child (CRC). Taking into consideration and accounting for children's suggestions and views in all matters affecting them is in support of their participation rights noted in Article 12 of the CRC [73].

This study is a secondary analysis of existing data, as such poses no direct risks to the study participants. Patient identifiers in the translated transcripts will be de-identified by the study team from the main CDP study prior to the analysis for the current study. Quotes from data will be used in the reporting of the results; hence pseudonyms will be utilized and any details that could be used to identify the speaker will be omitted. Although the current study will have no direct benefits on the participants, however, their input is of critical importance to the long-term care of HIV-positive children.

9. Study Limitations

"Qualitative inquiry demands meticulous attention to language…and meanings of human experience", pg.10, [74]. The proposed analyses will be limited by the chosen local languages of the participants. Since most responses will be in Xhosa and later translated into English, the authors will not be able to directly discern the different usages of semantics from the transcripts that could be meaningful for the interpretation of the data.

10. Logistics

As this is an analysis of existing data, no further cost or payment will be required for the course of this study.

11. Write Up and Dissemination of Findings

The findings of this study will be submitted as part of the fulfilment of the requirements for the Masters of Public Health programme at the University of Cape Town. Results will also be submitted to a peer-reviewed journal for publication, AIDS and Behavior. Findings will also be written in the form of a report and disseminated to associated members at MSF, appropriate Southern African HIV-/child-related conferences or scientific meetings, and in the Khayelitsha community.

REFERENCES

1. UNAIDS. *Global HIV & AIDS Statistics*. 2023 [cited 2023 December 26, 2023]; Available from: https://www.unaids.org/sites/default/files/media_asset/data-book-2023_en.pdf.
2. Ubesie, A.C., et al., *HIV status disclosure rate and reasons for non-disclosure among infected children and adolescents in Enugu, southeast Nigeria.* SAHARA J : journal of Social Aspects of HIV/AIDS Research Alliance, 2016. **13**(1): p. 136-141.
3. Nichols, J., A. Steinmetz, and E. Paintsil, *Impact of HIV-Status Disclosure on Adherence to Antiretroviral Therapy Among HIV-Infected Children in Resource-Limited Settings: A Systematic Review.* AIDS Behav, 2017. **21**(1): p. 59-69.
4. Hayfron-Benjamin, A., et al., *HIV diagnosis disclosure to infected children and adolescents; challenges of family caregivers in the Central Region of Ghana.* BMC Pediatr, 2018. **18**(1): p. 365.
5. Kakkar, F., et al., *Challenges to achieving and maintaining viral suppression among children living with HIV.* Aids, 2020. **34**(5): p. 687-697.
6. World Health Organization. *Guideline on HIV disclosure counselling for children up to 12 years of age. Geneva: World Health Organisation*. 2011. Geneva: World Health Organization. Available: http://www.who.int/hiv/pub/hiv_disclosure/en/
7. Kalembo, F.W., et al., *Primary caregivers, healthcare workers, teachers and community leaders' perceptions and experiences of their involvement, practice and challenges of disclosure of HIV status to children living with HIV in Malawi: a qualitative study.* BMC public health, 2018. **18**(1): p. 884-884.
8. Paintsil, E., et al., *Clinic-Based Pediatric Disclosure Intervention Trial Improves Pediatric HIV Status Disclosure in Ghana.* J Acquir Immune Defic Syndr, 2020. **84**(1): p. 122-131.
9. Kitetele, F.N., et al., *HIV Disclosure to Infected Children Involving Peers: A New Take on HIV Disclosure in the Democratic Republic of Congo.* Children (Basel), 2023. **10**(7).
10. Mugo, C., et al., *From research to international scale-up: stakeholder engagement essential in successful design, evaluation and implementation of paediatric HIV testing intervention.* Health Policy Plan, 2020. **35**(9): p. 1180-1187.
11. World Health Organization, *Disclosure and psychosocial support for children*, in *Manual on Paediatric HIV Care and Treatment for District Hospitals: Addendum to the Pocket Book of Hospital Care of Children*. 2011, World Health Organization
Copyright: Geneva. p. 1-109.
12. Africa, N.D.o.H.S., *Disclosure Guidelines for Children and Adolescents in the context of HIV, TB and non-communicable diseases.* 2016.
13. Vreeman, R.C., et al., *Disclosure of HIV status to children in resource-limited settings: a systematic review.* Journal of the International AIDS Society, 2013. **16**(1): p. 18466-18466.
14. Ramsammy, C.W., et al., *Children's Positive and Negative Emotional Responses to an HIV Disclosure Study in South Africa.* Front Pediatr, 2022. **10**: p. 857336.
15. Amankwah-Poku, M., D.A. Klutsey, and K.O. Asante, *Disclosure and health-related outcomes among children living with HIV and their caregivers.* AIDS Res Ther, 2021. **18**(1): p. 13.
16. Kitetele, F.N., et al., *Lessons Learned from the Impact of HIV Status Disclosure to Children after First-Line Antiretroviral Treatment Failure in Kinshasa, DR Congo.* Children (Basel), 2022. **9**(12).

17. Shabanova, V., et al., *Pediatric HIV Disclosure Intervention Improves Immunologic Outcome at 48 Weeks: The Sankofa Trial Experience.* J Acquir Immune Defic Syndr, 2023. **94**(4): p. 371-380.

18. Arrivé, E., et al., *HIV status disclosure and retention in care in HIV-infected adolescents on antiretroviral therapy (ART) in West Africa.* PLoS One, 2012. **7**(3): p. e33690.

19. WHO. *Guideline on HIV disclosure counselling for children up to 12 years of age*. 2011; Available from: http://www.who.int/hiv/pub/hiv_disclosure/en/

20. Murnane, P.M., et al., *Extent of disclosure: what perinatally HIV-infected children have been told about their own HIV status.* AIDS care, 2017. **29**(3): p. 378-386.

21. Lemma, T., et al., *HIV Serostatus Disclosure and Its Predictors Among Children Living With HIV in Ethiopia: A Systematic Review and Meta-Analysis.* Front Public Health, 2022. **10**: p. 859469.

22. Doat, A.R., R. Negarandeh, and M. Hasanpour, *Disclosure of HIV Status to Children in Sub-Saharan Africa: A Systematic Review.* Medicina (Kaunas), 2019. **55**(8).

23. Guta, A., et al., *HIV-positive status disclosure and associated factors among children in public health facilities in Dire Dawa, Eastern Ethiopia: A cross-sectional study.* PLoS One, 2020. **15**(10): p. e0239767.

24. Armoon, B., et al., *Prevalence, socio-demographics and service use determinants associated with disclosure of HIV/AIDS status to infected children: a systematic review and meta-analysis by 1985-2021.* Arch Public Health, 2022. **80**(1): p. 154.

25. Vreeman, R.C., et al., *'Why did you not tell me?': perspectives of caregivers and children on the social environment surrounding child HIV disclosure in Kenya.* Aids, 2015. **29 Suppl 1**: p. S47-55.

26. Dake, S., et al., *Coping strategies among adolescents and young adults living with HIV/AIDS in Accra-Ghana.* BMC Public Health, 2023. **23**(1): p. 2350.

27. Moskowitz, J.T. and J. Wrubel, *Coping with HIV as a chronic illness: Illness appraisals, coping, and well-being.* . Psychology and Health, 2005. **20**: p. 509-531.

28. Moskowitz, J.T., et al., *What works in coping with HIV? A meta-analysis with implications for coping with serious illness.* Psychological bulletin, 2009. **135**(1): p. 121-141.

29. Chem, E.D., et al., *Health-related needs reported by adolescents living with HIV and receiving antiretroviral therapy in sub-Saharan Africa: a systematic literature review.* J Int AIDS Soc, 2022. **25**(8): p. e25921.

30. Sariah, A., et al., *"Experiences with disclosure of HIV-positive status to the infected child": Perspectives of healthcare providers in Dar es Salaam, Tanzania.* BMC Public Health, 2016. **16**(1): p. 1083.

31. Britto, C., et al., *Prevalence and Correlates of HIV Disclosure Among Children and Adolescents in Low- and Middle-Income Countries: A Systematic Review.* J Dev Behav Pediatr, 2016. **37**(6): p. 496-505.

32. Reynolds, N.R., et al., *SANKOFA: a multisite collaboration on paediatric HIV disclosure in Ghana.* Aids, 2015. **29 Suppl 1**: p. S35-45.

33. Vreeman, R.C., et al., *Characteristics of HIV-infected adolescents enrolled in a disclosure intervention trial in western Kenya.* AIDS Care, 2015. **27 Suppl 1**: p. 6-17.

34. Tadesse, B.T., B.A. Foster, and Y. Berhan, *Cross Sectional Characterization of Factors Associated with Pediatric HIV Status Disclosure in Southern Ethiopia.* PLoS One, 2015. **10**(7): p. e0132691.

35. Namasopo-Oleja, M.S., D. Bagenda, and E. Ekirapa-Kiracho, *Factors affecting disclosure of serostatus to children attending Jinja Hospital Paediatric HIV clinic, Uganda.* Afr Health Sci, 2015. **15**(2): p. 344-51.

36. Kalembo, F.W., et al., *Socio-demographic, clinical, and psychosocial factors associated with primary caregivers' decisions regarding HIV disclosure to their child aged between 6 and 12 years living with HIV in Malawi.* PloS one, 2019. **14**(1): p. e0210781-e0210781.

37. Appiah, S.C.Y., et al., *A Phenomenological Account of HIV Disclosure Experiences of Children and Adolescents from Northern and Southern Ghana.* International journal of environmental research and public health, 2019. **16**(4): p. 595.

38. Gyamfi, E., et al., *Prevalence of, and barriers to the disclosure of HIV status to infected children and adolescents in a district of Ghana.* BMC international health and human rights, 2017. **17**(1): p. 8-8.

39. Kiwanuka, J., E. Mulogo, and J.E. Haberer, *Caregiver perceptions and motivation for disclosing or concealing the diagnosis of HIV infection to children receiving HIV care in Mbarara, Uganda: a qualitative study.* PLoS One, 2014. **9**(3): p. e93276.

40. Sariah, A., et al., *"Experiences with disclosure of HIV-positive status to the infected child": Perspectives of healthcare providers in Dar es Salaam, Tanzania.* BMC public health, 2016. **16**(1): p. 1083-1083.

41. Britto, C., et al., *Prevalence and Correlates of HIV Disclosure Among Children and Adolescents in Low- and Middle-Income Countries: A Systematic Review.* Journal of developmental and behavioral pediatrics : JDBP, 2016. **37**(6): p. 496-505.

42. Kairania, R., et al., *'Mummy told me that I have HIV, that is the only thing she told me': Experiences of HIV status disclosure to children in Masaka Region, Uganda.* PLoS One, 2023. **18**(5): p. e0285990.

43. Wariri, O., et al., *"What will my child think of me if he hears I gave him HIV?": a sequential, explanatory, mixed-methods approach on the predictors and experience of caregivers on disclosure of HIV status to infected children in Gombe, Northeast Nigeria.* BMC Public Health, 2020. **20**(1): p. 373.

44. Mkwanazi, N.B., T.J. Rochat, and R.M. Bland, *The Amagugu intervention: a qualitative investigation into maternal experiences and perspectives of a maternal HIV disclosure support intervention in rural South Africa.* Health policy and planning, 2017. **32**(9): p. 1231-1240.

45. Mburu, G., et al., *Adolescent HIV disclosure in Zambia: barriers, facilitators and outcomes.* 2014. **17**(1): p. 18866.

46. Domek, G.J., *Debunking common barriers to pediatric HIV disclosure.* J Trop Pediatr, 2010. **56**(6): p. 440-2.

47. Mburu, G., et al., *Adolescent HIV disclosure in Zambia: barriers, facilitators and outcomes.* J Int AIDS Soc, 2014. **17**(1): p. 18866.

48. Mandalazi, P., C. Bandawe, and E. Umar, *HIV Disclosure: Parental dilemma in informing HIV infected Children about their HIV Status in Malawi.* Malawi Med J, 2014. **26**(4): p. 101-4.

49. Desclaux, A. and C. Alfieri, *[Disclosure of infant HIV status: mothers' experiences and health workers' interpretations in Burkina Faso].* Sahara j, 2013. **10 Suppl 1**: p. S81-92.

50. Aderomilehin, O., A. Hanciles-Amu, and O.O. Ozoya, *Perspectives and Practice of HIV Disclosure to Children and Adolescents by Health-Care Providers and Caregivers in sub-Saharan Africa: A Systematic Review.* Frontiers in Public Health, 2016. **4**(166).
51. Reynolds, N.R., et al., *SANKOFA: a multisite collaboration on paediatric HIV disclosure in Ghana.* Aids, 2015. **29 Suppl 1**(Suppl 1): p. S35-45.
52. Kallem, S., et al., *Prevalence and pattern of disclosure of HIV status in HIV-infected children in Ghana.* AIDS Behav, 2011. **15**(6): p. 1121-7.
53. Murphy, D.A., W.D. Marelich, and D.M. Herbeck, *Impact of maternal HIV health: a 12-year study of children in the Parents And Children Coping Together project.* The Journal of adolescent health : official publication of the Society for Adolescent Medicine, 2012. **51**(4): p. 313-318.
54. Folkman, S. and R.S. Lazarus, *If it changes it must be a process: study of emotion and coping during three stages of a college examination.* J Pers Soc Psychol, 1985. **48**(1): p. 150-70.
55. Lazarus, R.S. and S. Folkman, *Stress, appraisal, and coping* 1984, New York: Springer Pub. Co.
56. Lorenz, R., et al., *Caregivers' Attitudes towards HIV Testing and Disclosure of HIV Status to At-Risk Children in Rural Uganda.* PloS one, 2016. **11**(2): p. e0148950-e0148950.
57. Mweemba, M., et al., *"When am I going to stop taking the drug?" Enablers, barriers and processes of disclosure of HIV status by caregivers to adolescents in a rural district in Zambia.* BMC public health, 2015. **15**: p. 1028-1028.
58. Mengesha, M.M., Y. Dessie, and A.A. Roba, *Perinatally acquired HIV-positive status disclosure and associated factors in Dire Dawa and Harar, Eastern Ethiopia: a health facility-based cross-sectional study.* BMJ open, 2018. **8**(8): p. e019554-e019554.
59. Krauss, B.J., S. Letteney, and C.N. Okoro, *Why Tell Children: A Synthesis of the Global Literature on Reasons for Disclosing or Not Disclosing an HIV Diagnosis to Children 12 and under.* Frontiers in public health, 2016. **4**: p. 181-181.
60. Petersen, I., et al., *Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: a qualitative investigation.* AIDS Care, 2010. **22**(8): p. 970-978.
61. Louthrenoo, O., P. Oberdorfer, and V. Sirisanthana, *Psychosocial functioning in adolescents with perinatal HIV infection receiving highly active antiretroviral therapy.* Journal of the International Association of Providers of AIDS Care, 2014. **13**(2): p. 178-183.
62. Eneh, A.U., R.O. Ugwu, and N.I. Paul, *HIV Disclosure in Children in a Tertiary Hospital in Southern Nigeria–Child's Perspective.* Asian Journal of Medicine and Health, 2020. **18**(1): p. 16-27.
63. Medecins Sans Frontieres *Khayelitsha 2001–2011, Activity Report: 10 years of HIV/TB care at primary health care level*. 2011.
64. Strategic Development Information and GIS Department CoCT *City of Cape Town—2011 Census—Khayelitsha Health District*. 2013.
65. Hsieh, H.-F. and S.E. Shannon, *Three Approaches to Qualitative Content Analysis.* Qualitative Health Research, 2005. **15**(9): p. 1277-1288.
66. Oken, B.S., I. Chamine, and W. Wakeland, *A systems approach to stress, stressors and resilience in humans.* Behavioural brain research, 2015. **282**: p. 144-154.

67. Folkman, S. and R.S. Lazarus, *If it changes it must be a process: a study of emotion and coping during three stages of a college examination.* Journal of Personality and Social Psychology, 1985. **48**: p. 150-170.
68. Carver, C.S., *COPE Inventory . Measurement Instrument Database for the Social Science.* Retrieved from www.midss.ie, 2013.
69. Pargament, K., M. Feuille, and D. Burdzy, *The Brief RCOPE: Current Psychometric Status of a Short Measure of Religious Coping.* Religions, 2011. **2**(1): p. 51-76.
70. Connor-Smith, J.K., et al., *Responses to stress in adolescence: Measurement of coping and involuntary stress responses.* Journal of Consulting and Clinical Psychology, 2000. **68**(6): p. 976-992.
71. Murphy, D.A., M.J. Rotheram-Borus, and W.D. Marelich, *Factor Structure of a Coping Scale Across Two Samples1.* Journal of Applied Social Psychology, 2003. **33**(3): p. 627-647.
72. Moneyham, L., et al., *The effectiveness of coping strategies used by HIV-seropositive women.* Research in Nursing & Health, 1998. **21**(4): p. 351-362.
73. United Nations Health Rights. *Convention on the Rights of the Child*. 1990; Available from: http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx.
74. Saldana, J., *The coding manual for qualitative researchers*. 2 ed. An introduction to codes and coding. 2013: Sage Publications.

PART B: JOURNAL MANUSCRIPT[2]

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[2] This manuscript will be submitted to the peer-reviewed journal, Aids and Behavior. Submission guidelines are listed in Appendix 5. Tables are not included in the body of the manuscript, but is included in *Part C: Appendices*, as part of the guideline for submission of the aforementioned journal.

Title of Article:	Stressors and Coping Behaviours of Caregivers and Children Across the Pediatric HIV Disclosure Stages in Resource-limited Settings
Suggested Running Head:	COPING BEHAVIOURS ACROSS THE PEDIATRIC HIV DISCLOSURE STAGES
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INTRODUCTION

Pediatric HIV Disclosure

There are an estimated 7.6 million people living with HIV South Africa in 2022; up to 520,000 of which are children (<14 years old) [1]. An important undertaking that can support the long-term management of children infected with perinatally-acquired HIV is pediatric HIV disclosure. When conducted appropriately, disclosure can alleviate the challenges seen in pediatric HIV care: i.e. improve ART adherence, positive psychological outcomes, positive dyads relationship, social support, self-care promotion, and reduction in peer-to-peer transmission [2-12].

The World Health Organization recommended that children of school age should be fully disclosed of their and their parent's HIV positive status; while younger children should be partially disclosed of their status and their parents, incrementally, responding to their cognitive skills and emotionally maturity. The literature recommends early disclosure to ensure early preparations for dealing with the challenges associated with children's HIV [13]. Specifically, full disclosure is recommended prior to children reaching adolescents for adequate transitioning into management of their own health and to prevent initiation of HIV-risk behaviours [13-15].

However, despite recent increases in full HIV disclosure rates, the current level remains inadequate [10, 16-19]. Recent systematic reviews found that HIV serostatus disclosure among children is still relatively low, with prevalence ranging between 9% to 72% and varied dramatically between age (with most children knowing their status only years later after diagnosis); in some cases, with a median disclosure age of 13 years [10, 16, 17, 20, 21]. The likelihood of informing a child aged 10 years and older that they are HIV-positive is 3.01 times higher than the odds of younger children being informed [3]. Additionally, the high prevalence reported in the literature has been suggested to be an overestimation of reporting since caregivers are more likely to report full-disclosure, compared to self-reported status by children [22].

Barriers of Pediatric HIV Disclosure

The low disclosure rates of children/adolescents with perinatally-acquired HIV in resource-limited settings have been largely contributed by the compounded barriers associated with HIV-disclosure.

HIV alone is already an extremely stressful and demanding illness to those affected, involving factors such as stigma, the risk of death, adherence to complex medication regimens, side effects of ART, disease progression symptoms, frequent hospital visits, and identity challenges [18, 23-27].

Disclosure adds further complexity, in that it implicates both the caregiver and the child. Caregivers often fear harm to the parent-child relationship, shame, the child's inability to cope, self-harm, and emotional distress (e.g., sadness, resentment, or depression) [2, 16, 26, 28-42]. Studies highlight disclosure as a painful experience for caregivers, inducing guilt, anxiety, and fear, often involving the exposure of family secrets [7, 10, 11, 14, 38, 42-46]. Additionally, disclosure can lead to harmful discrimination and stigmatization towards the dyads from the community or family members [11, 22, 33, 34, 36, 38-40, 42, 46-54].

Disclosure and Coping Behaviours

Lazarus and Folkman conceptualized coping as a cognitive and behavioral response aimed at managing stressful appraisals (involving threats, challenges, or losses) that surpass an individual's resources [55-57]. Coping serves a functional purpose by either regulating distressing emotions (emotion-focused coping) or addressing the problem causing distress (problem-focused coping). Problem-Focused Coping is used in situations where individuals believe they can influence the outcome or perceive the situation as changeable. This involves taking direct actions to manage or solve the problem. Emotion-Focused Coping is used when the stressor is perceived as beyond one's control to regulate their emotional response. This may involve seeking social support, positive reframing, or acceptance. Emotion-focused coping is employed in encounters viewed as unchangeable [55].

Although no formal study has explored caregivers' and children’s coping mechanisms amidst all the stressors associated with pediatric HIV disclosure, related studies however have touched on coping behaviors. For example, caregivers would often provide minimal explanation of the disease during the pre-disclosure stage using non-stigmatizing chronic illnesses to delay pediatric disclosure, or provide minimal explanation for hospital visits to the child [18]. Other coping strategies are *selective* disclosure *and seeking social support*, including caregivers seeking advice from HIV counselors [58]. In children, confusion and frustration about medication use and hospital visits often lead to *confrontive coping behaviors*, such as persistent questioning and threats to stop medications [2, 7, 14, 58-60].

Studies investigating coping strategies of post-disclosure found that children used resignation to deal with medication adherence-related stressors [61] or *prayer/religions* to deal with HIV-related stressors [62]. Children also used techniques such as, ventilating feelings and being humorous to promote psychological adjustment after disclosure [63]. To cope with self-stigma or perceived stigma, youth living with HIV often used non-disclosure with family, friends, and workplaces/school, and avoidance of romantic relationships and health care [25]. Studies in low- and middle-income countries highlight the importance of positive coping mechanisms, like medication adherence, treatment optimism, and familial/peer social support, for adolescents' overall well-being [53, 64, 65]. In a recent systematic review, Chem et al, 2022, identified “self-management needs (desire for better coping strategies)” as one of the top 3 category health needs among ALWH [66].

Current Study

Careful management of stressors is crucial. Understanding effective coping behaviours is vital for promoting optimal disclosure processes, outcomes, and timely disclosure. The lack of empirical studies on stressors and coping behaviours during pediatric HIV disclosure stages underscores the need for further research.

Applying Lazarus and Folkman's (1984) [55] transactional theory of stress and coping, this research study aimed to explore disclosure stressors that emerged during the various stages of pediatric HIV disclosure and examine how the associated behaviours of caregivers and children align within the context of coping. This study used qualitative data from a larger research project that investigated the disclosure experiences of caregivers and children with perinatally-acquired HIV in South Africa.

Understanding disclosure stressors and coping use during the disclosure stages is pertinent for the development of relevant interventions that can improve rates of pediatric HIV-disclosure. This study is important for intervention development for caregivers and children/adolescents with perinatally-acquired HIV facing disclosure stressors, and for the health-care providers who work with them.

METHODOLOGY

1. Study Design

This study utilized data derived from a larger research project conducted by the University of Cape Town and MSF Khayelitsha: The Caregiver-led Disclosure Programme (CDP) Research Study. The principal objective of the CDP study was to capture the reality and barriers surrounding the disclosure processes to inform the development and enhancement of program materials. The CDP study delved into the disclosure experiences of caregivers and perinatally infected HIV-positive children through conducting focus groups (FGD) and in-depth interviews (IDI). Participants were prompted to recount the diverse day-to-day experiences and difficulties they had faced throughout the disclosure stages. The CDP research study had an iterative design and data reached saturation.

For this particular analysis, data from all the IDIs and FGDs of the original study were extracted and examined. Specific aspects from the transcripts related to disclosure stressors and associated behaviours of caregivers and children throughout the disclosure stages were analyzed to see how they align within the context of coping.

The CDP recruited 54 consenting caregivers and 27 children (not dyads) between 2014-2015 in Khayelitsha, Cape Town, South Africa. Participants were chosen by way of purposive sampling from 1 clinic and 2 local NGOs involved in disclosure practices. To be eligible for the study, caregivers had to care for a HIV positive child and were involved in the disclosure process of the child (partial or full). The child had to be between the ages of 6-18 years during the enrolment of the study, HIV positive, and already fully disclosed of their status. Initial recruitment of caregivers and children at clinics and NGOs was conducted by clinic staff (i.e. counselors) and institutional staff who have worked closely with the caregivers and children on disclosure.

During the time of data collection, Khayelitsha was known to be the largest township in the Western Cape Province and has one of the highest burdens of HIV infection in South Africa, with prevalence of HIV antenatal at a high of 26% in 2010 [67]. It was in 2004 that pediatric ART was decentralized to primary clinics. ART programmes for children in Khayelitsha resulted in significant improved mortality at 5 years on ART. Mortality rates has steadily decreased between 2003 to 2009 for infants on ART [67].

2. Data Analysis

To promote a more structured process than the conventional method of qualitative synthesis, a directed approach to content analysis [68] was utilized for the current study in establishing stressors and coping behaviours. Codes for stressors and coping mechanisms were defined before and during data analysis. Transcripts were highlighted for all texts that on initial impression appeared to represent a disclosure stressful appraisal, reported emotions, instances/experiences of coping or coping behaviours. All highlighted passages were coded using the predetermined codes. To increase the trustworthiness and internal validity of the findings, text that could not be categorized with the initial coding scheme were given a new code, as recommended by Hsieh & Shannon, 2005 [68].

Establishing Disclosure Stressors

In accordance with Lazarus and Folkman's Transactional Model of Stress and Coping [55-57], it was important to establish that disclosure stressors existed within the disclosure stages. Disclosure stressors were circumstances/events that caused stress to the caregivers and children. Oken and colleagues [69] explained that, “the state of stress results from a perturbation arising from the internal or external environment (stressor).” Hence, without stressors, stress does not exist and there is not much need for coping. Similarly, Folkman and Lazarus, 1985, defined stress as ‘a relationship between the person and the environment that is appraised by the person as relevant to his or her well-being and in which the person’s resource are taxed of exceeded’, pg. 152. Coping methods are efforts to manage this negative person-environment-relationship. Within this framework, we studied the data to define and understand the stressors (causes of stress) during disclosure that initiated caregivers and children’s coping. Examination of stressors involved two aspects: stressful appraisals (i.e. threat, challenge or harm-loss) and/or reported emotions [56]. Only data that held either of these two variables were considered as stressors.

Identifying Behaviours as Conventional Coping Mechanisms

Transcripts were highlighted for all texts that on initial impression appeared to depict behavioral responses to the stressors associated with disclosure. Behavioural responses to disclosure stressors were then analyzed to see if they correspond with the current definition of conventional coping mechanisms from commonly use batteries in the HIV literature [24]: the COPE Inventory [70], Ways of Coping Battery [71], The Brief RCOPE [72], and Responses to Stress Questionnaire [73]. Other scales that were developed specifically for coping with HIV were also considered:

- Murphy et al. (2003) [74]: Positive Action, Passive Problem Solving, Self-Destructive Escape, Social Support, Spiritual Hope, Depression/Withdrawal, and Nondisclosure/Problem Avoidance.
- Moneyham et al.'s (1998) [75]: Seeking Peer Support, Living Positively, Managing HIV Disease, Seeking Support of Family/Friends, Isolation/Withdrawal, Spiritual Activities, Denial/ Avoidance, and Seeking Information.

Behavioural data were also analyzed with the goal to identify new types of coping strategies that was specific to pediatric-HIV disclosure.

To ensure further validity and reliability of interpretation of data, triangulation of sources and negative deviant case analysis were utilized to achieve analytical roundedness and trustworthiness. Consistency of findings were compared with the existing coping literature. Elements of data that contradicted patterns or explanations were taken into consideration to add, refine, or revise the interpretation of the findings.

For the purpose of this study, only situational behaviours (how one copes with the recent event, i.e. disclosure stressors) was assessed. Dispositional coping behaviours (how one usually copes with stress) was not within the interest of this study. Although there was certainly overlap between dispositional and situational coping in our data, they were not identical.

3. Ethical Considerations

Permission for use of data was obtained from the University of Cape Town Research Ethics Committee (REF: 399/2021). Voluntary written and verbal informed consent were obtained during the main CDP study: invitation sessions and the consent process were conducted in the preferred language of the participants; written consent and assent were obtained prior to the interviews and FGDs; children with legal guardians who were not readily accessible were consented by their main caregiver after efforts of contacting the guardian was taken without success.

Inclusion of children's views and coping use' in this study is essential and in line with the UN Convention of the Rights of the Child (CRC). Taking into consideration and accounting for children's suggestions and views in all matters affecting them is in support of their participation rights noted in Article 12 of the CRC[76].

RESULTS

Demographics

All the IDIs (n=8) and FGDs (n=6) from the original (CDP) study were extracted and examined for the purpose of this study. This includes data from all the participating 54 caregivers and 27 children. It's important to note that the eight IDIs exclusively involved caregivers, while the six FGDs encompassed three groups of caregivers, two groups of children, and one mixed group of both caregivers and children. Notably, the participants in all the IDIs and FGDs were distinct to ensure a diverse range of perspectives and experiences in the research findings. Participants' summary statistics are described in Table 1.

The transcripts of the original study captured a comprehensive exploration of caregivers' and children's experiences, encompassing the periods preceding, during, and following disclosure. This includes actions taken before and after pediatric HIV disclosure, strategies employed in managing the disclosure process, and insights gained about HIV. The transcripts also revealed identification of supportive figures, encountered barriers and challenges throughout the disclosure stages, and factors contributing to their coping during disclosure and post-disclosure behaviors. Emotional responses and concerns such as fears and anxiety were also reported by caregivers and children in the transcripts. Additionally, the transcripts provided reflections on existing disclosure interventions and the desired changes or additions to enhance these interventions, along with any utilized resources (i.e. clinics).

1. Disclosure Stressors

Recall that examination of stressors involved two aspects: stressful appraisals (i.e. threat, challenge or harm-loss) and/or reported emotions [55-57]. Only data that held either of these two variables were investigated as stressors.

Table 1. Characteristics of Study Participants (N=81)

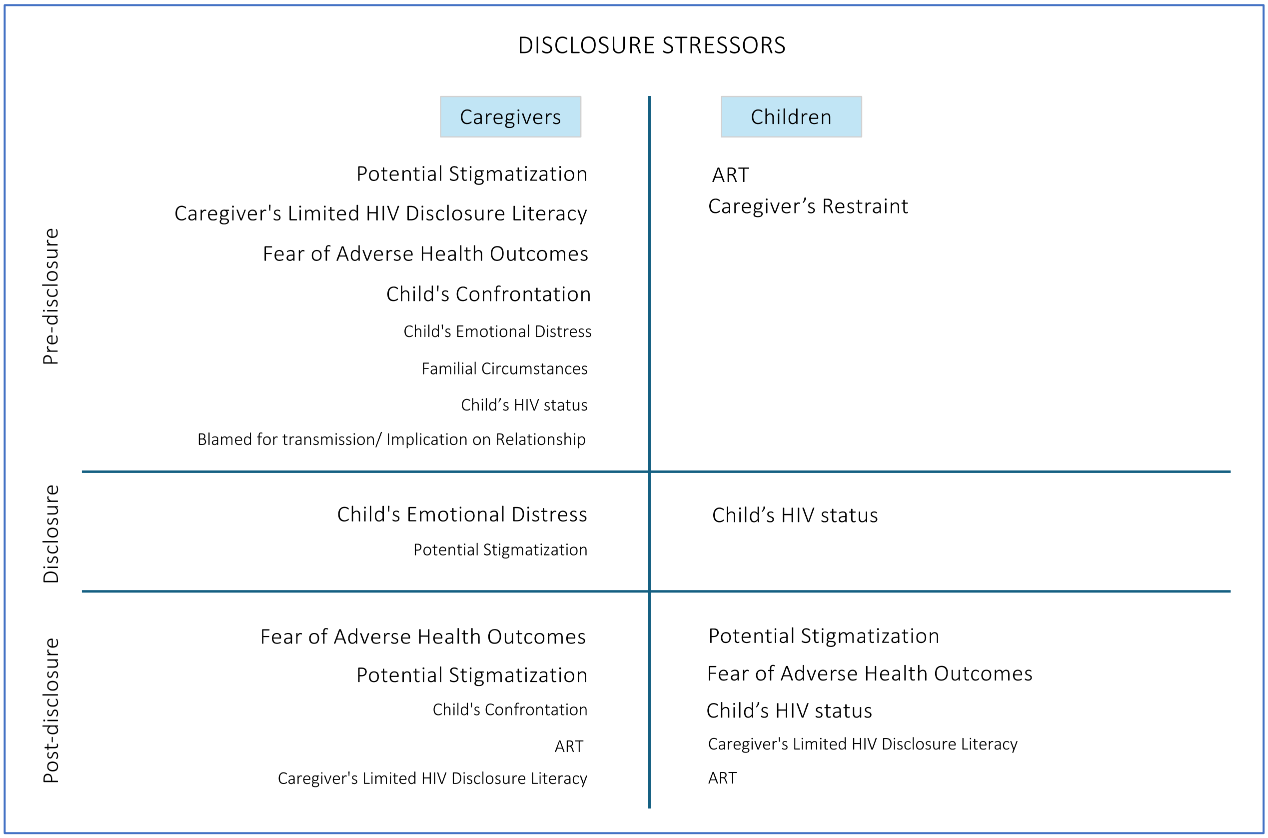
Characteristics	n (%)
Caregivers	54 (67)
Children	27 (33)
Caregiver’s Age	
20-30	15 (28)
31-40	27 (50)
41-50	1 (2)
Unknown	11 (20)
Caregiver’s Sex	
Female	51 (94)
Male	3(6)
Caregiver’s relationship to the child	
Mother	46 (85)
Father	1 (2)
Aunt	6 (11)
Uncle	1 (2)
Caregiver’s HIV status	
Positive	6 (11)
Negative	2 (4)
Unknown	46 (85)
Child’s ages	
5-7	5 (19)
8-10	15 (56)
11-15	7 (26)
Child’s sex	
Female	18 (65)
Male	9 (35)
Child’s age at disclosure	
5-7	3 (11)
8-10	18 (67)
11-15	4 (15)
Unknown	2 (7)
Child on ART	
Yes	23 (85)
No	4 (15)

Analysis of the transcriptions identified 10 main disclosure stressors during the course of the disclosure stages: Potential Stigmatization, Child's Confrontation, Child's Emotional Distress, Blamed for vertical transmission, Caregiver's Limited HIV Disclosure Literacy, Caregiver’s Restraint, Familial Circumstances, ART, Child’s HIV status, and Fear of Adverse Health Outcomes. Out of the 10 stressors, five could not be categorized using the initial coding scheme, thereby given a new code: Child's Confrontation, Caregiver's Restraint, Caregiver's Limited HIV Disclosure Literacy, Familial Circumstances, and Fear of Adverse Health Outcomes. Factors shaping the stressors were at the level of the disease, caregiver, child, or the community. The majority of the disclosure stressors presented as a threat or harm to either the caregiver or child's health (physical/mental) or their social well-being. Reported emotions associated with the stressors for both caregivers and children were a combination of fear/anxiety, anger, frustration, confusion, sadness, and/or guilt. Table 2 provides a full description of the stressors, along with the supporting quotes.

Most reported disclosure stressors by both caregivers and children were *Fear of Adverse Health Outcomes* and *Potential Stigmatization*, which was experienced throughout the disclosure stages. Caregivers' highest reported stressor was their own *Limited HIV Disclosure Literacy (pre-disclosure phase),* as it impeded their ability to conduct full-disclosure. Children's highest reported stressors were ART and Caregiver's Restraint, experienced during the pre-disclosure phase. Figure 1 depicts the placements of stressors throughout the disclosure stages, with highly reported stressors highlighted in bold.

Potential Stigmatization:

Caregivers experienced persistent concerns about potential stigmatization, a recurring stressor, particularly in the pre-disclosure stage. This anxiety stemmed from worries about their children facing discrimination due to their HIV-status, fueled by concerns about the child's inability to keep the diagnosis confidential. Factors contributing to this stressor included the child's young age, level of maturity, poor understanding of negative social views of HIV/AIDS, and child's



DISCLOSURE STRESSORS

	Caregivers	Children
Pre-disclosure	Potential Stigmatization Caregiver's Limited HIV Disclosure Literacy Fear of Adverse Health Outcomes Child's Confrontation Child's Emotional Distress Familial Circumstances Child's HIV status Blamed for transmission/ Implication on Relationship	ART Caregiver's Restraint
Disclosure	Child's Emotional Distress Potential Stigmatization	Child's HIV status
Post-disclosure	Fear of Adverse Health Outcomes Potential Stigmatization Child's Confrontation ART Caregiver's Limited HIV Disclosure Literacy	Potential Stigmatization Fear of Adverse Health Outcomes Child's HIV status Caregiver's Limited HIV Disclosure Literacy ART

Figure 1. Stressors Reported by Caregivers and Children Throughout the Disclosure Stages.

talkative nature. Additionally, accidental disclosure of the child's HIV-status raised concerns about inadvertently revealing the caregiver's own HIV-status. Post-disclosure, children also reported fearing stigmatization from family members or close friends. Table 2 provides descriptions of disclosure stressors and supporting quotes of caregivers and children.

Child's Confrontation:

Children's resistance to the extended use of medications before and after disclosure posed a recurring stressor for caregivers. This resistance was marked by expressions of anger directed at caregivers, persistent questioning about medication responsibilities, and instances of 'standing one's ground' through consistent refusals of Antiretroviral Therapy (ART), indicating non-adherence. Children's refusal to take ART post-disclosure was due to late disclosure.

Child's Emotional Distress:

Caregivers conveyed concerns and apprehensions regarding the potential emotional distress and negative psychological impact that full disclosure might impose on the child, such as feelings of anger, fear, or sadness. There was a prevailing fear that the child might struggle to cope effectively, leading to outcomes such as non-acceptance, withdrawal, and diminished self-esteem. Caregivers found these perceived fears or worries to be particularly challenging to manage, with limited capacity to address them effectively.

Blamed for vertical transmission/Negative Implication on Relationship:

Pediatric HIV-disclosure often led to the disclosure of the caregiver's own HIV-status to the child. Caregivers had fears about being 'blamed' for transmitting HIV to their children. They were concerned that children's knowledge of the vertical transmission would negatively impact the relationship they had with their children. There were reports of children blaming their caregivers for 'infecting' them and 'not protecting' them. Caregivers reported that most children believed that their caregivers wanted them to have HIV.

Caregiver's Limited HIV Disclosure Literacy:

Caregiver's limited knowledge about HIV or disclosure emerged as a widely reported stressor to Caregivers themselves. Caregivers faced challenges in various aspects, including not knowing:

- When to initiate disclosure or how to conduct it appropriately to mitigate negative outcomes such as emotional distress, the risk of stigmatization, or blame.

- How to support children in adhering to medications over the long term.
- How to respond to post-disclosure questions from children regarding HIV.
- How to communicate with younger children about their disease and medication responsibilities.

Inadvertently, caregiver's lack of HIV knowledge is also a stressor for children during the post-disclosure stage, preventing children from obtaining essential answers to their questions about HIV. In some cases, caregivers reportedly discouraged children from asking questions about their disease due to their own uncertainties about how to address them.

Caregiver’s Restraint:

Caregiver's decision to withhold pediatric HIV full-disclosure emerged as a stressor for children in the pre-disclosure stage. This restraint was classified as caregivers delaying disclosure until they deemed it appropriate. For instance, caregivers will provide minimal or false explanations about the illness or false explanations about medication responsibilities, such as framing it as asthma or tuberculosis.

Familial Circumstances:

Distinct family circumstances emerged as stressors during the pre-disclosure stage, impeding full disclosure. Examples include:

- Unsupportive family members cohabiting in the same household.
- The caregiver not being the biological parent, a fact unknown to the child.
- Husband infected the mother, left the family after HIV diagnosis, and died of AIDS.

ART:

ART emerged as the most frequently reported stressor for children during the pre-disclosure stage, attributable to its long-term use and complex medication regimen. In this phase, children perceived ART as purposeless due to the lack of explanation for medication use and it being disruptive to their social life. Adherence to ART also posed challenges after full disclosure, particularly among late-disclosed children. Furthermore, the long-term use of ART imposed in children the need to form a new identity with 'others who eat pills like them'. The need to form a new identity was reported as a stressor for children. For caregivers, post-disclosure, accepting and ensuring their children's need for long-term use of ART was also challenging.

Child's HIV status:

The revelation of the child's HIV diagnosis reported to be a stressful experience for both caregivers (pre-disclosure) and children (during disclosure or immediately following disclosure). Learning about HIV status or the vertical transmission of HIV was stressful for both caregivers and children. Caregivers reported feelings of fear and shock upon initially learning about their child's diagnosis. Simultaneously, children underwent a range of emotional responses, including worry, anxiety, sadness, anger, a sense of injustice, confusion, fear, hopelessness, and stress, following the disclosure of their diagnosis. Following full-disclosure, it was commonly reported that most children exhibited signs of emotional distress, such as crying, immediately after the revelation. One child was reported to cope poorly post-disclosure, such as hitting and harming their peers. However, these reactions were short and non-lasting. Children also reported fear and resentment towards the caregiver after disclosure due to the vertical transmission or for lying to them about the disease.

Fear of Adverse Health Outcomes:

Both caregivers and children perceived HIV as a 'death sentence'. This perception was a major stressor for caregivers and children, which led to various coping mechanisms.

2. Coping Behaviours of Caregivers and Children

Analysis of the transcriptions identified 12 primary behaviours exhibited by both caregivers and children in response to the 10 stressors across the disclosure stages. Out of the 12 reported behaviours, ten of which corresponded with the conventional description of coping strategies (identified in commonly used batteries from the HIV and coping literature): COPE Inventory [70], Ways of Coping [71], Responses to Stress Questionnaire [73], Murphy et al., 2013 [74], and Moneyham, 1998 [75]. Table 3 (Appendix 6) presents the 10 disclosure coping behaviors identified in this study, accompanied by the matched item descriptions from the 4 coping batteries and relevant literatures. Two new coping strategies were identified from the transcriptions (Selective Disclosure Coping and Suicidal). Table 4 lists the coping strategies and their associated stressors.

Figure 2 depicts the types of coping used throughout the disclosure stages by both caregivers and children. The transcripts revealed a spectrum of Adaptive coping strategies, including Social Support, Restraint Coping, Selective Disclosure, Active Coping/Problem Solving, Positive Thinking/Cognitive Restructuring, Religious Coping, Acceptance, Information-seeking, etc.. However, children were reported to use more maladaptive coping strategies at post-disclosure than caregivers.

Table 2. Description of Stressors and Supporting Quotes Identified Throughout the Disclosure Stages

Stressors	Description	Quotes
Potential Stigmatization *Caregivers: All stages, but mainly pre-disclosure* *Children: Post-disclosure*	• Discrimination from peers, friends, community members, or family due to the child's HIV status • Contributing factors: child's inability to keep diagnosis a secret, child's young age, level of maturity, poor understanding or awareness of the negative social views of HIV/AIDS, and talkative nature • Caregivers feared the unintentional disclosure of child's HIV-status might unveil their own HIV status to the community	• *"They are childish and don't know about secrets, that's why it's difficult to tell them. They may share their status with friends who will later tease them." – Caregiver, FGD* • *"Yes I had them (fears). My son is someone who talks. I was scared that if I tell my son that he is HIV-positive, he will go out and tell it to other kids. Other kids will be told at their homes to not play with my son because my son is sick, he is not right." –Caregiver, FGD* • *"If I'm not ready yet for the community to know my status, it won't be wise to tell a 6 year old. Because once you tell a 6-year-old, he will tell others. So, you need to be ready first that the community will potentially know of your status" –Caregiver, FGD* • *"I'm not gonna tell my cousins because they will laugh." –Child, FGD*
Child-related Stressors		
Child's Confrontation *Caregivers: Pre- and post-disclosure*	• Children's resistance to medication use before or after full-disclosure • Expressions of anger directed at caregivers • Persistent questioning about medication responsibilities (pre-disclosure) • Instances of 'standing one's ground' through consistent refusals of Antiretroviral Therapy (ART), indicating non-adherence (pre- and post-disclosure) • Children's refusal to take ART post-disclosure was due to late disclosure	• *"My child asked me every time when I gave her medication. She said, "It is for what?" Sometimes she doesn't want to eat. So, I used to force her." – Caregiver, IDI* • *"…I had to tell the child because he was refusing to take his treatment and he was always asking why I even call him when he is busy playing to come take his treatment, but I do not call the other kids to come and take medication like him. I had to then tell him that he is living with HIV." – Caregiver, FGD* • *"Mum, I tested positive today, but I know I was positive from birth because I was taking the medication, so I knew that medication. But you didn't tell me that I'm HIV positive. I (had to) find out at school with my friends. Then he refused to take the medication at all." –Caregiver, FGD* • *"I couldn't force her. I thought to give her time and prayed to God that she would not get sick since she is off the medication, but thank God she is still fine." –Caregiver, IDI*
Child's Emotional Distress *Caregivers: Pre- and*	• Concerns and apprehensions that full-disclosure will cause emotional distress to the child: anger, fear, or sadness • Fear of negative psychological impact: child not coping well, non-acceptance of diagnosis, withdrawal, and diminished self-esteem	• *"Parents are scared... afraid that the daughter will cry or get angry." – Caregiver, IDI* • *"(parents don't disclose) …because they think their children will have a low self-esteem, withdrawing from their parents or peers… maybe they will look down on themselves now… commit suicide and be angry at the parent" – Caregiver, IDI*

during-disclosure		- *"I was scared for the child as well, because my biggest fear was him not wanting to know anything about it (or to acknowledge it)." –Caregiver, IDI* - *"The first time that I told him, eish, it was not nice, he cried." – Caregiver, IDI*
	Caregiver-related Stressors	
Blamed for vertical transmission/ Negative Implication on Relationship *Caregivers: Pre-disclosure*	- Pediatric HIV-disclosure frequently results in the revelation of the caregiver's own HIV-status to the child. - Caregivers express fears of being 'blamed' for transmitting HIV to their children during disclosure. - Concerns arise about the potential negative impact on the caregiver-child relationship due to the child's understanding of vertical transmission. - Reports indicate instances where children attribute blame to their caregivers, accusing them of 'infecting' and 'not protecting' them. - Caregivers report that a majority of children believe their caregivers intended for them to acquire HIV.	- *"A lot of kids like placing the blame on their mothers, and say the reason why I am like this is because of you. They refuse to accept their status for what it is. They make it seem like it is their mother who wanted it to be that way, as they wonder why you never protected me, because I depended on you in every way, you see. There is a child who rebelled and started drinking, saying that he/she is already dead anyway because her mother never cared for her, so they like placing the blame on people. Therefore, the parents have fear that keeps them from disclosing." –Caregiver, IDI* - *"(parents don't disclose) …they do not want to spoil the relationship with the child, they brought it to them. Blame the parents." –Caregivers, IDI*
Caregiver's Limited HIV Disclosure Literacy *Caregivers: Pre- and post-disclosure* *Children: Post-disclosure*	- Caregiver's limited knowledge about HIV or disclosure - Challenges faced by caregivers (mainly at pre-disclosure): uncertainty about when to initiate disclosure or how to conduct it appropriately; lack of knowledge on supporting children in adhering to medications over the long term; uncertainty about responding to post-disclosure questions from children regarding HIV; difficulty in communicating with younger children about their disease and medication responsibilities - A stressor for children (post-disclosure) who want to obtain essential answers to their questions about HIV	- *"I don't have the guts to tell him. So, the group tried to constantly teach me ways in which I can disclose to him, but I could not accept it. I took time without telling him. Yes, I had them (fears). I even used to come to my counsellor and tell her that I have no idea where to even start. My son is someone who talks." –Caregiver, IDI* - *"You must explain that this medication is for life, that is the other thing that is so difficult for; It is for life, it is not nice to take medication for life." –Caregiver, FGD* - *"I always wanted to tell her, but I didn't know how. But because of these books, it made it very easy for me to disclose." –Caregiver, FGD* - *"When my parents don't like answering questions, I go to the clinic and ask questions to the counsellor." –Child, Mix FGD* - *"If I can't answer my child's questions, I will simply ask him to talk to the clinic's support group." – Caregiver, Mix FGD*
Caregiver's Restraint *Children: Pre-disclosure*	- Caregiver's decision to withhold/delay pediatric HIV disclosure until deemed appropriate - Caregivers providing minimal explanations about the illness to children - Offering false explanations about medication	- *"I told her the sleeping germ was HIV when she started attending the group. Previously, I used to tell her that she has TB, as I was scared of telling her about HIV. She also had TB as well, so I used to tell her that TB is infectious and that she needs to drink her pills. She used to get angry; she used to*

	responsibilities (e.g., framing it as asthma or tuberculosis)	*have that anger...even if she drinks the pills, she will say, 'Always we drink these pills all the time!" –Caregiver, IDI* - *"My child was also asking me, 'why mommy I always take these tablets? When am I going to be finished with these tablets?' So I always say, 'Never, because you've got eczema.' Then she'd say, 'Mommy, I don't have eczema now, why (do) I still (have to) take these tablets?' So she was always pressurising me." –Caregiver, FGD*
Familial Circumstances *Caregivers: Pre-disclosure*	- Unique family situations became stressors during pre-disclosure For example: - Unsupportive family members living in the same household - Caregiver not the biological parent, unbeknownst to the child - Husband infected the mother, left the family after HIV diagnosis, and died of AIDS	- *"Parents do not disclose because maybe they are with their families, weather they get along with their family or get along with who they are staying with. Are they supportive? The parents will chase you out. It happens with HIV too, you see. You can't use the same cup, you must have your own. IT depends on the understanding of the family. When they react differently with you because you are HIV, … I think that is a thing with our community." –Caregiver, IDI* - *"What stressed me, as the foster mother…the child will ask where they got (HIV) from. Unfortunately, that required me to first tell and explain to the child that I am not the biological mother, I am the foster mother." –Caregiver, FGD* - *'I hoped that God granted me the serenity to accept it (husband left her and child after HIV diagnosis, and husband died due to AIDS)" –Caregiver, IDI*
Disease-related Stressors		
ART *Caregivers: Post-disclosure* *Children: Pre- and post-disclosure*	Children Pre-disclosure: - Frequency: Most frequently reported - Attribution: Long-term use and complex medication regimen - Perception by Children: Purposeless due to lack of explanation, disruptive to social life Post-disclosure: - Adherence issues, especially among late-disclosed children - Additional Stressor: Imposed need to form a new identity with 'others who eat pills like them' Caregivers: - Post-disclosure Challenge: Ensuring and accepting children's long-term use of ART	- *"She used to...she used to get angry; she used to have that anger of...even if she drinks the pills, she will always say, 'We drink these pills all the time,' you see?" -Caregiver, IDI* - *"You see before, he used to raise repeatedly the issue of the pills. He used to ask why he had to eat pills, at what point can he stop eating these pills. Sometimes he will go crazy." –Caregiver, IDI* - *"My child asked me every time when I gave her medication. She said, 'It is for what?' Sometimes she doesn't want to eat. So I used to force her." –Caregiver, IDI* - *"If I were to give it to her, she won't take it, I would (later) find it lying around the house. I couldn't force her to take it. She drinks in front of me, but then the next morning, I see it lying around the house. She told me that she will not take the pills anymore, she is tired of taking the pills." –Caregiver, IDI*

		• *"I said I would buy him the sneaker if he took his treatment properly and his blood tests are good in January. So, he got that Airmax because I am basically begging him for his wellbeing." –Caregiver, FGD* • *"We cannot tell them because they are children who cannot understand properly. When the child takes the pills, they do not actually want to see it, so we had to make them porridge or yoghurt and hide the pill in it and they swallow it like that." – Caregiver, FGD*
Child's HIV status *Caregivers: Pre-disclosure* *Children: During or post-disclosure*	• Child's HIV diagnosis revelation; Learning about HIV status or vertical transmission • Stressful for caregivers (pre-disclosure) and children (during/post-disclosure) Caregivers: • Caregivers reported feelings of fear and shock Children: • Children experienced worry, anxiety, sadness, anger, sense of injustice, confusion, fear, hopelessness, stress (however, reactions were short and non-lasting) • Most children exhibited signs of emotional distress, such as crying, immediately during full-disclosure • One child reported coping poorly, engaging in hitting and harming peers. • Fear and resentment towards the caregiver (due to vertical transmission or for lying to them about the disease)	• *"When you first hear about this (the child's diagnosis), you get such a fright. So, we get help and courage from counsellors here at the clinic." Caregiver, FGD* • *"The child used to vent her frustration, saying that she does not understand why she tested positive when all her siblings tested negative." – Caregiver, FGD* • *"Some kids would think that there is no need for them to study further after learning about their HIV status. So that child would decide not to continue with school." – Caregiver, FGD* • *"I was scared to stay with my mother after she told me about my status. Then I left to stay with my aunt. I felt safer to stay with my aunt." –Child, FGD* • *"(post- disclosure) I played outside all day and came back home only to sleep. This went on for two weeks. (to avoid the parent)." –Child, FGD* • *"Yes, she became angry because I told her (of her HIV-diagnosis). Even here at home she would start hitting other children...when I told her that it can't be healed. Eish, it is difficult when a child starts hitting others. – Caregiver, IDI* • *"One thing to look out for after disclosure is that the child could commit suicide." –Child, FGD*
Fear of Adverse Health Outcomes *Caregivers: Pre- and post-disclosure* *Children:*	• HIV as a 'death sentence' • Constant stressors for caregivers and children due to the likelihood of disease progression or death, which led to various coping mechanisms	• *"I think the other thing that makes it difficult for the parents is...what the children know is that if someone has AIDS, then they are going to die...so it will be difficult...we are supposed to explain all those things to them." – Caregiver, FGD* • *"(post-disclosure) The community believes that if you have got HIV you are going to die. So, I thought my child was thinking the same thing." – Caregiver, IDI* • *"I told the teacher at his school that he is HIV positive because I want him safe. I will also tell the next teacher, next year about his status." –Caregiver, IDI*

Post-disclosure		• *"Even, maybe, (the case of) a grandmother's daughter passed away because of HIV, so now the grandmother is afraid of telling her grandchild, you are now eating ARVs because you are HIV positive." –Caregiver, IDI* • *"What you can tell a newly infected child is: 'It is best to adhere to your treatment and eat healthy food so that you remain in good health.'" –Child, FGD* • *(post-disclosure) "God is going to help us to live long." –Child, FGD* • *"And what is very important is that we tell them that there is life. Even though they are HIV positive, they've got life, they can be married, and they can have kids. Because if they don't know (this), they will think that they do not have a life" –Caregiver, FGD* • *"(post-disclosure) So I just make it like it is any other diseases… like any other sickness. I didn't want her to take it seriously, because almost everyone is sick and taking meds." –Caregiver, IDI* • *"And I just told her now that if every time she takes her blood test and it is LDL then, I will give her R50 the first time and then if the second time it is still LDL then I will give her R100, and it has been working.'"-Caregiver, FGD*

Acceptance Coping: Adaptive

Caregivers' and Children's accounts of acceptance behaviors aligned with the Acceptance Coping tendencies outlined in the COPE Inventory (Items 13, 21, 44, and 54) (Carver, 2013).

Caregivers (pre-disclosure): In the pre-disclosure stage, caregivers employed acceptance coping, which involved acknowledging and personally accepting the reality that their child had HIV, recognizing the inability to change the diagnosis. Acceptance coping for caregivers also extended to embracing the child's long-term use of antiretroviral medication.

Table 4. List of Coping Strategies and Corresponding Disclosure Stressors

Coping Strategies	Disclosure Stressors
Acceptance Coping	ART (long-term use); Child’s HIV Status; Fear of Adverse Health Outcomes
Active Coping/ Problem-Solving	ART (non-adherence); Fear of Adverse Health Outcomes; Potential Stigmatization
Behavioural Disengagement	Blamed (vertical transmission); Child's Emotional Distress; Child’s HIV Status; Familial Circumstances; Potential Stigmatization
Confrontive Coping	ART (long-term use); Caregiver’s Restraint
Escape-Avoidance/ Tension Reduction	Blamed (vertical transmissions); Child’s HIV Status
Information-seeking	Child’s HIV status
Positive Thinking/ Cognitive Restructuring	Child's Emotional Distress; Child’s HIV status; Fear of Adverse Health Outcomes
Religious Coping	Child’s HIV status; Confrontive Coping; Familial Circumstances; Fear of Adverse Health Outcomes
Restraint Coping	Blamed (vertical transmission); Confrontive Coping; Child’s Emotional Distress; Potential Stigmatization
Selective Disclosure	Potential Stigmatization
Social Support	Caregiver's Limited HIV Disclosure Literacy; Child’s HIV Status; Potential Stigmatization;
Suicidal	Caregiver’s Restraint; Child’s HIV status

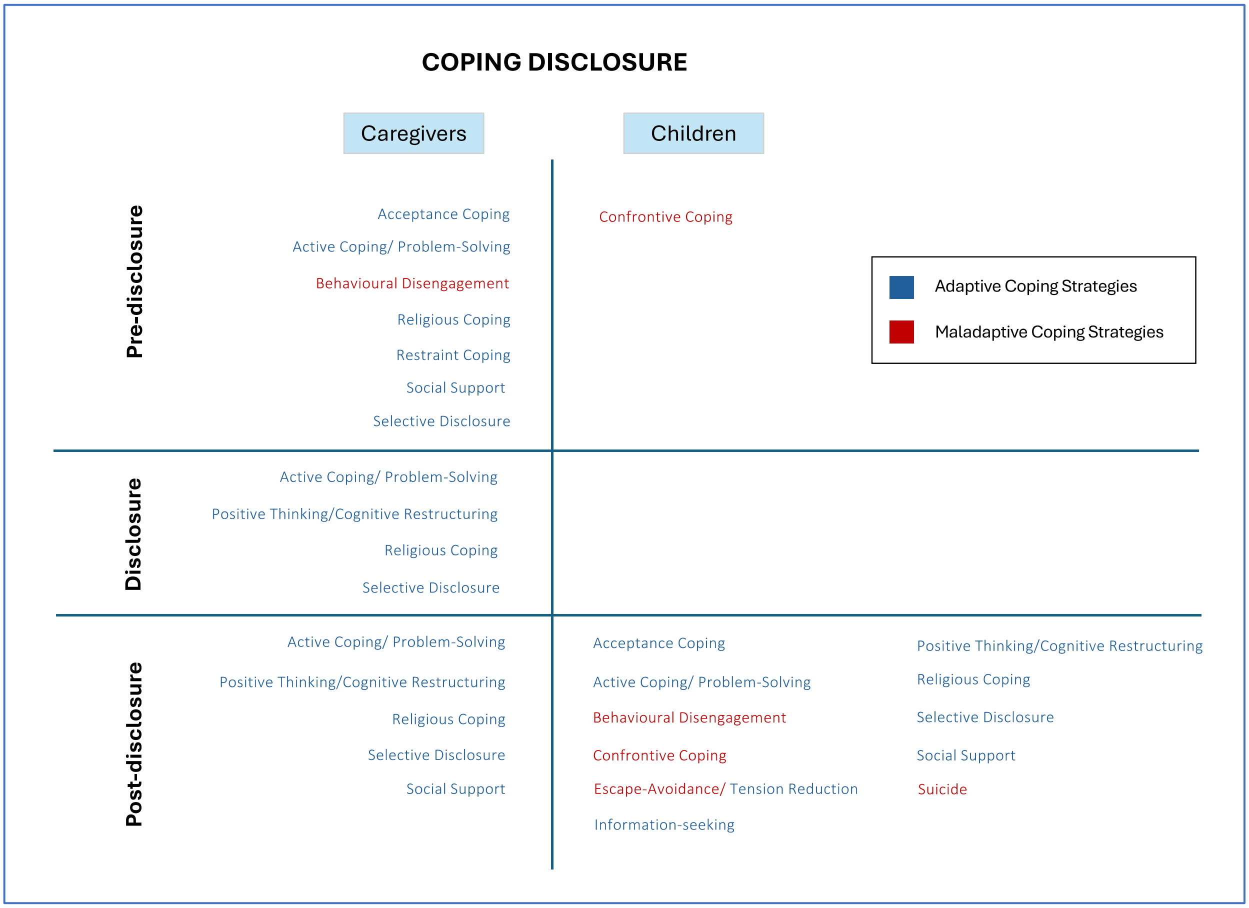


Figure 2. Coping Strategies Used by Caregivers and Children Across the Disclosure Stages.

Children (Post-disclosure): At post-disclosure, children adopted acceptance coping as they reported "getting used to the disease." This process involved coming to terms with the fact that HIV was a part of their lives, something they had to face and live with. It represented a realization that living with HIV was the "way things are now." For some children, this understanding occurred later in the post-disclosure stage.

Child's HIV Status	*"I am not going to change it, so I accepted it (child HIV). I believe in that policy that I have to accept the things I cannot change." –Caregiver, IDI*
ART (long-term use); Fear of Adverse Health Outcomes	*"Even the treatment, you have to accept the treatment if you want to live." –Caregiver, IDI*
Child's HIV Status	*"I was scared to stay with my mother after she told me about my status. Then I left to stay with my aunt. I felt safer to stay with my aunt. But then I came back to my mother, I accepted my status." –Child, FGD*
	"(post- disclosure) I played outside all day and came back home only to sleep. This went on for two weeks (to avoid the parent). What made me ok later was that I got used to the disease and realized that I have to face the disease." –Child, FGD

Active Coping/ Problem-Solving: Adaptive

Caregivers' and Children's accounts of active or problem-solving behaviors aligned with the Active Coping and Problem-Solving tendencies outlined in the COPE Inventory (Items 5, 25, 47, and 58) (Carver, 2013) and Ways of Coping (Items 1, 26, 39, 48, 49, and 52)[71].

***Caregivers (pre-, during, and post-disclosure)**:* This approach is marked by caregivers actively and directly investing efforts to safeguard the child's well-being through targeted behaviors, utilizing their immediate resources to address the situation. Examples of these behaviors encompassed:

- Collaborating with the child's teacher to monitor the child's health and receiving timely updates about any incidents at school.

- Developing creative solutions, such as incorporating antiretroviral medications into foods to ensure the child's adherence or incentivizing the child with monetary rewards or gifts after blood tests with a low viral load.

Fear of Adverse Health Outcomes; ART (non-adherence)	*"I told the teacher at his school that he is HIV positive because I want him safe. I will also tell the next teacher, next year about his status." –Caregiver, IDI*
	"I said I would buy him the sneaker if he took his treatment properly and his blood tests are good in January. So, he got that Airmax because I am basically begging him for his wellbeing." –Caregiver, FGD
	"My son knows (his status). When I am not around; I call and ask if he has taken his pills." –Caregiver, FGD

Additionally, engaging in full-disclosure was a proactive coping and problem-solving behavior. Caregivers recognized that disclosing the child's HIV status was essential to address the persistent issue of non-adherence to antiretroviral medications, thereby safeguarding the child's overall well-being. Through this disclosure, the child gained awareness of their status, enabling them to better self-care and take necessary precautions against the disease.

ART (non-adherence)	*"I must make a plan to disclose to my daughter this year, so that she can get back on medication. I know if she is back on meds, I will be fine, nothing will happen to her. I must make sure that she is taking the meds, that is why I have to tell her. So that she can know it is important to take her meds." –CG 5*

Children (post-disclosure): For children in the post-disclosure stage, active coping aimed at maintaining their well-being and keeping their status confidential. Children embraced active coping by:

- Following instructions meticulously, ensuring a healthy outcome by independently managing their medications, rather than relying on others.

- Devising creative strategies to take antiretroviral medications discreetly, avoiding disclosure of their status to others.

Fear of Adverse Health Outcomes; Potential Stigmatization	*"Since we disclosed to him, he does not wait to receive medication from people, he knows how to prepare the pills himself and put them in the treatment box. Now he even knows how to make plans when he visits his mother; he has that box that carries his medication. He hides it when he has to take his pills and drink them in the washroom because his mother said to not drink it in front of their friends." – Caregiver, IDI*
	"She knows her medication well and she even reminds me about clinic dates. She keeps her own clinic card." –Caregiver, IDI

Behavioural Disengagement: Maladaptive

Caregivers' and Children's accounts of disengagement aligned with the Behavioural Disengagement Coping tendencies outlined in the COPE Inventory (Items 9, 24, 37, and 51) (Carver, 2013).

Caregivers (pre-disclosure): Behavioral Disengagement, utilized during the pre-disclosure stage, involved caregivers frequently avoiding the initiation of full-disclosure or the disclosure process with their children due to various disclosure stressors. The anticipated outcomes associated with full-disclosure were perceived as overwhelming and unmanageable during this period. This tendency was most commonly observed in the early phases of the pre-disclosure stage.

Child's HIV Status	*"Yoh, I was unable to, I could not. It was my sister who was able to disclose. I could not (disclose) because I think I was full of anger at the child's mother for what she did. I would look at the child and see that he is too young for her to have infected him (with HIV) and not protect him, you see? I was scared for the child as well, because my biggest fear was him not wanting to know anything about it (or to acknowledge it)." –Caregiver, IDI*
Child's Emotional Distress	*"Parents are scared… a grandmother's daughter passed away because of HIV, so now the grandmother is afraid of telling her grandchild, you are now eating ARVs because you are HIV positive. So afraid that the daughter will cry or get angry." –*

	Caregiver, IDI
Potential Stigmatization; Familial Circumstances	*"Parents do not disclose because maybe they are with their families, weather they get along with their family or get along with who they are staying with. Are they supportive? The parents will chase you out. It happens with HIV too, you see. You can't use the same cup; you must have your own. IT depends on the understanding of the family. When they react differently with you because you are HIV, … I think that is a thing with our community." –Caregiver, IDI*
Being Blamed (vertical transmission)	*"A lot of kids like placing the blame on their mothers and say, 'The reason why I am like this is because of you.' They refuse to accept their status for what it is. They make it seem like it is their mother who wanted it to be that way. They wonder why, "You never protected me, because I depended on you in every way." That's why the parents are afraid, that keeps them from disclosing." –Caregivers, IDI*

Children (post-disclosure): In the case of children, this coping mechanism surfaced post-disclosure. While not reported frequently, some children opted not to continue with school as a response to the stress experienced after learning about their HIV status.

Child's HIV Status	*"Some kids would think that there is no need for them to study further when they learnt about their HIV status. So that child would decide not to continue with school." –Caregiver, FGD*

Confrontive Coping: Adaptive and Maladaptive

Children's accounts of being confrontive aligned with the Confrontive Coping tendencies outlined in the Ways of Coping (Items 6, 7, 17, 28, 34, and 46) (S. Folkman & R. S. Lazarus, 1985).

Children (pre- and post-disclosure): Confrontive coping emerged prominently in children during the pre-disclosure stage, triggered by the prolonged use of medications and frustration arising from unanswered questions regarding medication use. This coping mechanism at the disclosure level was characterized by:

- Expressions of anger directed towards caregivers.

- Confrontation of caregivers with persistent questions regarding medication responsibilities.
- Acts of 'standing one's ground' through persistent refusals to take antiretroviral therapy (ART).

These behaviors were perceived as attempts to encourage caregivers to disclose the true reason for the medication use.

ART; Caregiver's Restraint	*"My child was also asking me, 'Why mommy I always take the tablets? When am I going to be finished with these tablets?' So, I always say, 'Never, because you've got eczema.' Then she'd say, 'Mommy I don't have eczema now, why do I still take these tablets?' So she was always pressurising me. I told her, 'You know what, I'm going to tell you something but you must not say. Me and you are HIV positive, we are sick, even me I take tablets. So, this is our secret, it's only me and my sister that knows this and my mother before she passed away,' So she was understanding."–Caregiver, FGD*
	"Sometimes we get questions from the kids, 'Why am I eating all these pills each and every day? Sometimes they get bored eating the pills. But by that time, we were not ready to disclose. So, they all are asking those questions of tired eating their meds." –Caregivers, FGD

Post-disclosure, children continued to employ Confrontive Coping, particularly as a means of expressing anger resulting from late disclosure. Similar to the pre-disclosure stage, confrontive coping at this juncture manifested in the form of refusals to adhere to medication.

ART; Caregiver's Restraint	*"She told her son last year at 14 years old. He asked her this year, how long should he take the medication, and she told him that they are going to take it for life: 'We are going to take the medication for life', but he gave her a tough time in taking the medication." –Caregiver, FGD*
	"Mum, I tested positive today but I know I was positive from birth because I was taking the medication so I knew that medication. But you didn't tell me that I'm HIV positive, I found out at school with my friends. Then he refused to take the medication at all." –Caregivers, FGD

Though confrontive coping is reported to be a useful tool for children and effective in encouraging full disclosure, it is maladaptive since it puts the child's health at risk.

Escape-Avoidance/ Tension Reduction: Adaptive and Maladaptive

Children's accounts of escaping, avoiding or taking it out on others to reduce emotional tension aligned with the Escape-Avoidance/Tension Reduction Coping tendencies outlined in the Ways of Coping (Tension Reduction: Items 32, 33, and 66; Escape-Avoidance: Items 33, 40, and 47) (S. Folkman & R. S. Lazarus, 1985)

Children (post-disclosure): This coping strategy was employed by children immediately post-disclosure. In accordance with Folkman and Lazarus (1985), this coping style involved briefly distancing oneself from the stressor, engaging in physical activities for emotional relief, avoiding people, directing frustration toward others, or substance use, all aimed at reducing emotional tension.

In the context of pediatric disclosure, the stressor was often the caregiver, serving as a reminder of the child's HIV diagnosis: "I was ignoring my mother" (Child, FGD). Consequently, children exhibited various avoidance and tension-reducing behaviors. Within our data, children exhibited two distinct approaches when employing this coping mechanism: destructive or non-destructive.

Non-destructive escape-avoidance or tension reduction behaviors included temporarily relocating to live with a supportive family member or using play as an escape to avoid interactions with caregivers. This form of escape or tension reduction appeared to be short-term for some and diminished as acceptance of the disease occurred.

> *"I was scared to stay with my mother after she told me about my status. Then I*

Child's HIV Status	*left to stay with my aunt. I felt safer to stay with my aunt. But then I came back to my mother, I accepted my status." –Child, FGD*
	"(post- disclosure) I played outside all day and came back home only to sleep. This went on for two weeks (to avoid the parent). What made me ok later was that I got used to the disease and realized that I have to face the disease." –Child, FGD

Destructive escape-avoidance or tension reduction behaviors encompassed ignoring parents (resulting in poor antiretroviral adherence), substance use (alcohol), or directing frustration towards other children. One caregiver reported their child started hitting others after learning there was no cure for their disease. Another caregiver mentioned that some older children, particularly those with late disclosure, displayed a tendency to 'not care' and refused to 'die alone', expressing this by infecting others with HIV through sexual intercourse.

Child's HIV Status	*"Yes, she became angry because I told her (diagnosis), even here at home she would start hitting other children...when I told her that it can't be healed. Eish, it becomes difficult when a child starts hitting others. –Caregiver, IDI*
	"The kids sometimes ...at around the age of 16, 17 and going up to 18, they have the tendency to not care and refuse to die alone, they have also gotten it, so should others, you see? They do not care and want to infect every person. 'I never ordered it.' So, if I have it, it's ours and not mine. –Caregiver, FGDs
Blamed for vertical transmission	*"There is a child who rebelled and started drinking, saying that he/she is already dead anyway because her mother never cared for her, so they like placing the blame on people." –Caregiver, IDI*

Information-seeking: Adaptive

Children's accounts of seeking information after disclosure aligned with the Information-seeking Coping tendencies outlined in the Moneyham et al., 1998 (Items 11, 24, 41, 49, and 54).

Children (post-disclosure): This coping style was commonly employed by children immediately after caregivers disclosed their children's HIV status. It entailed actively seeking information about HIV and educating themselves on the disease and its treatment. In the context of pediatric

HIV disclosure, the goal of information-seeking coping was primarily to assess available resources and treatment options. This included activities such as asking solution-oriented questions about HIV or seeking information to better understand their disease, such as inquiries about HIV medications (ART), disease management, the possibility of a cure, HIV outcomes, and mode of transmission.

Child's HIV status	*"I have a lot of questions after disclosure, about HIV, but I didn't ask my mom." –Child, FGD*
	"(during-disclosure) I asked my mom how I got HIV..." –Child, FGD
	"She asks when her disease will end." –Caregiver, FGD
	"I could see that she was stressed, and she asked me whether HIV positive people live long. I said, 'Yes, they do, just like me and you.' She then asked if we are HIV positive and I said, 'Yes we are.' Then she asked why it is that we are not sick." –Caregiver, FGDs
	(immediately after disclosure) "How do the soldiers get into the body? If we want to take them out, can we remove them? I want to see it when it enters the body. Why does it enter the body?" –Child, FGD

Positive Thinking/Cognitive Restructuring: Adaptive

Caregivers and Children's accounts of thinking positively or restructuring their understanding aligned with the Positive Thinking/Cognitive Restructuring tendencies outlined in the Responses to Stress Questionnaire (Positive Thinking: Items 19, 50, and 52; Cognitive Restructuring: Items 34, 36, and 39) (Connor-Smith et al., 2000).

Caregivers (during/post-disclosure): Immediately after disclosure, caregivers commonly employed this coping strategy to mitigate the emotional impact on children and diminish the stigma or negative thoughts surrounding HIV, such as perceiving it as a "death sentence." This approach involved encouraging children to view HIV differently, treating it akin to other community diseases (e.g., diabetes, fever, high blood pressure, stroke, and heart attack), reshaping their outlook on the future (e.g., anticipating a long life with marriage and children), and emphasizing available solutions (e.g., ARVs, maintaining a healthy lifestyle).

The sharing of the importance of ARV adherence and caregivers' personal testimonies of living with HIV complemented positive thinking and cognitive restructuring coping. The goal was to instill the belief that "everything will be all right," that the disease "isn't a big deal," and that continuing to take medication was all they needed to do.

Fear of Adverse Health Outcomes; Child's Emotional Distress; Child’s HIV status	*“‘The first time that I told him, eish, it was not nice, he cried. Yet, even while crying, I told him that, ‘My child, your life is still long, it has not come to an end.’ I told him that, “Even I, I am raising you whilst HIV positive.’ I told him that I have not died, nor would I die anytime soon”’ –Caregiver, IDI*
	(post-disclosure) “The community believes that if you have got HIV you are going to die. So, I thought my child was thinking the same thing. So, I explained to her, ‘That it is that germ that is living in Jacob’s blood. What you also got, that is called HIV. That germ is called HIV. You are not going to die; you just have to carry on eating your medication. You see you are healthy. Have you been sick, No! You see, that is fine, you keep on eating your meds.’” –Caregiver, IDI
	“It is like being diabetic or having a fever, this disease as not as bad as other disease, like high blood pressure, stroke, heart attack... if you get treatment with HIV, and take it properly, as the clinic guides you on how to take the treatment, it is fine!” –Caregiver, IDI

Children (post-disclosure): Children also employed cognitive restructuring coping to alleviate the fear of death associated with the disease. They reassured themselves that by consistently taking their medications, they would be okay. This coping strategy was further utilized by children to counteract negative self-perceptions associated with HIV stigma. Caregivers themselves engaged in this type of coping during the pre-disclosure stage to minimize emotional distress from their own HIV diagnosis. This was considered crucial as it later facilitated caregivers in shaping the child’s positive reinterpretation of their HIV diagnosis post-disclosure.

Fear of Adverse Health Outcomes	*"It is best to adhere to your treatment and eat healthy food so that you remain in good health." –Child FGD*
	"A person must persevere, there is hope that HIV will be curable one day." –Child, FGD
Child's HIV status	*"I would say to a newly infected child is, 'Do not hate yourself because you are HIV because it is not written on your body that you are HIV.'" –Child, FGD*

Religious Coping: Adaptive

Caregivers' and Children's accounts of utilizing their faith aligned with the Religious Coping tendencies outlined in the COPE Inventory (Items 7, 18, 48, and 60) (Carver, 2013).

Caregivers (pre-, during, and post-disclosure): Caregivers consistently employed this coping approach throughout the disclosure process as a final recourse to address challenges related to caring for children living with HIV (i.e. child's non-adherence to ARVs). This method was characterized by either 'praying to God' or 'relying/trusting in God' to secure the child's health and well-being, seeking supernatural strength to overcome the repercussions of disclosure. It also entailed drawing on God's goodness and love to alleviate fears and thoughts of death and sickness associated with HIV. God served as a source of emotional support for caregivers, assisting them in managing the burden of living with HIV while caring for an HIV-positive child. Caregivers often extended this coping method to their children, reassuring them that God was with them and aware of their situation to diminish or prevent fear and worry.

Confrontive Coping	*"I couldn't force her. I thought to give my child time and prayed to God that she would not get sick since she is off the medication but thank God, she is still fine." –Caregiver, IDI*
Fear of Adverse Health Outcomes	*"You see, sometimes you hear from others' painful stories, it is so sensitive, but the only thing you have to understand is that God is there for us." –Caregiver, IDI*

	"I told my boy, 'You mustn't worry, as long as God is with us, don't worry. God knows this case of HIV.'" –Caregiver, FGD
Familial Circumstances; Child's HIV status	*"I just hope that God grants me the serenity to accept it (husband left her, child has HIV, and husband died due to AIDS). I prayed to God that He must grant me some more strength in the future." –Caregiver, IDI*

Children (post-disclosure): Children also turned to religious coping to confront the fear of death or negative outcomes associated with HIV. This involved entrusting their lives to God, seeking divine assistance in leading a long life despite their HIV diagnosis.

Fear of Adverse Health Outcomes	*(post-disclosure) "God is going to help us to live long." –Children, IDI*

Restraint Coping: Adaptive

Caregivers' accounts of withholding disclosure aligned with the Restraint Coping tendencies outlined in the COPE Inventory (Items 10, 22, 41, and 49) (Carver, 2013).

Caregivers (pre-disclosure): Within the context of disclosure, this coping mechanism was marked by caregivers intentionally refraining from pediatric full-disclosure. The focus is to avert or mitigate potential negative outcomes associated with disclosure by withholding information until deemed appropriate: *"I don't have a problem with disclosing. Just waiting for the right time." (Caregiver, IDI).* Activities under this coping style included:

- Withholding full-disclosure until the child attained sufficient cognitive maturity to comprehend the implications of the disease or until caregivers were prepared to manage the consequences of disclosure.

- Shielding the child from the severity of the situation (to prevent psychological distress or children’s confrontive coping) by offering minimal explanations about the illness or providing false explanations about medication responsibilities, such as attributing them to asthma or TB.

Potential Stigmatization; Confrontive Coping; Child’s Emotional Distress	*“I was so scared to disclose to him because he would go out and tell it to other kids. Other kids will be instructed at their houses not to play with him, that he is sick and not right. I thought of disclosing it when he was around 15 years old and had more awareness. When he could take care of himself. At least he has the brain; when you tell him certain things, he knows to keep it.” –Caregiver, IDI*
	“Also, she is a hyperactive child; when you tell her something, she will go to her friends and say, ‘you know, I am this!’ So, I didn't want to tell her at that moment.” –Caregiver, IDI
	“The first time I told her, I didn't tell her she had HIV. She asked me why she was eating the tablets, what is the medication for. The meds is for you not to get sick. So that was her understanding at first. So, I didn’t' tell her about the status right at that moment.” –Caregiver, IDI
	“When he was six years old, I saw that he was not ready to know about HIV. So, I told him that he was eating his medication because of his chest. I told him that as long as he has his chest, he will take the medication. It’s up to me as a caregiver because if I’m not ready yet for the community (about) my status, it won’t be wise to tell a 6-year-old. After all, he will tell others. So, you need to be ready first.” –Caregiver, FGD

In deploying this coping strategy, caregivers reported engaging in constant or repetitive assessments of the child's mental state, readiness for disclosure, and awareness of HIV. This process was recognized as a stressful transaction for caregivers, involving frequent inquiries into the child's knowledge of HIV/ART and their understanding of the disease outcome. Once caregivers determined that the child had acquired sufficient knowledge of HIV, disclosure often followed. We call this phenomenon, 'Testing the Child Loop.' If the child was deemed unready for disclosure, caregivers continued to employ restraint coping. Notably, restraint coping frequently coexisted with social support coping, as caregivers often enrolled their children in HIV groups at the clinic to enhance their knowledge and exposure to HIV.

Potential Stigmatization	*"First, you must see if the child is understanding. I started to test her about how much she knew and understood about HIV. That is when I decided to talk to her about her medications because I could see she was ready." –Caregiver, IDI*
	"I would ask him what he had done at the (HIV) group. I would then ask, 'What kind of people are in the group?' He would say, 'It's positive people.' I would then ask, 'What kind of person are you since you were there?' (Having asked these questions) I was finally able to get the courage to inform him." -Caregiver, IDI

Selective Disclosure: Adaptive

(Not in any coping battery)

This coping strategy was commonly employed by both children and caregivers to mitigate potential discrimination towards the child and to prevent inadvertent disclosure of the caregiver's HIV status.

Caregivers (pre-, during, and post-disclosure): During the pre-disclosure stage, many caregivers practiced selective disclosure by cautiously revealing their child's status to a limited circle of individuals. This approach aimed to prevent unintentional disclosure to the child before they were ready for full-disclosure. These individuals typically included those offering social support or close family members. In the post-disclosure phase, caregivers expanded their selection to include teachers, contributing to the child's well-being at school. The practice of selective disclosure was often imparted to the child immediately during full disclosure to prevent accidental disclosure of their HIV status.

Potential Stigmatization	*"We have not disclosed to the family as a whole, it's only within our own household: me, my father, and mother, as well as my sister, and sister's husband. We can tell the bigger family in the future because I am ready now. However, I*

	told my child to keep it a secret at school, but my sister says it's his choice." –Caregiver, IDI
	(during disclosure) "It is his secret because I told him that it's your secret, if you talk about it, other people will laugh about it, that you are sick." –Caregiver, IDI
	(during disclosure) "I told my child, 'Nobody needs to know about your status. About what I just told you. It is for me and you. You can share with someone who is very close to you when you are old enough. But for now, it is for me and you." –Caregiver, IDI

Children (post-disclosure): Similarly, children frequently employed selective disclosure coping by choosing specific individuals or friends to whom they disclosed their status. This coping mechanism was a learned behavior for children, instructed during full disclosure and reinforced over time by caregivers. Selective disclosure extended beyond verbal communication, such as discreetly taking pills in private, often in the washroom. The connection between Selective Disclosure coping and social support coping was evident, as one motivation for selective disclosure was to receive or seek social support from friends and other family members.

Potential Stigmatization	*"My child he was talking to another child about HIV, and about the future and marriage, but when another child enters the house, my child would change the topic and stopped talking" –Caregiver, FGD*
	"I'm not gonna tell my cousins because they will laugh." –Child, FGD
	"Even my daughter, she knows that this (HIV diagnosis) is between us, not for everyone, because even the other families they have their own secret. I said, 'you must not talk to anyone about your status... not to anyone.' She understands that. She doesn't talk to all her friends about her status, only those in her group." –Caregiver, IDI

Social Support: Adaptive

Caregivers' and Children's accounts of seeking social support aligned with the Social Support Coping tendencies outlined in the COPE Inventory (Instrumental: Items 4, 14, 30, and 45;

Emotional: Items 11, 23, 34, and 52) (Carver, 2013), Ways of Coping (Items 8, 18, 22, 28, 31, 42, and 45) (S. Folkman & R. S. Lazarus, 1985), and Murphy et al., 2003.

Caregivers (pre- and post-disclosure): In the context of disclosure, Social Support Coping encompasses instrumental support and emotional support. Instrumental Support involves actively seeking assistance from individuals or groups to acquire knowledge on overcoming distressing situations, while Emotional Support entails reaching out to others for identification, emotional soothing, sympathy, and understanding.

During the pre-disclosure stage, caregivers utilized both types of social support coping, with instrumental support being more prevalent. Instrumental social support was sought to learn how to disclose to their children and navigate the challenges of disclosure (potential stigmatization of the child, emotional distress, blame for HIV transmission, and the need to disclose the mother's HIV status). Many caregivers expressed hesitation and uncertainty about when and how to start the disclosure process. Having social support allows caregivers to share their fears, receive appropriate help, and alleviate the stress associated with disclosure. To ease the burden, caregivers also enrolled their children in HIV groups to enhance their HIV literacy.

Social Support included:

- Attending HIV support groups to gain knowledge.
- Seeking emotional support and encouragement from caregivers with similar experiences.
- Consulting health professionals or HIV support groups for advice on disclosure techniques, preparing the child, and minimizing potential stigmatization.

- Counselors and groups not only provided instrumental and emotional support but also monitored and held caregivers accountable for performing full disclosure.

Caregiver's Limited HIV Disclosure Literacy; Potential Stigmatization	*"So, as time went on, I joined a group as I was not ready to tell that he is positive. So, I went to the group and explained that I have this problem. I don't have the guts. So, they tried to constantly teach me ways to disclose to him, but I could not do it. It took time. Yes, I had them (fears). I even told my counsellor that I have no idea where to even start. My son is someone who talks. He has no hidden things (secrets). So, I was scared that if I will tell my son that he is HIV-positive, he will go out and tell it to other kids and explain the situation. Other kids will be told at their houses to not play with my son because he is sick, he is not right." –Caregiver, IDI*
	"When my child starts hitting others, I come to the group and report to other mamas. So, I can say that I was also helped by the group because we advised one another." –Caregiver, IDI
	"I met one of the members of the group here. I explained my problem, that I have a child like this, they then asked if they could assist me, they explained to me how to disclose, how he can eat treatment, how I can accept him...because I found it hard to accept him" –Caregiver, IDI
	"If I can't answer my child's questions, I will simply ask him to talk to the clinic's support group." –Caregiver, FGD

Children (post-disclosure): Children also engaged in Social Support coping by discussing their feelings with counselors, community support groups, teachers, or friends regarding the challenges related to their HIV status. These individuals offered psychosocial and educational support, providing advice, and fostering a sense of identity and belonging for children navigating young adulthood with HIV. Social support coping was a means for children to learn about their disease when caregivers were hesitant to discuss the topic. Additionally, as the long-term use of ART necessitated forming a new identity with peers facing similar challenges, support groups offered children a sense of belonging.

Child's HIV status	*"The child used to vent her frustration to them (HIV-group), saying that she does not understand why she tested positive when all her siblings tested negative." –Caregiver, IDI*

	(Post-disclosure) "My child likes going to the group at the clinic and the youth centre. He said, 'I want to go with you to see the counsellor. The counsellor and group make me very happy and make us happy to be there.' The youth centre empowers him because he knows that there are others who eat pills like him." –Caregiver, IDI
	(post-disclosure) "My daughter goes to Community Mothers where she gets support, and able to talk and share." –Caregiver, IDI
	"The sadness and fear from knowing my diagnosis left because of the support I get at home from my parents and family." –Child, FGD
Caregiver's Limited HIV Disclosure Literacy	*"When my parent don't like answering questions, I go to the clinic and ask questions to the counsellor." –Child, FGD*

Suicidal: Maladaptive

(Not in any coping battery)

Children (post-disclosure): Both caregivers and children acknowledged the potential emergence of suicidal behaviors in children as a reaction to the stress of being aware of their HIV status. This harmful coping mechanism was also associated with instances of delayed disclosure.

Caregiver's Restraint; Child's HIV status	*"Not 15, because maybe she will get a suicide. 15 is too late. Supposed to disclose earlier, because when you tell your child too late, maybe she will kill herself. It is a risk" –Caregiver, IDI*
	"(parents don't disclose) …because maybe the parents are fearing that if the child knows this, she will commit suicide and withdraw…" –Caregiver, IDI
	"One thing to look out for after disclosure is that the child could commit suicide." –Child, FGD

DISCUSSION

The stressful nature of pediatric HIV-disclosure has contributed to the less than optimal disclosure rates in many resource-limited settings. Identification of disclosure stressors and effective coping use are pertinent to the development of relevant interventions that can improve rates of pediatric HIV-disclosure. Our study has contributed to the literature by identifying the disclosure stressors and associated coping mechanisms experienced by dyads as they journeyed through the pediatric HIV-disclosure stages.

Through the identification of stressors rather than the ‘stress’ (a subjective reaction/response to a stressor), we were able to provide a more robust data to inform disclosure intervention development since stressors were generally more invariable across disclosure experiences.

We found that the current reported barriers in the literature (i.e. stigma, caregiver’s unpreparedness for disclosure) are in fact stressors that led to caregiver’s use of different coping mechanisms, which then acted as barriers and shapers of disclosure outcomes.

We saw that use of coping strategies throughout the disclosure stages became dynamic, and shifting in nature, depending upon the perceived consequences or implications of full-disclosure (i.e. stigmatization) and the specific situational dynamics inherent at different stages of disclosure. This corresponds with Folkman and Lazarus’s claim that people’s coping styles are not locked down to one mode of responding, but changes with changing circumstances [57, 71, 77].

In this study, we were also able to further unravel the full nature of Restraint Coping (in the context of disclosure) from what was currently defined by Carver and colleagues [78]. We saw that *Testing the Child Loop* process (repetitive reassessment of the child's state of mind/readiness/awareness) determines the use of Restraint Coping during the pre-disclosure stages. If the child was assessed as not ready for disclosure, caregivers will continue to use Restraint Coping.

We found that the caregivers and children were frequently faced with 10 disclosure stressors that were managed by 12 coping strategies. Ten of these coping styles were comparable to the current coping frameworks used in the HIV and coping literature [70, 71, 73-75], while two coping tendencies were specific to HIV-disclosure: Selective Disclosure and Suicide. Highest reported stressors mentioned by both caregivers and children were the likelihood of death or negative outcomes associated with HIV and potential stigmatization. Caregivers were most stressed by their own lack of disclosure or HIV knowledge. Children were most stressed by the long-term and complex use of ART medications and caregiver's use of Restraint Coping.

Our findings on caregiver's Behavioral Disengagement Coping (to full-disclosure) corresponded with that of Hayfron-Benjamin et al. (2018) and others who also found that low or delayed disclosure rates among caregivers were associated with lack of knowledge regarding the disclosure process, fear of child's reaction, and fear of stigmatization and associated social consequences [79, 80].

The Importance of Social Support. Social Support was the most commonly used coping mechanism by caregivers before and after full-disclosure. This coincides with a study by Lorenz et al. (2016) that found as many as two thirds (64%) of their caregivers sought the advice from an HIV counsellor prior to disclosure[58]. Our data highlights the important contributions of organizational support groups. Disclosure was a difficult process and a stressful transaction for caregivers, but was made reassured through the support of health care professionals. For fully-disclosed children, support groups encouraged social placement, an avenue that cultivated the creation of a new identify. The need for both emotional and instrumental support highlight the importance of incorporating an aspect of social support to any types of pediatric HIV programmes. Our finding supports the recent publication by Dawson-Rose et al., 2020, that provided disclosure support to newly-diagnosed persons living with HIV through peer educators. Dawson-Rose at al., 2020, concluded that, "there are extensive challenges related to understanding the implications of their illness; social support from clinical care teams can be vital in planning and coping" [81].

Previous studies have reported that that ventilation of one's feeling may not always be functional[82-84], as it can impede adjustment [85] and distract caregivers from active coping adjustment [83] however, we saw in our study that the utilization of clinics or organizational support group as a form of emotional coping was not maladaptive to the dyads.

Importance of Simultaneous Intervention. Our study found that certain stressors can perpetuate others. For instance, caregivers' fear of potential stigmatization was largely fueled by the child's lack of understanding of sickness, poor awareness of HIV-related stigma/negative social values, or lack of maturity to hold the diagnosis a secret. Similarly, we also saw that certain coping mechanisms can perpetuate the use of others. For instance, children's Confrontive Coping were largely fueled by caregiver's Restraint Coping; the longer the caregiver withhold full-disclosure, the more frequent the child's use of Confrontive Coping to get their resolution.

Hence, pediatric disclosure interventions should employ an intervention design that will simultaneously target propagating stressors or coping mechanisms. For instance, in the management of stressors, there is a need to educated caregivers with techniques on minimizing risk of potential stigmatization, while simultaneously providing the child with child-friendly, age-appropriate HIV-information that will encourage understanding of the implications of the disease, both on the level of health and social well-being. In the management of coping use, disclosure interventions should employ a monitoring system for coping strategies that co-occur.

Current recommendations for disclosure interventions have only focused on removing disclosure barriers [86, 87], such as empowerment with culturally appropriate skills and platforms [88], provision of psychosocial support services and training on age-appropriate disclosure [16], to name a few. There is a need to design disclosure interventions with coping use in mind.

Prevention of Maladaptive Coping by way of Identification of Stressors and Promotion of Effective Coping Methods. The prevention of poor coping strategies (i.e. behavioural disengagement, suicidal behaviours, and destructive tension-reduction) is important for the improvement of disclosure rates and children's well-being. Use of maladaptive coping may be tied to caregiver's lack of self-efficacy towards the management of the disclosure process[45]. We saw in the data that there could be more than one coping strategies for the management of a single stressor, and that these coping methods could either have a maladaptive or effective outcomes. Therefore, our findings highlight the importance of the identification of stressors experienced by caregivers and children in order to anticipate the different maladaptive coping methods that will be used. Once the stressors are identified, prevention of the use of maladaptive coping styles could be easily achieved by teaching the dyads effective coping strategies to manage the stressors. For instance, to further prevent caregivers' utilization of behavioural disengagement coping (at early pre-disclosure phase) to avoid potential stigmatization, health workers should immediately demonstrate the use of Selective Disclosure Coping strategy or short-term Restraint

Coping.

Monitoring of Effective and Ineffective Disclosure Coping Strategies. Several effective coping strategies emerged from our data: Social Support, Restraint Coping, Selective Disclosure, Active Coping/Problem Solving, Positive Thinking/Cognitive Restructuring, Religious Coping, Acceptance, Information-seeking, and Confrontive coping. These coping strategies were considered as effective since they brought the user to one or more of the items listed in the primary or secondary effectiveness categories (i.e. full-disclosure, resolution of the stressful situation, maintained positive self-esteem, adherence to antiretroviral medications, etc.). For instance, we found that the confrontive nature of children was efficient at encouraging full-disclosure in caregivers. This finding coincides with other studies that found that disclosure level was higher among children who frequently asked about their health status or posed threats of non-adherence [14, 89]. In fact, a study by Kalembo et al. (2019) found that the odds of non-disclosure were higher among children who were not asking why they were taking ARVs [34].

However, our data also revealed that for some coping mechanisms, when over-utilized for a long period of time, it became maladaptive. These coping mechanisms were: Restraint Coping, Confrontive Coping, and Selective Disclosure. For instance, we saw that regardless of Restraint Coping's promotion of avoiding unwanted consequences (i.e. stigmatization), our data revealed that long-term restraint of full-disclosure could increase anxiety in children (due to unanswered questions) and poor health behaviours (i.e. children's non-adherence to ART due to Confrontive Coping) and, in some instances, promoted suicide for reasons of delayed full-disclosure.

Another example is Confrontive Coping. Despite children's success at persuading the caregivers to disclose the true reason for the use of medications (by way of withholding the use of ART), this in fact could be detrimental for the child, as it increased the risk of disease progression and did not promote health. Similarly, when used long-term, Selective Disclosure Coping could be maladaptive for the child and mother, as it was reported to not promote acceptance of the disease.

Therefore, Restraint Coping, Confrontive Coping, and Selective Disclosure Coping could also be placed under the category of ineffective coping when used long-term, along with Behavioural Disengagement, (destructive) Escape-Avoidance/Tension Reduction, and suicide. There is a need for long-term monitoring of coping use among the dyads.

Distinguishing Perceived Stressors (i.e. the child will cry) vs. Actual Instances (I.e. the child did cry). It is interesting to see in the data that caregivers coped differently towards stressors that were 'perceived' vs. stressors that 'actually happened'. In the case of caregivers' perception that the child will undergo distress post-disclosure, caregivers took more of an *avoidance* approach to coping (Restraint or Disengagement). However, when the distress actually happened, the caregivers took on an *approach* strategy to coping, such as Social Support Coping or Positive Thinking/Cognitive Reframing. Hence, it is pertinent that disclosure interventions help caregivers distinguish the difference between caregivers' own subjective fear vs. actual stressors.

STUDY LIMITATIONS

Temporality of Coping Use: the data collection methods for the current study brought about cross-sectional information of coping styles, and thus did not bring direct data on temporal relationship between stressors and coping use, or direct data on which coping mechanisms remained relatively fixed across the disclosure stages overtime. However, this limitation was mitigated by capturing and recording caregivers' and children's experiences at different stages of the disclosure process. In doing so, we were able to analyze the relationship between the stressors and coping methods, and mitigate the inherent bias found in cross-sectional information.

Usage of Semantics: "Qualitative inquiry demands meticulous attention to language…and meanings of human experience", pg.10,[90]. The analyses was limited by the chosen local languages of the participants. Since most responses was in Xhosa and later translated into English, the authors could not directly discern the different usages of semantics from the transcripts that could be meaningful for the interpretation of the data.

In this qualitative study, it's important to acknowledge that a potential limitation lies in the reliance on a single coder for the analysis, which may introduce a subjective element to the interpretation of the data. However, to promote a more structured and reliable process, the author used a directed approach to content analysis [68].

CONCLUSION

The investigation into the disclosure stressors and coping behaviors within the pediatric HIV-disclosure stages has provided further insight into the factors hindering full disclosure, thereby contributing to the development of appropriate disclosure interventions. The prevention of maladaptive coping is crucial for disclosure rates and overall well-being, achievable through the identification of stressors and the promotion of effective coping methods.

Encouraging and teaching effective coping strategies to caregivers early in the disclosure process is essential. It is important to educate caregivers and children on skills to differentiate between perceived and actual stressors, while informing them of alternative coping methods effective during the disclosure processes. Monitoring the overuse of effective coping strategies is necessary, as it may lead to maladaptive outcomes or encourage ineffective coping in others. Monitoring coping use is also crucial to ensure children's well-being.

Pediatric HIV disclosure interventions should recognize the significance of Social Support and simultaneous intervention when promoting full disclosure. These interventions should also consider potential stressors that caregivers and children may experience, thereby adjusting coping strategies accordingly. Healthy coping strategies are essential in addressing the stressful nature of pediatric HIV disclosure and promoting full disclosure.

REFERENCES

1. UNAIDS. *Global HIV & AIDS Statistics*. 2023 [cited 2023 December 26, 2023]; Available from: https://www.unaids.org/sites/default/files/media_asset/data-book-2023_en.pdf.
2. Mengesha, M.M., et al., *The association between HIV diagnosis disclosure and adherence to anti-retroviral therapy among adolescents living with HIV in Sub-Saharan Africa: A systematic review and meta-analysis.* PLoS One, 2023. **18**(5): p. e0285571.
3. Armoon, B., et al., *Prevalence, socio-demographics and service use determinants associated with disclosure of HIV/AIDS status to infected children: a systematic review and meta-analysis by 1985-2021.* Arch Public Health, 2022. **80**(1): p. 154.
4. Odiachi, A., *The Impact of Disclosure on Health and Related Outcomes in Human Immunodeficiency Virus-Infected Children: A Literature Review.* Front Public Health, 2017. **5**: p. 231.
5. World Health Organization. *Guideline on HIV disclosure counselling for children up to 12 years of age. Geneva: World Health Organisation*. 2011. Geneva: World Health Organization. Available: http://www.who.int/hiv/pub/hiv_disclosure/en/
6. Goga, A.E., et al., *Enhancing HIV Treatment Access and Outcomes Amongst HIV Infected Children and Adolescents in Resource Limited Settings.* Matern Child Health J, 2016.
7. Aderomilehin, O., A. Hanciles-Amu, and O.O. Ozoya, *Perspectives and Practice of HIV Disclosure to Children and Adolescents by Health-Care Providers and Caregivers in sub-Saharan Africa: A Systematic Review.* Frontiers in Public Health, 2016. **4**(166).
8. O'Malley, G., et al., *"If I take my medicine, I will be strong: " evaluation of a pediatric HIV disclosure intervention in Namibia.* J Acquir Immune Defic Syndr, 2015. **68**(1): p. e1-7.
9. Vreeman, R.C., et al., *Characteristics of HIV-infected adolescents enrolled in a disclosure intervention trial in western Kenya.* AIDS care, 2015. **27 Suppl 1**(sup1): p. 6-17.
10. Vreeman, R.C., et al., *Disclosure of HIV status to children in resource-limited settings: a systematic review.* Journal of the International AIDS Society, 2013. **16**(1): p. 18466-18466.
11. Reynolds, N.R., et al., *SANKOFA: a multisite collaboration on paediatric HIV disclosure in Ghana.* Aids, 2015. **29 Suppl 1**(Suppl 1): p. S35-45.
12. Shabanova, V., et al., *Pediatric HIV Disclosure Intervention Improves Immunologic Outcome at 48 Weeks: The Sankofa Trial Experience.* J Acquir Immune Defic Syndr, 2023. **94**(4): p. 371-380.
13. WHO. *Guideline on HIV disclosure counselling for children up to 12 years of age*. 2011; Available from: http://www.who.int/hiv/pub/hiv_disclosure/en/
14. Murnane, P.M., et al., *Extent of disclosure: what perinatally HIV-infected children have been told about their own HIV status.* AIDS care, 2017. **29**(3): p. 378-386.
15. Africa, N.D.o.H.S., *Disclosure Guidelines for Children and Adolescents in the context of HIV, TB and non-communicable diseases.* 2016.
16. Doat, A.R., R. Negarandeh, and M. Hasanpour, *Disclosure of HIV Status to Children in Sub-Saharan Africa: A Systematic Review.* Medicina (Kaunas), 2019. **55**(8).
17. Dahourou, D., J.P. Raynaud, and V. Leroy, *The challenges of timely and safe HIV disclosure among perinatally HIV-infected adolescents in sub-Saharan Africa.* Curr Opin HIV AIDS, 2018. **13**(3): p. 220-229.

18. Toromo, J.J., et al., *"I have never talked to anyone to free my mind" - challenges surrounding status disclosure to adolescents contribute to their disengagement from HIV care: a qualitative study in western Kenya.* BMC Public Health, 2022. **22**(1): p. 1122.
19. Tucho, W.A., A.N. Tekelehaimanot, and M.B. Habte, *Disclosure Status and Associated Factors Among Children on Antiretroviral Therapy in Ethiopia.* Pediatric Health Med Ther, 2021. **12**: p. 299-306.
20. Lemma, T., et al., *HIV Serostatus Disclosure and Its Predictors Among Children Living With HIV in Ethiopia: A Systematic Review and Meta-Analysis.* Front Public Health, 2022. **10**: p. 859469.
21. Kairania, R., et al., *'Mummy told me that I have HIV, that is the only thing she told me': Experiences of HIV status disclosure to children in Masaka Region, Uganda.* PLoS One, 2023. **18**(5): p. e0285990.
22. Vreeman, R.C., et al., *'Why did you not tell me?': perspectives of caregivers and children on the social environment surrounding child HIV disclosure in Kenya.* Aids, 2015. **29 Suppl 1**: p. S47-55.
23. Moskowitz, J.T. and J. Wrubel, *Coping with HIV as a chronic illness: Illness appraisals, coping, and well-being. .* Psychology and Health, 2005. **20**: p. 509-531.
24. Moskowitz, J.T., et al., *What works in coping with HIV? A meta-analysis with implications for coping with serious illness.* Psychological bulletin, 2009. **135**(1): p. 121-141.
25. Robinson, A., et al., *Examining the Relationship Between HIV-Related Stigma and the Health and Wellbeing of Children and Adolescents Living with HIV: A Systematic Review.* AIDS Behav, 2023. **27**(9): p. 3133-3149.
26. Loveday, M., et al., *'If I am playing football, I forget that I have this virus': the challenges and coping strategies of adolescents with perinatally acquired HIV in KwaZulu-Natal, South Africa.* BMC Infect Dis, 2022. **22**(1): p. 796.
27. Dake, S., et al., *Coping strategies among adolescents and young adults living with HIV/AIDS in Accra-Ghana.* BMC Public Health, 2023. **23**(1): p. 2350.
28. Sariah, A., et al., *"Experiences with disclosure of HIV-positive status to the infected child": Perspectives of healthcare providers in Dar es Salaam, Tanzania.* BMC Public Health, 2016. **16**(1): p. 1083.
29. Britto, C., et al., *Prevalence and Correlates of HIV Disclosure Among Children and Adolescents in Low- and Middle-Income Countries: A Systematic Review.* J Dev Behav Pediatr, 2016. **37**(6): p. 496-505.
30. Reynolds, N.R., et al., *SANKOFA: a multisite collaboration on paediatric HIV disclosure in Ghana.* Aids, 2015. **29 Suppl 1**: p. S35-45.
31. Vreeman, R.C., et al., *Characteristics of HIV-infected adolescents enrolled in a disclosure intervention trial in western Kenya.* AIDS Care, 2015. **27 Suppl 1**: p. 6-17.
32. Tadesse, B.T., B.A. Foster, and Y. Berhan, *Cross Sectional Characterization of Factors Associated with Pediatric HIV Status Disclosure in Southern Ethiopia.* PLoS One, 2015. **10**(7): p. e0132691.
33. Namasopo-Oleja, M.S., D. Bagenda, and E. Ekirapa-Kiracho, *Factors affecting disclosure of serostatus to children attending Jinja Hospital Paediatric HIV clinic, Uganda.* Afr Health Sci, 2015. **15**(2): p. 344-51.

34. Kalembo, F.W., et al., *Socio-demographic, clinical, and psychosocial factors associated with primary caregivers' decisions regarding HIV disclosure to their child aged between 6 and 12 years living with HIV in Malawi.* PloS one, 2019. **14**(1): p. e0210781-e0210781.
35. Appiah, S.C.Y., et al., *A Phenomenological Account of HIV Disclosure Experiences of Children and Adolescents from Northern and Southern Ghana.* International journal of environmental research and public health, 2019. **16**(4): p. 595.
36. Gyamfi, E., et al., *Prevalence of, and barriers to the disclosure of HIV status to infected children and adolescents in a district of Ghana.* BMC international health and human rights, 2017. **17**(1): p. 8-8.
37. Biadgilign, S., et al., *Factors associated with HIV/AIDS diagnostic disclosure to HIV infected children receiving HAART: a multi-center study in Addis Ababa, Ethiopia.* PLoS One, 2011. **6**(3): p. e17572.
38. Domek, G.J., *Debunking common barriers to pediatric HIV disclosure.* J Trop Pediatr, 2010. **56**(6): p. 440-2.
39. Sariah, A., et al., *"Experiences with disclosure of HIV-positive status to the infected child": Perspectives of healthcare providers in Dar es Salaam, Tanzania.* BMC public health, 2016. **16**(1): p. 1083-1083.
40. Britto, C., et al., *Prevalence and Correlates of HIV Disclosure Among Children and Adolescents in Low- and Middle-Income Countries: A Systematic Review.* Journal of developmental and behavioral pediatrics : JDBP, 2016. **37**(6): p. 496-505.
41. Ramsammy, C.W., et al., *Children's Positive and Negative Emotional Responses to an HIV Disclosure Study in South Africa.* Front Pediatr, 2022. **10**: p. 857336.
42. Kasande, M., et al., *Experiences of Caring for Adolescents Living with HIV (ALHIV): A Qualitative Interview with Caregivers.* HIV AIDS (Auckl), 2022. **14**: p. 577-589.
43. Desclaux, A. and C. Alfieri, *[Disclosure of infant HIV status: mothers' experiences and health workers' interpretations in Burkina Faso].* Sahara j, 2013. **10 Suppl 1**: p. S81-92.
44. World Health Organization, *Disclosure and psychosocial support for children*, in *Manual on Paediatric HIV Care and Treatment for District Hospitals: Addendum to the Pocket Book of Hospital Care of Children*. 2011, World Health Organization
Copyright: Geneva. p. 1-109.
45. Kiwanuka, J., E. Mulogo, and J.E. Haberer, *Caregiver perceptions and motivation for disclosing or concealing the diagnosis of HIV infection to children receiving HIV care in Mbarara, Uganda: a qualitative study.* PLoS One, 2014. **9**(3): p. e93276.
46. Kallem, S., et al., *Prevalence and pattern of disclosure of HIV status in HIV-infected children in Ghana.* AIDS Behav, 2011. **15**(6): p. 1121-7.
47. Mkwanazi, N.B., T.J. Rochat, and R.M. Bland, *The Amagugu intervention: a qualitative investigation into maternal experiences and perspectives of a maternal HIV disclosure support intervention in rural South Africa.* Health policy and planning, 2017. **32**(9): p. 1231-1240.
48. Demmer, C., *Experiences of families caring for an HIV-infected child in KwaZulu-Natal, South Africa: an exploratory study.* AIDS Care, 2011. **23**(7): p. 873-879.
49. Mburu, G., et al., *Adolescent HIV disclosure in Zambia: barriers, facilitators and outcomes.* 2014. **17**(1): p. 18866.
50. Kouyoumdjian, F.G., T. Meyers, and S. Mtshizana, *Barriers to disclosure to children with HIV.* J Trop Pediatr, 2005. **51**(5): p. 285-7.

51. Mandalazi, P., C. Bandawe, and E. Umar, *HIV Disclosure: Parental dilemma in informing HIV infected Children about their HIV Status in Malawi.* Malawi Med J, 2014. **26**(4): p. 101-4.
52. Mburu, G., et al., *Adolescent HIV disclosure in Zambia: barriers, facilitators and outcomes.* J Int AIDS Soc, 2014. **17**(1): p. 18866.
53. Petersen, I., et al., *Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: a qualitative investigation.* AIDS Care, 2010. **22**(8): p. 970-978.
54. Moodley, K., et al., *Paediatric HIV disclosure in South Africa -- caregivers' perspectives on discussing HIV with infected children.* S Afr Med J, 2006. **96**(3): p. 201-4.
55. Lazarus, R.S. and S. Folkman, *Stress, appraisal, and coping* 1984, New York: Springer Pub. Co.
56. Folkman, S. and R.S. Lazarus, *If it changes it must be a process: a study of emotion and coping during three stages of a college examination.* Journal of Personality and Social Psychology, 1985. **48**: p. 150-170.
57. Folkman, S., et al., *Dynamics of a stressful encounter: Cognitive appraisal, coping, and encounter outcomes.* Journal of Personality and Social Psychology, 1986. **50**(5): p. 992-1003.
58. Lorenz, R., et al., *Caregivers' Attitudes towards HIV Testing and Disclosure of HIV Status to At-Risk Children in Rural Uganda.* PloS one, 2016. **11**(2): p. e0148950-e0148950.
59. Mengesha, M.M., Y. Dessie, and A.A. Roba, *Perinatally acquired HIV-positive status disclosure and associated factors in Dire Dawa and Harar, Eastern Ethiopia: a health facility-based cross-sectional study.* BMJ open, 2018. **8**(8): p. e019554-e019554.
60. Krauss, B.J., S. Letteney, and C.N. Okoro, *Why Tell Children: A Synthesis of the Global Literature on Reasons for Disclosing or Not Disclosing an HIV Diagnosis to Children 12 and under.* Frontiers in public health, 2016. **4**: p. 181-181.
61. Orban, L.A., et al., *Coping strategies of adolescents living with HIV: disease-specific stressors and responses.* AIDS Care, 2010. **22**(4): p. 420-30.
62. Eneh, A.U., R.O. Ugwu, and N.I. Paul, *HIV Disclosure in Children in a Tertiary Hospital in Southern Nigeria–Child's Perspective.* Asian Journal of Medicine and Health, 2020. **18**(1): p. 16-27.
63. Sopena, S., et al., *Coping and psychological adjustment in adolescents with vertically acquired HIV.* AIDS Care, 2010. **22**(10): p. 1252-8.
64. Louthrenoo, O., P. Oberdorfer, and V. Sirisanthana, *Psychosocial functioning in adolescents with perinatal HIV infection receiving highly active antiretroviral therapy.* Journal of the International Association of Providers of AIDS Care, 2014. **13**(2): p. 178-183.
65. Kitetele, F.N., et al., *HIV Disclosure to Infected Children Involving Peers: A New Take on HIV Disclosure in the Democratic Republic of Congo.* Children (Basel), 2023. **10**(7).
66. Chem, E.D., et al., *Health-related needs reported by adolescents living with HIV and receiving antiretroviral therapy in sub-Saharan Africa: a systematic literature review.* J Int AIDS Soc, 2022. **25**(8): p. e25921.
67. Medecins Sans Frontieres *Khayelitsha 2001–2011, Activity Report: 10 years of HIV/TB care at primary health care level*. 2011.
68. Hsieh, H.-F. and S.E. Shannon, *Three Approaches to Qualitative Content Analysis.* Qualitative Health Research, 2005. **15**(9): p. 1277-1288.

69. Oken, B.S., I. Chamine, and W. Wakeland, *A systems approach to stress, stressors and resilience in humans.* Behavioural brain research, 2015. **282**: p. 144-154.

70. Carver, C.S., *COPE Inventory . Measurement Instrument Database for the Social Science.* Retrieved from www.midss.ie, 2013.

71. Folkman, S. and R.S. Lazarus, *If it changes it must be a process: study of emotion and coping during three stages of a college examination.* J Pers Soc Psychol, 1985. **48**(1): p. 150-70.

72. Pargament, K., M. Feuille, and D. Burdzy, *The Brief RCOPE: Current Psychometric Status of a Short Measure of Religious Coping.* Religions, 2011. **2**(1): p. 51-76.

73. Connor-Smith, J.K., et al., *Responses to stress in adolescence: Measurement of coping and involuntary stress responses.* Journal of Consulting and Clinical Psychology, 2000. **68**(6): p. 976-992.

74. Murphy, D.A., M.J. Rotheram-Borus, and W.D. Marelich, *Factor Structure of a Coping Scale Across Two Samples1.* Journal of Applied Social Psychology, 2003. **33**(3): p. 627-647.

75. Moneyham, L., et al., *The effectiveness of coping strategies used by HIV-seropositive women.* Research in Nursing & Health, 1998. **21**(4): p. 351-362.

76. United Nations Health Rights. *Convention on the Rights of the Child*. 1990; Available from: http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx.

77. Folkman, S. and R.S. Lazarus, *An Analysis of Coping in a Middle-Aged Community Sample.* Journal of Health and Social Behavior, 1980. **21**(3): p. 219-239.

78. Wilson, M., *Suicidal Behavior: Toward an Explanation of Differences in Female and Male Rates.* Suicide and Life-Threatening Behavior, 1981. **11**(3): p. 131-140.

79. Hayfron-Benjamin, A., et al., *HIV diagnosis disclosure to infected children and adolescents; challenges of family caregivers in the Central Region of Ghana.* BMC pediatrics, 2018. **18**(1): p. 365-365.

80. Nzota, M.S., et al., *Determinants and processes of HIV status disclosure to HIV--infected children aged 4 to 17 years receiving HIV care services at Baylor College of Medicine Children's Foundation Tanzania, Centre of Excellence (COE) in Mbeya: a cross-sectional study.* BMC pediatrics, 2015. **15**: p. 81-81.

81. Dawson-Rose, C., et al., *Effects of a peer educator program for HIV status disclosure and health system strengthening: Findings from a clinic-based disclosure support program in Mozambique.* PLoS One, 2020. **15**(5): p. e0232347.

82. Billings, A.G. and R.H. Moos, *The role of coping responses and social resources in attenuating the stress of life events.* J Behav Med, 1981. **4**(2): p. 139-57.

83. Carver, C.S., M.F. Scheier, and J.K. Weintraub, *Assessing coping strategies: a theoretically based approach.* J Pers Soc Psychol, 1989. **56**(2): p. 267-83.

84. Costanza, R.S., V.J. Derlega, and B.A. Winstead, *Positive and negative forms of social support: Effects of conversational topics on coping with stress among same-sex friends.* Journal of Experimental Social Psychology, 1988. **24**(2): p. 182-193.

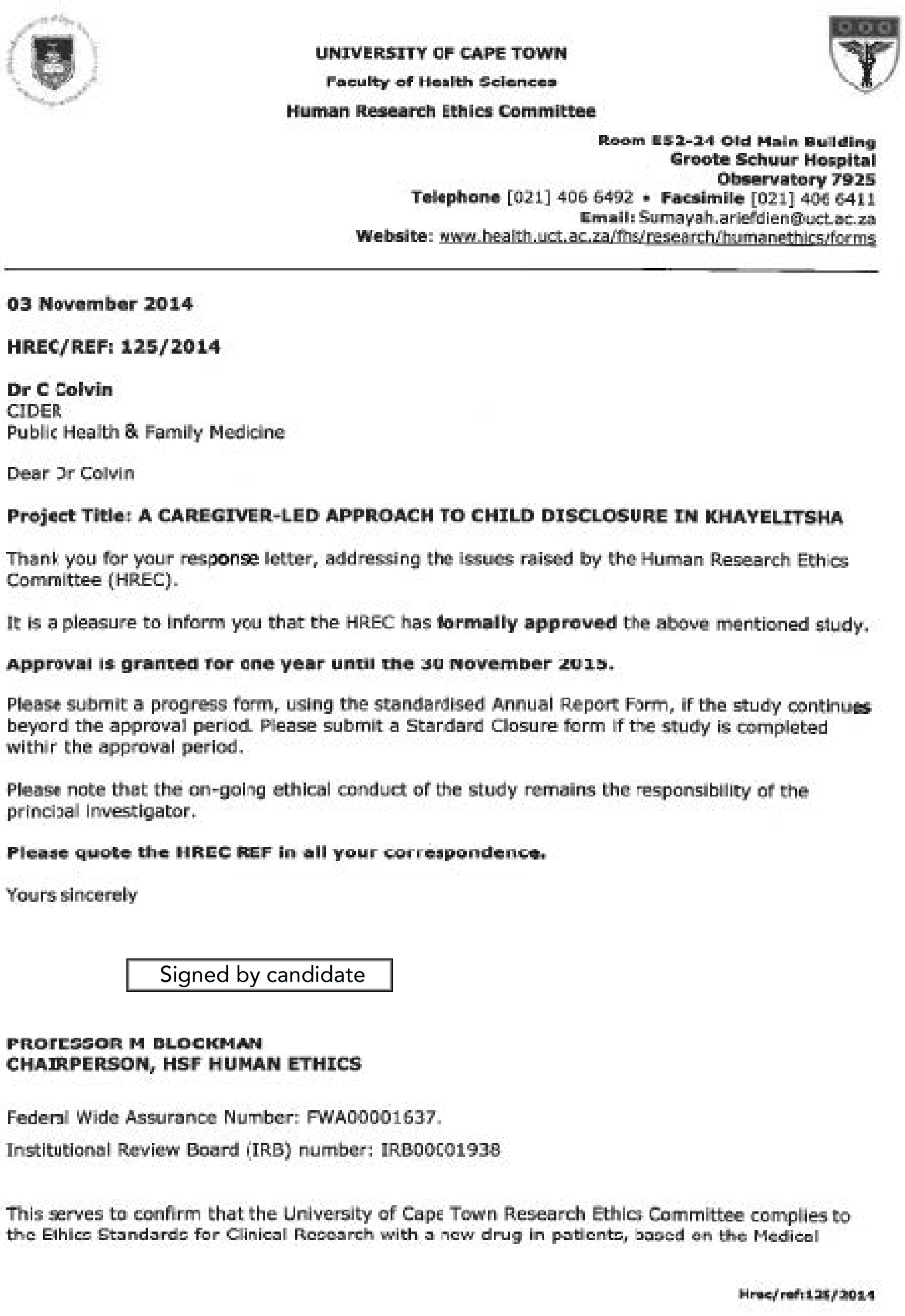
85. Felton, B., T. Revenson, and G. Hinrichsen, *Stress and coping in the explanation of psychological adjustment among chronically ill adults.* Social science & medicine (1982), 1984. **18**: p. 889-98.

86. Guta, A., et al., *HIV-positive status disclosure and associated factors among children in public health facilities in Dire Dawa, Eastern Ethiopia: A cross-sectional study.* PLoS One, 2020. **15**(10): p. e0239767.

87. Sutcliffe, C.G., et al., *Timing of and factors associated with HIV disclosure among perinatally infected children in rural Zambia.* Aids, 2020. **34**(4): p. 579-588.
88. Mukhtar-Yola, M., M. Kuczawski, and O.O. Oniyangi, *Should children know their HIV status? Prevalence, caregiver's perspectives and barriers to disclosure at the National Hospital Abuja, Nigeria.* Niger J Clin Pract, 2020. **23**(10): p. 1419-1425.
89. Mweemba, M., et al., *"When am I going to stop taking the drug?" Enablers, barriers and processes of disclosure of HIV status by caregivers to adolescents in a rural district in Zambia.* BMC public health, 2015. **15**: p. 1028-1028.
90. Saldana, J., *The coding manual for qualitative researchers*. 2 ed. An introduction to codes and coding. 2013: Sage Publications.

PART C: APPENDICES

Appendix 1: Ethics approval letter of parent study



UNIVERSITY OF CAPE TOWN
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Human Research Ethics Committee

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Website: www.health.uct.ac.za/fhs/research/humanethics/forms

03 November 2014

HREC/REF: 125/2014

Dr C Colvin
CIDER
Public Health & Family Medicine

Dear Dr Colvin

Project Title: A CAREGIVER-LED APPROACH TO CHILD DISCLOSURE IN KHAYELITSHA

Thank you for your response letter, addressing the issues raised by the Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above mentioned study.

Approval is granted for one year until the 30 November 2015.

Please submit a progress form, using the standardised Annual Report Form, if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

Please note that the on-going ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC REF in all your correspondence.

Yours sincerely

Signed by candidate

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

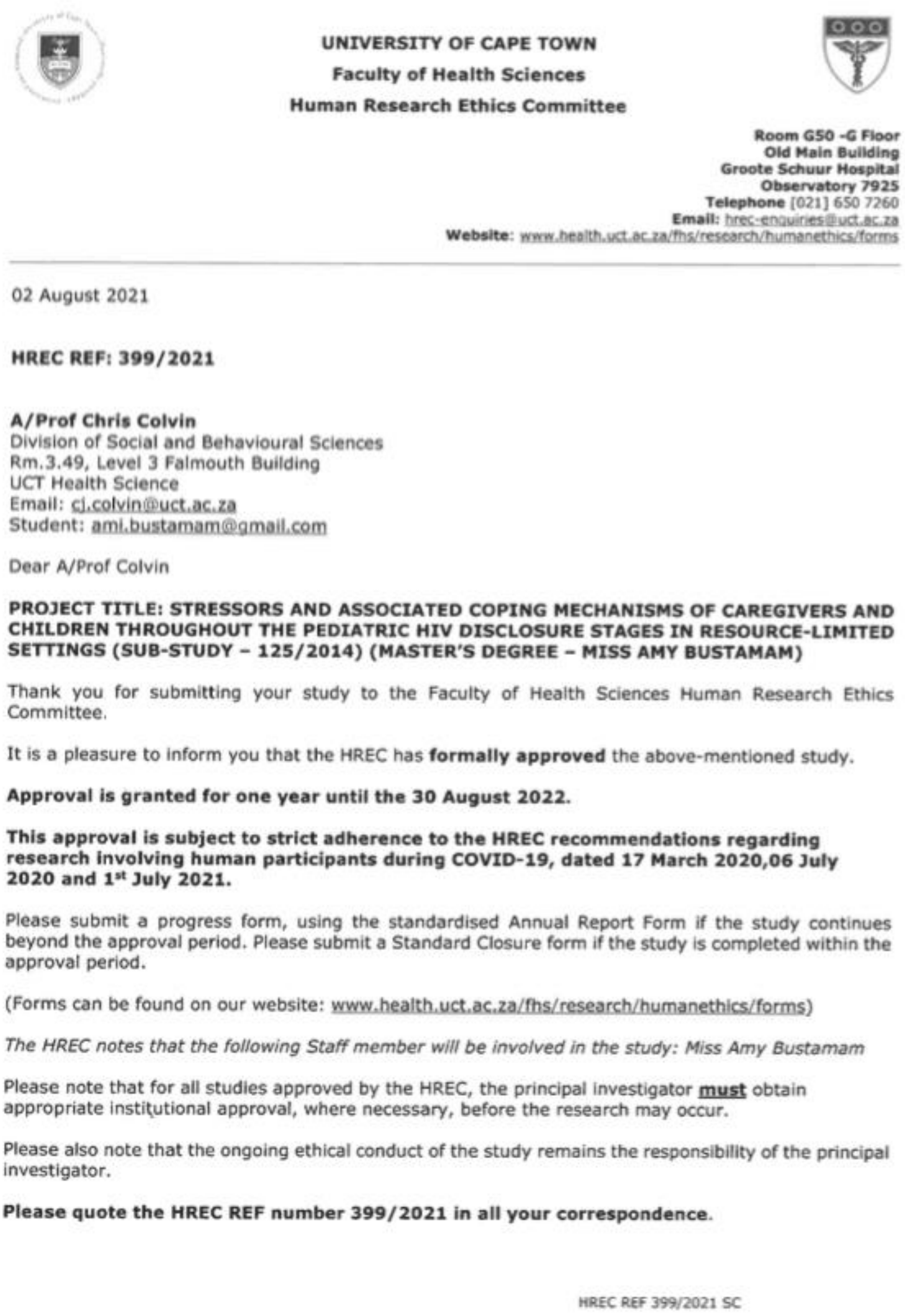
Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical

Hrec/ref:125/2014

Appendix 2: Ethics approval letter for current study



UNIVERSITY OF CAPE TOWN
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02 August 2021

HREC REF: 399/2021

A/Prof Chris Colvin
Division of Social and Behavioural Sciences
Rm.3.49, Level 3 Falmouth Building
UCT Health Science
Email: cj.colvin@uct.ac.za
Student: ami.bustamam@gmail.com

Dear A/Prof Colvin

PROJECT TITLE: STRESSORS AND ASSOCIATED COPING MECHANISMS OF CAREGIVERS AND CHILDREN THROUGHOUT THE PEDIATRIC HIV DISCLOSURE STAGES IN RESOURCE-LIMITED SETTINGS (SUB-STUDY – 125/2014) (MASTER'S DEGREE – MISS AMY BUSTAMAM)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 August 2022.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID-19, dated 17 March 2020,06 July 2020 and 1st July 2021.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC notes that the following Staff member will be involved in the study: Miss Amy Bustamam

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Please also note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC REF number 399/2021 in all your correspondence.

Yours sincerely

Signed by candidate

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCE HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2020), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

HREC REF 399/2021 SC

Appendix 3: Caregiver Consent Form (including consent child participation)

Informed Consent Form

The following informed consent form is for the caregiver-child pairs at the Ubuntu Clinic Family Club in Khayelitsha, who are invited to participate in the following research study.

Name of Principle Investigator:	Christopher J. Colvin & Ruth Henwood
Co-investigators:	Lynne Wilkinson, Gabriela Patten, Virginia de Azevedo, Martin Vandendyck & Saar Baert
Name of Organization(s):	Médecins Sans Frontières (MSF) & University of Cape Town (UCT)
Name of Project:	A Caregiver-led Approach to Child Disclosure in Khayelitsha
Site:	Khayelitsha

This Informed Consent Form has two parts:
- Information Sheet (to share information about the study with you)
- Certificate of Consent (for signatures if you choose to participate, and if you agree that your child may participate)

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Introduction

In South Africa, there is little support to guide caregivers on how to disclosure HIV status to their children. The World Health Organisation (WHO) says that child disclosure is a process which should happen over a few years. But, in South Africa, child disclosure programmes at local clinics and facilities have many problems in the way that they are run and managed.

As a result of these problems, Médecins Sans Frontières (MSF) will be starting a new child disclosure programme, called the Caregiver-led Disclosure Programme (CDP) that focuses on supporting caregivers like you, to start and be responsible for the disclosure process. Moving from the old disclosure programme to the new caregiver-led programme is important to make sure that more children and families can be targeted, and the process of disclosure fits into your home and community. CDP will start in March 2015 at the the Ubuntu Clinic in Khayelitsha.

Purpose of the research

Before the start of CDP, MSF and the University of Cape Town (UCT) are going to run a qualitative research study to make sure that the caregiver-led programme will operate without any problems. This first phase of the CDP will look at the experiences and opinions of people (like yourself) who are involved in child disclosure practices in Khayelitsha. The findings from this first phase will be used to strengthen the CDP and be used to develop learning materials for the programme. The first phase will be run between November – December 2014.

As part of our study, we would like to invite you and your child to participate in a discussion so that we can learn about your experiences in child disclosure. We also want to find out from you what you think of the CDP and your worries about it, issues you feel may come up once the programme has started, and how much guidance you would like in this programme.

Voluntary Participation

You and your child's participation in this study is voluntary. If you or your child wishes to leave the study, you may both do so at any time, without giving any reasons for doing so. The choice that you make will not affect the treatment and care that you and your family get at Ubuntu Clinic. You may change your mind later and stop participating even if you agreed earlier. If you decide to leave the study, this will not affect your relationship with the Ubuntu Clinic and Family Club, Médecins Sans Frontières, University of Cape Town, or any other organisation.

Procedures

You and your child are invited to participate in a discussion, which will be run by the research team at the Ubuntu Clinic. You and your child will attend separate workshops and discussion groups, which will happen at the same time. You and your child will be told about your role and commitments if you choose to participate in the study, and you may contacted to participate in future workshops or discussion groups after the first phase of the study.

The workshop will begin with a brief explanation about the study and information about the workshop. Then the team will talk to you in a discussion group about the materials and books already used in the old disclosure programme, and what you think about the new materials and books. At the end, there will be time for Q & A.

During the workshop, we will not ask you to share personal beliefs, practices or stories and you do not have to share any information that you are not comfortable sharing.

Only the participants and the researchers involved in the study will be present at the workshop, no one else. The workshop and discussion groups will be tape-recorded, but you and your child will not be identified on the tape. The tape will be kept stored in a safe cabinet at the University of Cape Town. The information recorded is private, and no one else except the research team will have access to the tapes. The tapes will be destroyed after 52 weeks.

Your participation will be important as we believe it is valuable to involve you and your children in the development of the new child disclosure materials and books.

Risks

There will be no social or physical risks to you or your child if you decide to participate in the study. We will ask you to share some personal information, and you may feel uncomfortable talking about some of the topics. You and your child do not have to answer any questions or take part in the group discussions if either of you are uncomfortable. You do not have to give us any reason for not responding to any question, or for refusing to take part in the discussions.

Benefits

If you decide to participate with your child, this will help to improve the new caregiver-led programme and your community because then caregivers, like yourself, will be able to disclose HIV status to their children and help them stay on their ARV treatment.

Reimbursements

You and your child will be given lunch and refreshments during the workshop, and you will be given grocery vouchers of R50 for your participation.

Confidentiality & Sharing of Results

The information that you share during the workshop and discussion groups will be kept private. The information will not be discussed with anyone other than the researchers. All information collected will be kept safe in locked filing cabinets or offices, and on password-protected computers. If you agree to take part in the study with your child, you are asked to keep any information that is shared in the group discussions private and not to share this with anyone outside of the workshop.

We want you to know, however, that we cannot stop or prevent caregivers or children in the workshop from sharing information that should be private.

When the results of the study become available, your name or name of your child in the workshop and discussion groups will not be mentioned in the report.

Right to Refuse or Withdraw

You do not have to take part in this research study if you do not wish to do so, and choosing to participate will not affect you in any way. You may stop participating in the group discussions at any time that you wish. The researchers will give you an opportunity at the end of the workshop to review your comments. You can ask to change or remove parts of the information, if you do not agree with our notes or if we did not understand you correctly.

Who to Contact

If you have any questions about this study, you can call Chris Colvin anytime at 084-684-7202. You may also call the team leader, Dr. Ruth Henwood (021 364 5490) between the working hours of 9am-5pm, Monday to Friday, if you have any questions.

If you have any questions or concerns about how you have been treated in this study, you may contact the UCT Faculty of Health Sciences Human Research Ethics Committee (021 406 6492) between the working hours of 9am-5pm, Monday to Friday.

This proposal has been reviewed and approved by University of Cape Town Faculty of Health Sciences Human Research Ethics Committee and Provincial Department of Health, who are responsible for making sure that participants in the study are safe from harm.

You can ask us any more questions about study, if you wish to. Do you have any questions?

Part II: Certificate of Consent

My child and I have been invited to participate in research study, which is about the caregiver-led disclosure programme. I have read the information letter, or it has been read to me. I have had the chance to ask questions about the study and any questions I have been asked have been answered. I consent voluntarily to be a participant in this study. I also give permission to the study team to approach my child to request participation in the study, and my child has the right to decide to participate or not. If my child is too young or immature to understand the study, I may decide my child's participation, as long as they do not object to participation.

Print Name of Participant/Caregiver: ____________________________

Print Name of the Child: ____________________________

Relationship to the Child: ____________________________

Please explain this relationship briefly (e.g. biological parent, adoptive parent, legal guardian (including customary law), social parent/caregiver)

Age of the Child: ____________________________

Signature of Participant: ____________________________

Date: ____________________________
Day/month/year

If illiterate:
I have witnessed the accurate reading of the consent form to the potential participant/caregiver, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness: ___________________________ Thumb print of participant ☐
Signature of witness: ___________________________
Date: ___________________________
Day/month/year

Statement by the researcher/person taking consent:

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the information provided in these documents. I confirm that the participant/caregiver was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant/caregiver.

Print Name of Researcher/person taking the consent: Christopher J. Colvin

Signature of Researcher /person taking the consent: _________________________________

Date:

An Informed Assent Form will _____ OR will not _____ be completed.

Appendix 4: Children's Assent Form

Informed Assent Form

The following informed consent form is for the **children** attending the **Ubuntu Clinic Family Club** in Khayelitsha, who are invited to participate in the following research study.

Name of Principle Investigator:	Christopher J. Colvin & Ruth Henwood Lynne Wilkinson, Gabriela Patten, Virginia de Azevedo, Martin Vandendyck & Saar Baert
Name of Organization(s):	Médecins Sans Frontières (MSF) & University of Cape Town (UCT)
Name of Project:	A Caregiver-led Approach to Child Disclosure in Khayelitsha
Site:	Khayelitsha

This Informed Assent Form has two parts:

- Information Sheet (gives you information about the study)
- Certificate of Assent (this is where you sign if you agree to participate)

You will be given a copy of the full Informed Assent Form

Part I: Information Sheet

Introduction

My name is Alison Swartz and my job is to help children understand their illness and teach them how to stay healthy. My friends at work and I have made a book that we would like to share with you if that is ok? We want to know if these books will help children like you to understand what is going on in their bodies, and how to stay healthy.

I am going to give you information and invite you to be part of a research study. We have spoken to your main caregiver about this research study and they have given us permission to ask you if you would like to participate. You can choose whether or not you want to take part. If you do not wish to take part in the research, you do not have to, even if your caregiver said you can.

You may discuss anything in this form with your caregivers or friends or anyone else you feel comfortable talking to. You can decide whether to take part or not after you have talked it over. You do not have to decide immediately.

There may be some words you don't understand or things that you want me to explain more about because you are interested or worried. Please ask me to stop at any time and I will take time to explain.

Purpose of the research: Why are you doing this research?

We want to find ways to help children with HIV to stay healthy and take their medicine. We also want to help their caregivers who need to tell their children that they are HIV positive.

Choice of participants: Why are you asking me?

We are asking children like you who have gone through the children's programme at the Ubuntu Clinic and have been told their HIV status.

Participation is voluntary: Do I have to do this?

You don't have to be in this research if you don't want to be. It is up to you. If you decide not to be in the research, it is okay and nothing changes. This is still your clinic; everything stays the same as before. Even if you say "yes" now, you can change your mind later and it's still okay.

I have checked with the child and they understand that participation is voluntary ____(initial)

Procedures: What is going to happen?

You are invited with your caregiver to take part in a discussion at the Ubuntu Clinic. You will be in a different workshop to your caregiver, but you will be able to see your caregiver at any time. In the workshop, we will put you into small groups where we will ask you questions about your experiences during the time when you were told about your HIV status.

We will also show you some new information books, which we will be using to tell children about their bodies and how to stay healthy. We want to know what you think about these books and if you think these books can be made better. At the end, there will be time for questions and answers.

During the workshop, we will not ask you to share any personal things about you or your family. You do not have to tell us any information that you do not want us to know.

It will only be you, children from the Ubuntu Club, the caregivers, and the research team who will be at the workshop, no one else. The group talks will be recorded on a tape-recorder, but no one will know that it is you speaking on the tape recorder. The tape will be kept in a safe and locked room at the University of Cape Town. Everything said on the tape will be private, and no one will hear it except the research team.

I have checked with the child and they understand the procedures _______(initial)

Risks: Is this bad or dangerous for me?

No – this study will not be bad or dangerous for you. If you do not want to talk about anything during the workshop or group talks, you do not have to answer the questions. You do not have to give any reasons if you do not want to answer any questions.

I have checked with the child and they understand the risks _______(initial)

Benefits: Is there anything good that happens to me?

If you want to take part in the study, you will help us to make the children's programme at the Ubuntu Clinic better for future children and caregivers. We will be very grateful if you choose to help us.

I have checked with the child and they understand the benefits _______(initial)

Reimbursements: Do I get anything for being in the research?
You will be given lunch and drinks during the workshop and group talks. Your caregiver will also be given R50 to buy food at the grocery store for you and your family.

I have checked with the child and they understand the reimbursements _______(initial)

Confidentiality: Is everybody going to know about my participation in the study?
We will not tell other people that you are in this study and we won't share information about you to anyone who does not work in the research team.

Personal information (e.g. age, name, etc.) about you will be put away and no-one but us will be able to see it. Anything you say in the workshop about your experiences will not be connected to your real name, instead we will use a false name to identify you (e.g. John or Sarah).

I have checked with the child and they understand the confidentiality of the research _______(initial)

Sharing the Findings: Will you tell me the results?
When we are finished with the study, I will sit down with you and your caregiver and I will tell you about what we learnt. Afterwards, we will be telling more people, scientists and others, about the research and what we found. We will do this by writing and sharing reports and by going to meetings with people who are interested in the work we do.

I have checked with the child and they understand how the findings will be shared _______(initial)

Right to Refuse or Withdraw: Can I choose not to be in the research? Can I change my mind?
You do not have to be in this study. No one will be mad or disappointed with you if you say no. It is your choice. You can think about it and tell us later if you want. You can say "yes" now and change your mind later and it will still be okay.

I have checked with the child and they understand their right to refuse or withdraw from the study _______(initial)

Who to Contact: Who can I talk to or ask questions to?
You can ask me questions now or later. You can also ask your caregiver questions. Here is a number—084-684-7202—which you can call if you want to speak to me. I can explain what we are doing in this study and what we are trying to understand. You may also call the team leader, Dr. Ruth Henwood (021 364 5490) between the working hours of 9am-5pm, Monday to Friday, if you have any questions.

If you have any questions or concerns about how you have been treated in this study, you may contact the UCT Faculty of Health Sciences Human Research Ethics Committee (021 406 6492) between the working hours of 9am-5pm, Monday to Friday. If you want to talk to someone else that you know, like your teacher or doctor or auntie, that's okay too."

If you choose to be part of this research I will also give you a copy of this paper to keep for yourself. You can ask your caregiver to look after it if you want.

You can ask me any more questions about any part of the research study, if you wish to. Do you have any questions?

Part II: Certificate of Assent

I have been invited to take part in this research study about how to tell children that they are HIV positive and how to help them stay healthy.

I have read this information (or had the information read to me). I have had my questions answered and know that I can ask questions later if I have them.

I agree to take part in the research.

OR

I do not wish to take part in this research and I have not signed the assent below.
___________ (initialed by child/minor)

Only if the child assents:

Print Name of child: ____________________________

Signature of child: ____________________________

Date: ____________________________

If illiterate:
I have witnessed the accurate reading of the assent form to the child, and the child has had the opportunity to ask questions. I confirm that the child has given assent freely.

Print name of witness (not a caregiver): ________________________ Thumb print of child ☐
Signature of witness: ________________________
Date: ________________________
Day/month/year

Statement by the researcher/person taking assent:

I have accurately read or witnessed the accurate reading of the assent form to the child, and to the best of my ability made sure that the child understands that the information provided in these documents. I confirm that the child was given an opportunity to ask questions about the study, and all the questions asked by him/her have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily. I confirm that the child has given assent freely.

A copy of this assent form has been provided to the child.

Print Name of Researcher/person taking the assent: Alison Swartz

Signature of Researcher /person taking the assent: ___________________________________

Date:

Appendix 5: Journal Submission Guidelines for AIDS and Behavior

Manuscript Preparation

- Type double-spaced on one side of 8 ½ × 11-inch white paper using generous margins on all sides, (including copies of all illustrations and tables).
- A title page is to be provided and should include the title of the article, authors name (no degrees), authors affiliation, and suggested running head. The affiliation should comprise the department, institution (usually university or company), city, and state (or nation) and should be typed as a footnote to the authors name. The suggested running head should be less than 80 characters (including spaces) and should comprise the article title or an abbreviated version thereof. For office purposes, the title page should include the complete mailing address, telephone number, fax number, and email address of the one author designated to review proofs.
- With the exception of Brief Reports and Behavioral Surveillance Reports, initial submissions to AIDS and Behavior do not have word or page limits. Briefer and more succinct papers tend to review better and papers may be reduced in length as part of the review process. However, the length of the original submission is left to author discretion.
- An abstract is to be provided, preferably no longer than 150 words.
- A list of 4-5 key words is to be provided directly below the abstract. Key words should express the precise content of the manuscript, as they are used for indexing purposes.
- All sections should carry headings (such as INTRODUCTION, METHODS, RESULTS, DISCUSSION, CONCLUSIONS, etc.), typed flush left. All acknowledgments (including those for grant and financial support) should be typed in one paragraph (so−headed) on a separate page, that directly precedes the References section.
- Illustrations (photographs, drawings, diagrams, and charts) are to be numbered in one consecutive series of Arabic numerals. The captions for illustrations should be typed on a separate sheet of paper. All illustrations must be complete and final, i.e., camera-ready. Photographs should be large, glossy prints, showing high contrast. Drawings should be

high quality laser prints or should be prepared with india ink. Either the original drawings or good–quality photographic prints are acceptable. Artwork for each figure should be provided on a separate sheet of paper. Identify figures on the back with authors name and number of the illustration. Electronic artwork submitted on disk should be in the TIFF or EPS format (1200 dpi for line and 300 dpi for halftones and grayscale art). Color art should be in the CYMK color space. Artwork should be on a separate disk from the text, and hard copy must accompany the disk.

- Tables should be numbered (with Roman numerals) and referred to by number in the text. Each table should be typed on a separate sheet of paper. Center the title above the table, and type explanatory footnotes (indicated by superscript lowercase letters) below the table.
- AIDS and Behavior does not have a limit on number of authors. However, if deemed to be excessive the editor may request author justifications and reductions.
- AIDS and Behavior uses Vancouver style as outlined in the American Medical Association Manual of style: A Guide for Authors and Editors, 10th Edition.
    1) A reference number is allocated to a source in the order in which it is cited in the text. In text, identify references as Arabic numerals in brackets (1). If the source is referred to again, the same number is used. References are listed in numerical order in the Reference List at the end of the paper. Do not alphabetize. Use abbreviated names of journals according to the journal list in PubMed. List all authors and/or editors up to 6; if more than 6, list the first 3 followed by “et al.” The following are examples.
    2) McKirnan DJ, Vanable PA, Ostrow DG, Hope B. Expectancies of sexual "escape" and sexual risk among drug and alcohol-involved gay and bisexual men. J Subst Abuse. 2001;13(1-2):137-54.
- Footnotes should be avoided. When their use is absolutely necessary, footnotes should be numbered consecutively using Arabic numerals and should be typed at the bottom of the page to which they refer. Place a line above the footnote, so that it is set off from the text. Use the appropriate superscript numeral for citation in the text.

Disclosures and declarations

All authors are requested to include information regarding sources of funding, financial or non-financial interests, study-specific approval by the appropriate ethics committee for research involving humans and/or animals, informed consent if the research involved human participants, and a statement on welfare of animals if the research involved animals (as appropriate).

The decision whether such information should be included is not only dependent on the scope of the journal, but also the scope of the article. Work submitted for publication may have implications for public health or general welfare and in those cases it is the responsibility of all authors to include the appropriate disclosures and declarations.

Appendix 6: Table 3. List of 12 Disclosure Coping Mechanisms and the Corresponding Coping Batteries, with items.

Coping Mechanism	Coping Batteries and HIV Literature
Acceptance Coping	COPE Inventory[70]: Q13. I get used to the idea that it happened. Q21. I accept that this has happened and that it can't be changed. Q44. I accept the reality of the fact that it happened. Q54. I learn to live with it.
Active Coping/ Problem-Solving	COPE Inventory[70]: Q5. I concentrate my efforts on doing something about it. Q25. I take additional action to try to get rid of the problem. Q47. I take direct action to get around the problem. Q58. I do what has to be done, one step at a time. Ways of Coping[71]: Q49. I knew what had to be done, so I doubled my efforts to make things work. Q26. I made a plan of action and followed it. Q1. Just concentrated on what I had to do next – the next step. Q39. Changed something so things would turn out all right. Q48. Drew on my past experiences; I was in a similar situation before. Q52. Came up with a couple of different solutions to the problem.
Behavioural Disengagement	COPE Inventory[70]: Q9. I admit to myself that I can't deal with it, and quit trying. Q.24. I just give up trying to reach my goal. Q.37. I give up the attempt to get what I want. Q.51. I reduce the amount of effort I'm putting into solving the problem.
Confrontive Coping	Ways of Coping[71]: Q6. I did something which I didn't think would work, but at least was doing something Q46. Stood my ground and fought for what I wanted. Q7. Tried to get the person responsible to change his or her mind. Q17. I expressed anger to the person(s) who caused the problem. Q28. I let my feelings out somehow. Q34. Took a big chance or did something very risky.
Escape-Avoidance/ Tension Reduction	Ways of Coping[71]: *Tension Reduction:* 32. Got away from it for a while; tried to rest or take a vacation. 33. Try to make myself feel better by eating, drinking, smoking, using drugs or medication, etc.

	66. I jog or exercise. *Escape-Avoidance:* 33. Tried to make myself feel better by eating, drinking, smoking, using drugs or medication, etc. 40. Avoided being with people in general. 47. Took it out on other people.
Information-seeking	Moneyham, 1998[75]: Q11. I try to stay informed about HIV. Q24. I ask lots of questions about my illness. Q41. I read all I can about HIV. Q49. I watch how other people respond to HIV/AIDS. Q54. I educate myself about my illness and its treatment.
Positive Thinking/ Cognitive Restructuring	Responses to Stress Questionnaire[73]: *Positive Thinking* Q19. I tell myself that I can get through this, or that I'll do better next time. Q50. I tell myself that everything will be all right. Q52. I think of ways to laugh about it so that it won't seem so bad. *Cognitive Restructuring* Q34. I tell myself that things could be worse. Q36. I tell myself that it doesn't matter, that it isn't a big deal. Q39. I think about the things I'm learning from the situation, or something good that will come from it.
Religious Coping	COPE Inventory[70]: Q7. I put my trust in God. Q18. I seek God's help. Q48. I try to find comfort in my religion. Q60. I pray more than usual.
Restraint Coping	COPE Inventory[70]: Q10. I restrain myself from doing anything too quickly. Q22. I hold off doing anything about it until the situation permits. Q41. I make sure not to make matters worse by acting too soon. Q49. I force myself to wait for the right time to do something.
Selective Disclosure	NA - Not in any coping battery
Social Support	Murphy et al., 2003[74]: • Went to a support group • Went to a friend or professional to help you feel better • Talked with others who are HIV+ • Went to a therapist our counselor or social worker • Tried to understand how other HIV+ people were thinking and feeling

	Ways of Coping [71]: Q8. Talked to someone to find out more about the situation. Q28. I let my feelings out somehow. Q31. Talked to someone who could do something concrete about the problem. Q42. I asked a relative or friend I respected for advice. Q45. Talked to someone about how I was feeling. Q18. Accepted sympathy and understanding from someone. Q22. I got professional help Q42. Ask a relative or friend I respect for advice. Q60. I pray. COPE Inventory[70]: *Use of instrumental social support:* Q4. I try to get advice from someone about what to do. Q14. I talk to someone to find out more about the situation. Q30. I talk to someone who could do something concrete about the problem. Q45. I ask people who have had similar experiences what they did. *Use of emotional social support:* Q11. I discuss my feelings with someone. Q23. I try to get emotional support from friends or relatives. Q34. I get sympathy and understanding from someone. Q52. I talk to someone about how I feel.
Suicide	Not in any coping battery